DISABILITY'S ENCOUNTER WITH LEGISLATION AND GOVERNANCE: LONG-TERM CARE HOMES IN ONTARIO

PO LAND LAI

A DISSERTATION SUBMITTED TO
THE FACULTY OF GRADUATE STUDIES
IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY

GRADUATE PROGRAM IN LAW
YORK UNIVERSITY
TORONTO, ONTARIO
January, 2020

© Po Land Lai, 2020

Abstract

This dissertation is a comprehensive study of the new legal framework for the long-term care (LTC) sector (also known as nursing homes) in Ontario, Canada. The research sought to answer the following question: What are the potential implications for persons with disabilities of the changes made by the Government of Ontario between 2004 and 2018 to the legislation and governance of treatment, care and living circumstances within LTC homes?

LTC is where many older women with disabilities and serious illnesses experience care. This study brings a gendered disability perspective to a public policy issue that is usually singularly associated with aging. To theorize the regulation and provision of care in LTC, the author situates LTC research within debates about care in disability scholarship. The concept of "caring relationships" is used to draw out tensions inherent in receiving and delivering care. Caring relationships are shaped by, among other political and market forces, the legal and administrative structure of a benefit scheme or a regulatory regime. The New Governance literature is employed to describe and examine new processes and procedures that shape caring relationships in LTC.

To create a more comprehensive account of the changes, the research methods used were document review, legal analysis and key informant interviews. The feminist political economy literature was relied upon to draw out critical insights about the LTC sector. The majority of changes identified in the review were the creation of new or the strengthening of existing processes. The few substantive changes can be described as fragmented efforts to reduce risks to the safety, physical survival and security of individual residents. These changes – if properly understood and implemented – are significant in that they afford more procedural protections to residents in caring relationships and allow residents to make claims for inclusion and participation in making care decisions and in influencing conditions within the home. However, the mechanisms were designed without careful consideration of how the actual circumstances of residents, connected to the intermeshing of disability, gender and age, will impact their proper implementation. Consequently, some LTC applicants and residents cannot benefit from the protections offered by the law.

Acknowledgments

The completion of this dissertation is the result of much nudging, pushing, and steering by my supervisory committee over a protracted period of time. I now appreciate the statement: “The most affirming thing anyone can do for you is demand that you push yourself further.” Professor Shelly Kierstead, my supervisor, is always available to provide much needed counsel and support. Supervising a part-time mature student comes with additional headaches. I am grateful to Professor Kierstead for being so understanding. Professor Joan Gilmour, who was my LLM supervisor, is kind enough to provide guidance again. It is hard to believe we have worked together for ten years! Professor Tamara Daly’s expertise on long-term care is invaluable and saves me from various intellectual mishaps.

I also wish to acknowledge members of my dissertation examination committee, including Professor C. Tess Sheldon and Professor Pat Armstrong. Their comments and questions were thought-provoking and extremely helpful.

The broader Oz community is also instrumental to this dissertation. I thank Professor Liora Salter for being frank (but with good humour and kindness) at all times. Many ideas in the dissertation were formulated in my study groups. I thank Professor Dan Priel and Professor Robert Wai for running excellent groups and my classmates for stimulating discussions. Staff members of the grad office and the Library have been extremely helpful.

My Oz friends kept me going when this project appeared to be an impossible and foolish undertaking. A few deserve special recognition: Agnese Bianchi, Manuela DiRe, Sheila Jennings, Natalia Angel-Cabo, Paula Madden, Sarah Alghamdi, Hayden McGuire, Mohammed Hassan, Mahnam Malamiry, Vanessa Scanga, Irma Spahiu, Ruba Ali Al-Hassani and Klodian Rado.

The interviewees of this project were very generous with their time. Their insights and knowledge were extremely helpful. Without their first-hand account of LTC regulation, this dissertation would undoubtedly be just another doctrinal project.

I acknowledge the assistance offered by the staff at the Ministry of Health and Long-Term Care, Consent and Capacity Board, Health Services Appeal and Review Board, Health

Quality Ontario, Office of the Chief Coroner, the Legislative Assembly and the Archives of Ontario.

Parts of the dissertation were presented at various conferences. I thank the participants for their thoughtful comments and suggestions.

My doctorial study was made possible by the generous financial assistance offered by the Ontario Graduate Scholarship, Hon. Willard Z. Estey Graduate Fellowship in Law and Susan Mann Dissertation Scholarship.

I want to acknowledge the support of my colleagues and friends in the Ontario Public Service. And thank you for tolerating me whenever I am having a “grad student moment”.

Finally, I thank my parents for tolerating my pursuit of yet another degree.

The views expressed in this dissertation do not represent the views of the Government of Ontario.

Table of Contents

7 INCLUSION AND PARTICIPATION 229

List of Tables

List of Illustrations

1 Introduction

Prologue

In the wake of the murders of eight long-term care (LTC) home residents in Southern Ontario by a single caregiver,[1] Ontarians were forced to confront a series of perplexing and uncomfortable questions that had no simple answers. Why did someone in a caring profession decide to commit the ultimate breach of trust? Is it even possible to eliminate potential risk of grievous harm to residents in institutional care? What is the government's appropriate role in "caring for" some of the most vulnerable citizens in our society? Does receiving care as currently conceived in our health and social services system inevitably mean living a life that is short, nasty and brutish? These questions inform my own examination and re-examination of some of the tensions and contradictions inherent in LTC. This dissertation engages scholarly research that is pertinent to answering these questions and offers an empirical account of LTC in Ontario that explains the regulatory context in which these criminal cases occurred. However, I reluctantly decided to put aside the grim details of these criminal cases and focus on the less sensational, more mundane reality of care in LTC homes. The responses – in the legal and political systems – to the tragic deaths are still unfolding at the time of writing. Some of these responses have been incorporated into this dissertation; others will have to be unpacked in a different project. To be certain, the recent Public Inquiry into the Safety and Security of Residents in the Long-Term Care Homes System[2] is worthy of eventual critical examination. It is my hope that by taking a small step back from the latest (but probably not the last) crisis in LTC, this research project will be part of a longer view of LTC in Ontario.

---

[1] Government of Ontario, *Statement from Attorney General and Minister of Health and Long-Term Care on a Public Inquiry into the Circumstances of the Elizabeth Wettlaufer Case* (Toronto: Government of Ontario, 2017). Elizabeth Wettlaufer was convicted of eight counts of first-degree murder, four counts of attempted murder, and two counts of aggravated assault.

[2] The Long-Term Care Homes Public Inquiry Report was released on July 31, 2019. Honourable Eileen E Gillese, *Report of the Public Inquiry into the Safety and Security of Residents in the Long-Term Care Homes System* (Toronto: Long-Term Care Homes Public Inquiry, 2019).

1.1 Research question and the aim of the research

My interest in regulation and governance grew out of a health context but has expanded to a broader context. This dissertation concerns potential implications of changes to regulation and governance from the standpoint of vulnerable groups and individuals. My inquiry into the potential implications will involve the use of a case study. According to Robert Yin, case studies are the preferred strategy when "why" or "how" types of research questions are being posed, when the researcher has little control over behavioural events, and when the focus is on a contemporary phenomenon within some real life context.[3] The case study that I have chosen is the LTC home sector (commonly known as residential care or nursing homes) in Ontario.

My research question is as follows: What are the potential implications for persons with disabilities of the changes made by the Government of Ontario between 2004 and 2018 to the legislation and governance of treatment, care and living circumstances within LTC homes? In this dissertation, I use 'persons with disabilities' and 'disabled persons' interchangeably because both terms are used in disability studies.

The governance and regulation of treatment, care and living circumstances – institutional or community-based – appears to be a "logical" field through which to examine a variety of issues related to disability. In chapter 2, I will explain the concept of disability in more detail. For now, suffice it to say that I have adopted a relational account of disability wherein disability is understood as the dynamic interaction of an individual with an impairment or health condition and the physical, social and political environment in which he or she is located.[4] However, because the concept of disability has traditionally been linked to care, welfare and charity,[5] regulation and governance have been put in place to control the provision of services and support to persons with disabilities. If we follow Julia Black's definition of regulation as "the intentional use of authority to affect behaviour of a different party according to set standards, involving instruments of information gathering and behaviour modification"[6], then the settlements with

---

[3] Robert K Yin, *Case Study Research: Design and Methods*, 5th ed (Los Angeles: SAGE, 2014).

[4] Tom Shakespeare, "Still a Health Issue" (2012) 5 Disability and Health Journal 129.

[5] Bernadette McSherry and Ian Freckelton, "Coercive Care: Rights, Law and Policy" in Bernadette McSherry & Ian Freckelton eds, *Coercive Care: Rights, Law and Policy* (New York: Routledge, 2013) 3 at 4.

[6] Julia Black, "Decentring Regulation: Understanding the Role of Regulation and Self-Regulation in a 'Post-Regulatory' World" (2001) 54:1 Curr Leg Probs 103.

former residents of institutions for adults with developmental disabilities[7] are grim examples of harm suffered by persons with disabilities when the "intentional use of authority" had clearly failed to affect the behaviours of those in charge of providing care and treatment; indeed, it appears to have permitted their harmful behaviours. Accordingly, regulation and governance may be studied in terms of the law's impact on the lives of persons of disability, for example, the quantity and quality of support provided by a public benefit scheme from a distributive justice perspective. When doing so, scholars and policy makers may discover that the law is too fragmented, too cumbersome or too complex to be implemented on the ground.[8] As well, solutions may be proposed to achieve a variety of policy outcomes, such as cost-effectiveness, "red-tape" reduction and client satisfaction. However, this project is not about improving the techniques of regulating LTC as a social policy for those who experience the effects of aging and disabilities.

I choose disability as my "lens" not because I equate disability with care, welfare and charity. Nor do I object to reform efforts to reduce fragmentation or enhance the consistency of laws governing care, treatment and living circumstances. Rather, I am concerned about the invisibility of disability in the regulation and governance of care, treatment and living circumstances. In my view, although the exclusionary practices of sweeping persons with disability from public view[9] may belong to old statute books, persons with disabilities continue to be invisible in the sense that their differences, needs and diversity are not recognized and acknowledged in regulation and governance. Manifestation of such invisibility may take many forms: the Supreme Court's formal approach to equality,[10] lack of consideration of the needs and

---

[7] On December 9, 2013, Ontario Premier Kathleen Wynne delivered a formal apology in the legislature to former residents of regional centres for people with developmental disabilities. Huronia provided supports, services and residential care to people with developmental disabilities until it closed in 2009. The $35 million settlement will provide compensation to those people who were residents of Huronia between 1945 – 2009 and suffered harm. See online:<http://news.ontario.ca/mag/en/2013/12/settlement-reached-in-huronia-class-action-lawsuit.html>. Rideau Regional Centre closed in 2009 and Southwestern Regional Centre closed in 2008. The combined value of the Rideau Regional Centre and Southwestern Regional Centre settlements is $32.7 million. Online:<http://news.ontario.ca/mag/en/2014/02/settlements-reached-in-rideau-and-southwestern-regional-centres-class-actions.html>. See also Ontario Ombudsman, *Nowhere to Turn: Investigation into the Province's Services for Adults with Developmental Disabilities Who Are in Crisis Situations* (Toronto: Ontario Ombudsman, 2016).

[8] For example, see Law Commission of Ontario, *The Law as it Affects Persons with Disabilities: Consultation Paper* (Toronto: Law Commission of Ontario, 2011).

[9] Janet E. Lord & Michael Ashley Stein, "Contingent Participation and Coercive Care" in Bernadette McSherry & Ian Freckelton, eds, *Coercive Care: Rights, Law and Policy* (New York: Routledge, 2013) 31 at 40.

[10] For example, see Dianne Pothier, "Equality as a Comparative Concept: Mirror Mirror on the Wall, What's the

experiences of persons with disabilities in the design of programs[11] or drafting of legislation[12], breach of confidentiality and disclosure of personal health information,[13] and involuntary treatment and substitute decision-making.[14]

To consider how persons with disabilities will be affected by changes to legislation and governance, their differences, needs and diversity must be purposively addressed. Even changes to legislation and governance that appear to be applicable to everyone may have a disproportionately negative impact on persons with disabilities or exclude them from the full enjoyment of the changes through which benefits are supposed to materialize. Further, without understanding why decisions were made without the "disability lens" in the first place, the danger is that the differences posed by disability will continue to be unaccounted for or overlooked. To put it differently, persons with disabilities could simply be ignored. The potential consequences of such invisibility mean persons with disabilities continue to be excluded from full political, social and economic participation – despite the formal equality guarantee under section 15 of the *Canadian Charter of Rights and Freedoms*.[15] David Lepofsky and Randal Graham express this succinctly: "Those who design, draft, or implement legislation have a fundamental duty to ensure that persons with disabilities can fully participate in and enjoy the rights, duties, and benefits that the legislation creates."[16]

1.2 Relevance, contributions and the expected benefits

Before explaining the relevance of this case study, it is important to situate myself in relation to this research. Prior to my doctoral work, I have been (and still am) a "policy wonk"

Fairest of Them All?' (2006) 2 SCLR 135.

[11] Law Commission of Ontario, *The Law as it Affects Persons with Disabilities: Consultation Paper* (Toronto: Law Commission of Ontario, 2011) at 8.

[12] M David Lepofsky & Randal N M Graham, "Universal Design in Legislation: Eliminating Barriers for People with Disabilities" (2009) 30:2 Statute Law Rev 97.

[13] Catherine Frazee, Joan Gilmour & Roxanne Mykitiuk "Now You See Her, Now You Don't: How Law Shapes Disabled Women's Experience of Exposure, Surveillance, and Assessment in the Clinical Encounter" in Dianne Pothier & Richard Devlin eds, *Critical Disability Theory: Essays in Philosophy, Politics, Policy and Law* (Vancouver: UBC Press, 2005) 223.

[14] For example, see Marcia Rioux, Joan Gilmour & Natalia Angel-Cabo, "Negotiated Capacity: Legally Constructed Entitlement and Protection" in Bernadette McSherry & Ian Freckelton, eds, *Coercive Care: Rights, Law and Policy* (New York: Rouledge, 2013) 51. C Tess Sheldon, Karen R Spector & Mercedes Perez, "Re-Centering Equality: The Interplay Between Sections 7 and 15 of the Charter in Challenges to Psychiatric Detention" (2016) 35 NJCL 193.

[15] *Canadian Charter of Rights and Freedoms*, Part I of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (UK), 1982, c.11.

[16] Lepofsky & Graham, *supra* note 12 at 98.

for many years. I am part of a policy generation that has lived through the upheavals brought on by New Public Management and other "flavour of the month" public management techniques. Despite changes in techniques, paradigms, and people, a common thread across time and subject matters is the pervasiveness of regulation. Regulation – especially in the form of black letter law – remains an important tool in the policy toolbox and I have attempted to use it to solve many pressing (and not so pressing) public policy problems. Over the years, I have contemplated why we choose to regulate certain behaviours and not others and the implications of such choices. Although this dissertation is by no means a much longer version of my day job, it is reflective of my own experiences in encountering regulation in Ontario. I also acknowledge that I am part of the governmental machinery that contributes directly or indirectly to the regulatory picture that I am trying to present here. As such, I do not claim to be neutral in the sense of not having a vested interest in the status quo or being free from any preconceived notions about what the most pressing public policy problems are. Rather, I draw upon my own observations, unanswered questions, conflicting opinions and even hunches developed through many different projects over the years to inform my research methodology and interpretation of research findings.

One of the questions that has always troubled me is how do we know the effect of a new or amended regulation *a priori*. Most certainly, one could do jurisdictional research, develop sophisticated economic models, or simply ask those who will be affected by the proposed regulation. The latter is rather tricky. We do not always know how to identify correctly who will be affected, how and when. This problem can be partially solved if there are well-positioned stakeholders who would not hesitate to share their thoughts about a proposed initiative. However, I have come to realize that the bigger problem is that the impact of law is mediated by social locations such disability, gender, age, immigration status and race and we do not pay enough attention to how the law affects different people differently in order to design regulation that is more sensitive to the intersection of privileges and disadvantages. We may not even know the impact *ex-poste* because the most marginalized groups are least likely to be well-represented – legally and politically – so that their concerns can be heard. Accordingly, the promise and limitations of regulation (by way of law) as a means of addressing public policy problems are not really well understood from a practical perspective – until it is too late. A case in point is the various seemingly benevolent social policies tailored for disabled people, such as institutionalization of people with intellectual disabilities.[17] It was this sense of a real world puzzle that motivated me to undertake this project. This comprehensive study of the new legal framework for the LTC sector will be relevant to policy makers, advocacy groups, industry associations and unions. The research findings will generate benefits in three main areas.

First, this dissertation aims to advance an understanding of how regulation and governance of a public benefit scheme affect its beneficiaries as well as others involved, such as the workers who implement the scheme and the families and friends of the beneficiaries of the scheme. As well, in addition to addressing questions of entitlement (such as who is entitled to which benefits for what duration), regulation and governance also directly construct other aspects of a benefit scheme, such as the responsibilities and rights of the state and service providers. I attend to other aspects of a public benefit scheme that have received less attention in the disability and the law literature and I borrow from the regulation and governance literature, which includes debates about legally mandated participatory mechanisms as well as compliance and enforcement. The research aims to be meaningful to the users of public benefit schemes that are intended to mitigate the effects of disability in a society where the perception of whether disabled people are "deserving"[18] of state support continues to evolve.

Next, this research will be also valuable in instrumental terms as the case study includes examples of regulatory tools commonly used, such as increasing transparency, promoting capacity for users / consumers seeking redress, and more generally clarifying accountability relationships and responsibilities.[19] As regulation is used increasingly to pursue welfare goals,[20] there is a need to examine whether such techniques have anything to offer contemporary public benefit schemes. I agree with Cass Sunstein that the experience of the regulatory state includes

---

[17] Dorothy M Griffiths, Frances Owen & Rosemary A Condillac, eds, *A Difficult Dream: Ending Institutionalization for Persons with Intellectual Disabilities with Complex Needs* (Kingston, New York: National Association for the Dually Diagnosed, 2016); Kelley Johnson & Rannveig Traustadottir, *Deinstitutionalization and People with Intellectual Disabilities: In and Out of Institutions* (London: Jessica Kingsley Publishers, 2005); Karen Watchman, "The Intersectionality of Intellectual Disability and Ageing" in Sue Westwood, ed, *Ageing, Diversity and Equality: Social Justice Perspectives* (Abingdon, Oxon ; New York, NY : Routledge, 2019) 245; Harvey G Simmons, *From Asylum to Welfare: The Evolution of Mental Retardation Policy in Ontario from 1831 to 1980* (Toronto: National Institute on Mental Retardation, 1982).

[18] Bill Hughes, "Disabled People as Counterfeit Citizens: The Politics of Resentment Past and Present" (2015) 30:7 Disability & Society 991.

[19] Colin Scott, "From Welfare State to Regulatory State: Meta-Regulation and Beyond" (2014) 11 University of Tokyo Journal of Law and Politics 159.

[20] David Levi-Faur, "The Welfare State: A Regulatory Perspective" (2014) 92:3 Public Administration 599.

many self-defeating regulatory strategies, which are “strategies that achieve an end precisely opposite to the one intended, or to the only public-regarding justification that can be brought forward in their support.”[21] Problems created by either government regulation or private markets are too particular and too dependent on the context of the problems they purport to solve. It is far more helpful to rely on particularized understandings of how both markets and regulation tend to break down in proposing reforms for the regulatory state.[22] This dissertation will be of particular interest to those who are interested in both normative and empirical questions about regulation. Public administrators, poverty law lawyers, and advocacy groups will find the discussion about the tools used in governing the LTC sector to be relevant to other public benefit schemes.

Finally, this dissertation helps to illuminate the range of Canada’s policy responses to an aging population. Aging is both a biological and a socio-cultural process, primarily measured in chronological years and coupled with age-based expectations.[23] It is a “problem” because of the extensive health care (and other) resources required by older adults.[24] Similar to other OECD countries, Canada is aging[25] and there is no shortage of responses to that from governments, think tanks, academics and so forth. Public and media commentary tends to rely on the imagery of “silver tsunami” to convey the challenges related to an aging population.[26] But scholars have challenged alarmist predictions about the growth and potential implications of population aging. Nonetheless, there is also agreement that population aging will require increased government spending, especially in such policy fields as health care, home care and public pensions.[27] For the group of older adults who are perceived to be located outside of the “successful aging”

---

[21] Cass Sunstein, “Paradoxes of the Regulatory State” (1990) 57 U Chi L Rev 407 at 407.

[22] *Ibid* at 441.

[23] Amanda Grenier, Meredith Griffin & Colleen McGrath, “Aging and Disability: The Paradoxical Positions of the Chronological Life Course” (2016) 12:2–3 Review of Disability Studies: An International Journal 11 at 12–13. For a discussion on attempts to identify a demographic marker as the basis for a socially and legally recognizable status of old age, see Margaret Isabel Hall, “Old Age (or, Do We Need a Critical Theory of Law and Aging) Special Topic: Aging: Discussion Piece” (2014) 35 Windsor Rev Legal Soc Issues 1.

[24] For example see Katie Aubrecht & Tamara Krawchenko, “Disability & Aging: International Perspective” (2016) 12:2–3 Review of Disability Studies: An International Journal 1.

[25] Statistics Canada, *Women in Canada: A Gender-based Statistical Report (Senior Women)* (Ottawa: Statistics Canada, 2016).

[26] Kenneth Kernaghan, “Serving Seniors: Innovation and Public Sector Service Delivery” (2015) 20:1 The Innovation Journal: The Public Sector Innovation Journal Article 3.

[27] Also for a discussion on funding for LTC (in community and institution) see Sharon Vanin & Owen Adams, “Funding Long-Term Care In Canada: Issues and Options” (2016) 15:4 HealthcarePapers 7; Sharon Vanin & Owen Adams, “It’s Time for a National Conversation about Long-Term Care Funding” (2016) 15:4 HealthcarePapers 55; Kernaghan, *supra* note 26.

paradigm, “which emphasizes health and functionality, absence of diseases and disability, and active engagement”,[28] their apparent dependency is constantly being scrutinized and measured in financial terms. Gender analysis, Charmaine Spencer and Ann Soden argue, needs to consider the short and long-term impact of policies and trends across the lifespan, the cumulative impact of discrete government policies, as well as the differential impact of policies on older couples and unattached older persons.[29] In light of the reality that most older adults, as well as those who care for them, are women, it is critical that scholars examine and expose the legal frameworks that define the personal, health, and income security of older adults. Law reform must take account of this reality and ensure that such “reform” does not exacerbate existing discrimination against and injustice towards older as well as younger women.[30] As Spencer and Soden observe, there is strong need for critical legal analysis in the areas of law affecting older adults since the law is rarely neutral or objective in its application to the lives of older adults. Analysis will need to examine the intersection of aging, gender, ability, race and other statuses in the context of social policy and law.[31]

This dissertation contributes to a broader debate about our collective responsibilities to those who require more resources for a variety of reasons, many of them older women with disabilities and diagnoses of serious illnesses. LTC is perceived to be a resource-intensive type of care and is often positioned as a last resort for those who could not remain in the community. By taking a critical look at LTC as an example of a policy response related to aging, this dissertation will have practical value to those who are interested in using law to recognize and respond to differences associated with (though not exclusively attributed to) aging.[32]

1.3 Hypothesis

The changes to regulation and governance of LTC homes in Ontario made between 2004 and 2018 – *if properly understood and implemented* – are significant for persons with

---

[28] Hailee M Gibbons, “Compulsory Youthfulness: Intersections of Ableism and Ageism in ‘Successful Aging’ Discourses” (2016) 12:2–3 Review of Disability Studies: An International Journal 70.

[29] Charmaine Spencer & Ann Soden, “A Softly Greying Nation: Law, Ageing and Policy in Canada” (2007) 2 J Int’l Aging L & Pol’y 1 at 6.

[30] A Kimberley Dayton, “Chapter 4 A Feminist Approach to Elder Law” in Israel Doron, ed, *Theories on Law and Aging: The Jurisprudence of Elder Law* (Berlin: Springer, 2009) 45.

[31] Spencer & Soden, *supra* note 29 at 29.

[32] For example see Hall, *supra* note 23.

disabilities. The substantive changes can be explained as fragmented efforts to improve the safety, physical survival and security of individual residents, premised on the medical model of disability and presumed gender neutrality. Part of my hypothesis is that these changes are also about strengthening or creating additional processes and procedures for participants – homes, residents, families, advocacy groups, industry organizations and government - to problem-solve challenges in the sector. I contend that while these procedures may not fundamentally improve the provisions of care, they may present themselves as opportunities for residents with disabilities to make claims on the larger society for inclusion and participation in making decisions about regulatory regimes or public benefit schemes. However, these processes and procedures are more likely to create an appearance of legitimacy of decisions – often made without adequate consideration of gendered disability. The result is a gap between the promise of the law and the reality of those who cannot enjoy its protections and benefits unless the appropriate supports are put in place.

1.4 Scope of the dissertation

Before I expand on how this dissertation will proceed, I should clarify the scope of this project. The boundary of what constitutes "regulation and governance" is difficult to pin down as many scholarly definitions and categorizations exist. This project concerns the tangible instruments through which the provincial government governs and regulates the LTC sector. Obviously, law found in statutes and in judicial decisions is an important instrument. But this is still too broad for my project given length limitations. I restrict my research to statutes enacted by the province and related soft law. With respect to the scope of judicial decisions, this research project does not include criminal law judicial decisions (such as homicide, murder, assault and sexual assault), private law judicial decisions (such as tort and contract) related to care, and decisions of regulatory colleges.

1.5 Roadmap of the dissertation

In Chapter 2, I engage the literature on regulation and governance as well as disability studies to set out the key definitions used in this dissertation. The chapter then engages the powerful criticisms of "care" in order to illustrate tensions inherent in LTC from a disability perspective. I make the case for advancing our understanding of caring relationships in the LTC context as a way to move away from dichotomies such as helper / helped. Caring relationships are shaped by, among other political and market forces, the legal and administrative structure of a benefit scheme or a regulatory regime. The changes to regulation and governance of LTC homes in Ontario can be accounted for by the New Governance literature. The methodology chapter (Chapter 3) will outline the research methods used: document review, legal analysis and key informant interviews.

Then I move on to the empirical chapters of this dissertation. Chapter 4 provides the background and context of analysis including the themes in LTC research grounded in the feminist political economy tradition. These themes provide constructive criticisms of LTC as currently conceived and suggest gaps in current research. The next four chapters present a comparison of the new and previous regimes in order to identify the recent changes to the regulation and governance of LTC in Ontario between 2004 and 2018: Chapter 5 explores what care means in LTC and how the law constructs care; Chapter 6 is devoted to describing how the notion of safety and security of the person is reflected in the regulatory changes; Chapter 7 interrogates participation and inclusion of residents and families in LTC homes; and Chapter 8 turns to the broader structural issues of the LTC sector and how law is implicated in those changes. In Chapter 9, I contend that many of the changes actually have taken into account criticisms of care, including the harm that can result from care. The main problem, I argue, is that the legal mechanisms are designed without careful consideration of how the actual circumstances of residents, connected to the intermeshing of disability, gender and age, will impact their proper implementation. The result is that some LTC applicants and residents cannot benefit from the protections offered by law. I demonstrate that the effectiveness of legally-enabled participation – for residents as well as families - is contingent upon having the necessary supports in place. The supports must go beyond reasonable accommodation of the physical impairments of residents. The necessary supports must also respect the autonomy of residents and need to be understood within the context of relationships in a home. Chapter 9 ends with a summary of the theoretical contributions of this dissertation. The final chapter summarizes the limitations of the research – doctrinal and methodological – and proposes directions for future research.

2 Literature Review: Theorizing the Regulation and Provision of Care

2.1 Introduction

The scholarly debates outlined in this chapter are intended to reflect the dual purposes of the contemporary LTC home program in Ontario. My starting point is that the program is a public benefit scheme as well as a regulatory regime. It is a public benefit scheme in that it confers rights, benefits and entitlements to residents according to a set of criteria in law. It is a regulatory regime, in that it also prescribes requirements and standards for those involved in the provision of care and treatment in LTC homes. The purpose of this chapter is two-fold: to identify the definitional issues and to situate my research in relation to existing scholarly debates.

This chapter engages debates in the regulation and governance literature and disability studies and it explains how these two bodies of work are brought together. The first section presents key definitions and assumptions used in this dissertation. In the second section, I draw on the criticisms of the concept of care to illustrate the theoretical considerations about studying LTC from a disability perspective. It is tempting to concede that the concept of "care" cannot be rescued from the legacy of institutionalization and the harmful impact of the "caring for" attitude. However, I contend that an unequivocal rejection of the concept of care is not necessary. In fact, an exploration of the competing understandings of "care" in disability studies and care research respectively can provide the basis for a richer and more comprehensive account of care in LTC. Indeed, caring relationships can be the conceptual bridge between disability studies and care research. I make the case for advancing our understanding of caring relationships in the LTC context as a way to move away from dichotomies such as helper / helped.[33] The focus of my research is on the law and caring relationships. Caring relationships are shaped by, among other political and market forces, the legal and administrative structures of a benefit scheme or a regulatory regime. To evaluate the changes to regulation and governance of LTC homes introduced between 2004 and 2018 in Ontario, I attend to aspects of the New Governance literature in an attempt to tease out the themes of negotiating tensions and contradictions in LTC and inclusion and meaningful participation opportunities for persons with disabilities.

---

[33] I thank Linda Steele for a discussion about how to move away from dichotomies such as "offender/victim" and "helper/helped".

The conceptualization of care that I offer here can be summarized as follows. First, care is grounded in caring relationships and is fundamentally important for human survival; that care embodies intermingled needs and interests of all involved in caring relationships but must also recognize the actual and potentials for harm in caring. Second, caring relationships are constructed by law in many different ways and the promotion of caring relationships is simultaneously limited by current legal tools such as “rights”. Third, caring relationships are shaped by the administrative processes and legal structures of public benefit schemes and regulatory regimes, many of which are indicative of the role of the state in supporting or neglecting care regardless of the setting in which care occurs.

The themes discussed in this chapter contribute to the unpacking of the complexity of tensions inherent in a legislative scheme that is closely connected to disability, gender and age. This discussion provides a foundation for describing and evaluating the changes in the regulation and governance of LTC. I will return to theoretical debates more specifically on LTC in Chapter 4 “Background” where I will draw on the themes in the feminist political economy literature.

2.2 Definitions of key terms and assumptions used in this dissertation

In this section, I will present the definitions and assumptions used in this dissertation. I will begin with key concepts used in the regulation literature to illustrate the debate about the tendency to deploy and privilege regulation. Then I will examine some of the concepts used in the disability studies literature that will guide my understanding of the case study (i.e., LTC in Ontario). Together the definitions in both fields provide a language to engage the theoretical debates and later the case study.

2.2.1 Governance through regulation

This dissertation concerns a case study that illustrates changes to “regulation” and “governance”. The concepts of “regulation” and “governance” are both contested and used inconsistently across a broad range of academic disciplines as well as within policy / political discourses. This brief section does not intend to match the breadth and depth of debates about definitions of these concepts in academic writings; rather, it aims to present my working definitions in order to illustrate the study focus of my research question.

2.2.1.1 The rise of the regulatory state

In this research project, the gradual expansion of the reach of regulation (especially in the form of law) is conceived as part of larger phenomenon – the rise of the regulatory state. The most obvious starting point for this discussion is the emergence of two modes of governance: the "old" post-war welfare state, distinguished from the regulatory state, which is something "new"[34]. Here the term 'welfare state' refers to *an ideal* - or at least acceptable - political and social compromise by proponents of egalitarian social policies. The term welfare state is used as an indication of the growth of the functions and capacities of the state within the social policy realm.[35] The welfare state is frequently associated with fiscal transfer, such as taxation and spending, as its choice of instrument.[36] More recently, one could speak of *the rise of the regulatory state*,[37] which is identified with the "application of informal and formal bureaucratic rule making, rule monitoring, and rule enforcement."[38] The rise of regulation and the regulatory state reflects the tendency to deploy and privilege regulation. In a nutshell, the regulatory state is a state that specializes in control via rules (rather than only in taxation and service provision).[39]

David Levi-Faur's view is that the regulatory state and the welfare state can coexist, and that the regulatory state may strengthen the welfare state.[40] To be certain, Levi-Faur is not suggesting that coexistence is necessarily always more progressive, egalitarian, or welfare maximizing. In fact, the most useful insight for this case study is his characterization of the choice between social regulation and social expenditures. By presenting nine different possible combinations of social regulation and fiscal expenditures using examples of rent control, parental leave and tax expenditures, Levi-Faur argues that the state can retrench, stagnate, and

---

[34] Luiz Leisering & Deborah Mabbett, "'Introduction: Towards a new Regulatory State in Old Age Security? Exploring the Issues'" in Luiz Leisering, ed, *The New Regulatory State: Regulating Pensions in Germany and the UK* (London: Palgrave Macmillan, 2011) 1 at 5.

[35] Levi-Faur, *supra* note 20 at 602; Michael Taggart, "The Nature and Functions of the State" in Mark Tushnet & Peter Cane, eds, *The Oxford Handbook of Legal Studies* (Oxford: Oxford University Press, 2005) 101 at 101.

[36] Levi-Faur, *supra* note 20 at 599.

[37] Michael Moran, "Review Article: Understanding the Regulatory State" (2002) 32:02 British Journal of Political Science 391; Jacint Jordana & David Levi-Faur, "The Politics of Regulation in the Age of Governance" in Jacint Jordana & David Levi-Faur, eds, *The Politics of Regulation: Institutions and Regulatory Reforms for the Age of Governance* (Cheltenham, UK: E. Elgar, 2004) 1; Karen Yeung, "The Regulatory State" in Robert Baldwin, Martin Cave & Martin Lodge, eds, *The Oxford Handbook of Regulation* (Oxford: Oxford University Press, 2010) 64.

[38] David Levi-Faur, "The Odyssey of the Regulatory State: From a 'Thin' Monomorphic Concept to a 'Thick' and Polymorphic Concept" (2013) 35:1–2 Law & Policy 29 at 30.

[39] *Ibid*.

[40] Levi-Faur, *supra* note 20 at 599–600.

expand with the retrenchment, stagnation, and expansion of each of the instruments (i.e., regulation and fiscal transfers) independently.[41] Accordingly, it makes more sense to describe welfare as a desired aim and regulation as an instrument. They should be brought together, not as a trade-off but as mutually constitutive.[42] As such, the application of regulatory instruments and fiscal transfers are political options rather than guarantees of a certain policy outcome.[43] Levi-Faur invites us to "identify the various ways in which fiscal and regulatory instruments are used and mixed in the design of a welfare regime".[44]

The notion of governance here is understood as "the changing boundaries between the public, private and voluntary sectors, and the changing role of the state"[45], as articulated by Rod Rhodes. To be certain, this understanding of governance appears to be transitional, contingent and contentious in nature.[46] This may be attributed to Peer Zumbansen's observation that governance illustrates the tension between state and non-state based conceptualization of political and social order.[47] In law, references to "governance" point to the "transformational character of existing institutional frameworks of order."[48] Further, in the public law context, governance "carries the burden of being the construction site for an encompassing reconsideration of the particular "public" nature of legislation, administration and adjudication."[49] "Public governance" is the manner, method, or system by which a particular society is steered or directed. Although public governance generally gives government a privileged role, this does not mean that government is the only institution steering or directing society.[50]

The "relative openness of the concept"[51] of governance debate raises the question of

---

[41] *Ibid* at 604–605.
[42] *Ibid* at 611.
[43] *Ibid* at 599–600.
[44] *Ibid* at 609.
[45] R A W Rhodes, "Waves of Governance" in David Levi-Faur, ed, *The Oxford Handbook of Governance* (Oxford: Oxford University Press, 2012) 32 at 32. See also Black, *supra* note 6.
[46] Peer Zumbansen, "Governance: An Interdisciplinary Perspective" in David Levi-Faur, ed, *The Oxford Handbook of Governance* (Oxford: Oxford University Press, 2012) 83 at 83. Zumbansen suggests that all engagement with the concept of governance must appear transitional and contentious in nature.
[47] *Ibid* at 89.
[48] *Ibid* at 90.
[49] *Ibid*..
[50] Eric Windholz, *Governing through Regulation: Public Policy, Regulation and the Law* (New York: Routledge, 2017).
[51] Zumbansen, *supra* note 46 at 83.

whether the concepts of regulation and governance can be used interchangeably. I adopt Julia Black's position that the concept of "regulation" is distinct from the governance debate.[52] Black reflects on the ever-expanding nature of "regulation"[53] and argues that a more fruitful task of the concept of "regulation" is to enable us "to see control, power, and ordering in unsuspected places, and as affected by unsuspected actors."[54] Accordingly, Black's articulation of the concept of regulation puts an emphasis on what the concept is intended to do: "regulation is a process involving the sustained and focused attempt to alter the behaviour of others according to defined standards or purposes with the intention of producing a broadly defined outcome or outcomes."[55] In sum, regulation is defined as an instrument of control.[56] An important point about this definition is that the activity of regulation (i.e., activity of attempting to control) can be de-coupled from the activities of governmental actors.[57] The decoupling of regulation from governmental actors is tied to the use of the concept of de-centring. While it encompasses many notions, de-centring is often used to express the observation that governments do not, and the proposition that they should not, have a monopoly over regulation.[58] Rather, regulation is occurring within and between other social actors such as associations and professional organizations – without the government's involvement or indeed formal approval.[59] While there are other uses of the concept of de-centring,[60] this use is particularly relevant to my research question because regulation in the health care sector often involves other non-governmental actors with formal legal authority, such as regulatory colleges[61] as well as those without formal legal authority, such as professional associations.

Another point about regulation that is relevant for this research is that regulation should not be treated as an *undifferentiated whole* and can be distinguished according to function.[62] The inquiry into regulatory functions is a normative inquiry into "what sort of problem the statute is

---

[52] Black, *supra* note 6.
[53] *Ibid* at 133.
[54] *Ibid* at 142.
[55] *Ibid*.
[56] Levi-Faur, *supra* note 38 at 46.
[57] Black, *supra* note 6 at 142.
[58] *Ibid* at 103.
[59] *Ibid* at 103–104.
[60] *Ibid* at 104.
[61] *Regulated Health Professions Act, 1991,* SO 1991, c 18.
[62] Cass R Sunstein, *After the Rights Revolution: Reconceiving the Regulatory State* (Cambridge, Mass: Harvard University Press, 1990) at 48.

most sensibly understood as addressing, and how the problem can most sensibly be resolved".[63] Sunstein proposes that statutes may be categorized as responses to the following: market failures, public-interested redistribution, collective desires and aspirations, diverse expectations and preference formations, social subordination, endogenous preferences, the problem of irreversibility, and finally interest group transfers and rent-seeking.[64] The "problem-solving" nature of regulatory inquiry points to the possibility of multiple functions that any regulation may serve. This informs how I interpret the regulatory changes in my case study.

Finally, I understand regulation in a substantive sense,[65] and therefore, adopt the position that the content of regulation has distributive and redistributive implications.[66] More specifically, regulation is not necessarily regressive nor the opposite of egalitarian: it all depends on how, when and to what end a regulation is put to use.[67] Following this line of reasoning, scholars must identify "the ways in which regulatory solutions that were intended to promote social justice are, in fact, experienced in people's lives as new sources of unequal and unjust power and difference."[68] This invites us to study empirically how regulatory effects occur and why they succeed or fail. As such, any endorsement or defense of government regulation should be balanced with a discussion of the instances in which regulation has failed.[69]

2.2.1.2 Who regulates and how?

A good starting point is to identify the conventional categories of regulation as instrument. At one end of the spectrum is the so-called "command and control" regulation, which is also known as "direct regulation". Behaviours expected of regulated entities can be specified with considerable clarity, making it relatively straightforward to identify breaches of legal standard and to enforce the law in the event of a breach. However, command-and-control

---

[63] *Ibid* at 73.
[64] *Ibid* at 48–71.
[65] Levi-Faur, *supra* note 20 at 603.
[66] Levi-Faur, *supra* note 38 at 46.
[67] *Ibid* at 45; Hanan Haber, "Regulation as Social Policy: Home Evictions and Repossessions in the Uk and Sweden" (2015) 93:3 Public Administration 806.
[68] Christine Parker, "Twenty Years of Responsive Regulation: An Appreciation and Appraisal" (2013) 7:1 Regulation & Governance 2 at 9.
[69] Sunstein, *supra* note 21; Stephen M Griffin, "Mending the Regulatory State" (1992) 11:3 Law and Philosophy 291.

regulation has also been criticized as being rigid, unresponsive and prescriptive.[70] At the other end of spectrum is self-regulation, where regulated entities themselves are responsible for developing and implementing the regulatory regime.[71] It is argued that self-regulation offers a number of strengths: greater speed, sensitivity to market circumstances, efficiency, and less government intervention. However, self-regulation may operate in service of the private interests of those who develop and implement it.[72] Between these two extremes, there are a variety of ways to account for how regulatory instruments are understood and used. Three concepts are particularly useful for my research: co-regulation, risk-based regulation and social regulation.

Co-regulation

The concept of co-regulation eloquently captures the phenomenon that numerous actors are involved in regulation, not just the government. According to Eric Windholz, co-regulation is situated between the extremes of government regulation and self-regulation and promises the best of the two extremes, while minimizing the disadvantages of each.[73] Co-regulation exists where government and regulated entities co-operate in the development and implementation of the regulatory regime.[74] Regulatory capture occurs when regulatory officials who are responsible for promoting collective welfare develop such close relationships with regulated entities that they promote the interests of this group instead of the public interest of the broader community.[75] The promise of co-regulation is that regulation is better targeted, more flexible, less burdensome and more effective than government regulation, but has the benefit of government involvement, which protects against the system being captured, compromised or manipulated. To be effective, co-regulation requires regulated entities to take responsibility for their own performance, and government to actively monitor how they discharge those responsibilities.[76] Four common models of co-regulation – facilitated co-regulation, devolved co-regulation, delegated co-regulation and enforced co-regulation – are used to illustrate the level of government

---

[70] For a comprehensive review of the competing understandings and criticisms of the concept of "command-and-control" in the literature, see Jodi L Short, "The Paranoid Style in Regulatory Reform" (2011) 63 Hastings LJ 633.

[71] Windholz, *supra* note 50 at 161.

[72] *Ibid* at 162.

[73] *Ibid* at 162–163.

[74] *Ibid*.

[75] Bronwen Morgan & Karen Yeung, *An Introduction to Law and Regulation: Text and Materials* (Cambridge: Cambridge University Press, 2007) at 43; Windholz, *supra* note 50 at 43–45.

[76] Windholz, *supra* note 50 at 164.

involvement. The scope of co-operation may vary as long as the regulatory arrangements are grounded in co-operative techniques and the legitimacy of the regime rests partly on public-private cooperation.[77]

Risk-based regulation

Listing which parties are involved in regulation tells us little about how regulation occurs. There is a rich literature on regulatory approaches and here I will just refer to one that is relevant to the case study. Risk, as Michael Moran puts it, has increasingly come to assume a central place in the analysis of the regulatory state.[78] In particular, a common account of what is shaping the regulatory state is that "risk and its management are critical social processes determining both the generation of regulatory failures and expansion of regulatory spheres."[79] The rise of risk-based regulation is part of broader efforts to make regulations more rational, analytical and orderly.[80] Scholars such as Eric Windolz, Julia Black, Martin Lodge, Paul Almond and Mike Esbester have traced how risk-based regulation is becoming a familiar regulatory strategy across a wide range of areas – from occupational health and safety to financial management – across the globe. Generally, systematic risk management has come to be used as a means of ensuring sustainable "good" governance.[81] "Risk", understood as the likelihood and seriousness of a particular harm, guides decisions about resource-allocation.[82] The core principle of risk-based regulation is deceptively simple: regulators should focus their efforts on the most serious risks that they face in achieving their objectives."[83] Such an approach admits to the existence of issues that are deemed to be low-risk i.e., issues that the regulator has chosen not to address.[84] Voluntary and self-regulatory methods are used if there is sufficient capacity and motivation to suggest that acceptable levels of compliance can be sustained via less intrusive means than state-

---

[77] David Levi-Faur, "Regulation and Regulatory Governance" in David Levi-Faur, ed, *Handbook on the Politics of Regulation* (Cheltenham, UK: Edward Elgar, 2011) 3 at 10.
[78] Moran, *supra* note 37 at 407.
[79] *Ibid*.
[80] Windholz, *supra* note 50 at 239.
[81] Paul Almond & Mike Esbester, "Regulatory Inspection and the Changing Legitimacy of Health and Safety" (2018) 12:1 Regulation & Governance 46.
[82] *Ibid*.
[83] Robert Baldwin & Julia Black, "Driving Priorities in Risk-based Regulation: What's the Problem?" (2016) 43:4 Journal of Law and Society 565.
[84] Julia Black & Robert Baldwin, "When Risk-Based Regulation Aims Low: Approaches and Challenges" (2012) 6 Regulation & Governance 2 at 2; Windholz, *supra* note 50 at 239.

led inspection. But identification, selection and prioritization of risks inevitably involve normative and political choices.[85]

Social regulation

Finally, the term "social regulation" is also relevant to this project**.** Traditionally, "social" and "economic" regulation have been conceptualized as contrasting policy pairs: economic regulation is designed to improve economic and market efficiency, while social regulation is designed to produce socially desirable outcomes either by correcting for the damaging effects of economic activity or by producing outcomes different to and better than those produced by efficiently operating markets.[86] However, the distinction between social regulation and economic regulation tends to be rigid, as increasingly, governments are using regulation to deliver social goals traditionally delivered through direct government action and using economically-based regulatory techniques to define and solve social problems.[87] Eric Windholz and Graeme Hodge are correct to point out that regulation is underpinned by a mix of interconnected and interdependent social and economic values. The distinction between social and economic regulation resides in the primacy of the values each is designed to advance while recognizing the presence of secondary values in defining the boundaries and providing the foundations for the stability and legitimacy of the regulatory regime.[88] For this reason, it is important that regulators acknowledge and substantively address the implicit role that "supporting values" play in their work.[89] For social policy such as LTC, regulators are also concerned about values such as efficiency and competition. I suggest that we need to go beyond the social values that regulators purport to support and unpack the secondary values. Equally important, it should be no surprise that economic regulation such as those related to corporate governance, securities law, and competition law affect the delivery of social policies.

---

[85] Baldwin & Black, *supra* note 83 at 566.
[86] Eric Windholz & Graeme A Hodge, "Conceptualising Social and Economic Regulation: Implications and Economic Regulation: Implications for Modern Regulators and Regulatory Activity" (2012) 38 Monash U L Rev 212.
[87] *Ibid*.
[88] *Ibid* at 216.
[89] *Ibid* at 235.

Law is central to regulation and governance.[90] As Almond and Esbester explain: "The regulation of conduct via law is a key mechanism through which broader social meanings are negotiated and expressed."[91] To understand the law's role in regulation and governance, I pay attention to law's content as well as different forms of law.[92] In this dissertation, I focus on what law *does* rather than what it is in some philosophical sense. The definition of law is as follows: "law is a system of rules to govern behavior enforced through institutions created for that purpose."[93] In other words, this definition is instrumental in nature. One could speak of the functional and expressive roles of law. With respect to the functional role, the law shapes behavior, facilitates certain arrangements or functions, and adjudicates disputes. The law's expressive role refers to how the law discharges these functions and how it gives expression to important constitutional, democratic, ethical and shared societal values.[94]

One such value expressed in law is equality. The Supreme Court of Canada has noted that the equality guarantee is "perhaps the *Charter*'s most conceptually difficult provision."[95] Legal scholars have written extensively on s.15 jurisprudence and attended to the challenges of equality-seeking or equity-seeking groups. The inclusion of disability as a prohibited ground of discrimination in the *Charter* was the result of a long political struggle of Canadian disability organizations and activists. To understand the legal, social and political significance of disability within the context of equality-seeking, I now turn to the theorization of disability.

2.2.2 Disability: Beyond Barriers and Oppression

The field of disability studies is now established to the extent that it is populated with many theoretical perspectives and subsequent self-criticisms of those perspectives. For many activists and scholars, the departure point of disability politics and critical analysis is the social model of disability, which is a model based on the radical social interpretation of disability introduced by disabled activists such as Paul Hunt and Vic Finkelstein in the 1970s.[96] The

---

[90] For example see Margit Cohn, "Law and Regulation: the Role, Form and Choice of Legal Rules" in David Levi-Faur, ed, *Handbook on the Politics of Regulation* (Cheltenham, UK: Edward Elgar, 2011) 185.

[91] Almond & Esbester, *supra* note 81 at 46.

[92] Windholz, *supra* note 50 at 185.

[93] *Ibid* at 9.

[94] *Ibid*.

[95] *Law v Canada (Minister of Employment and Immigration)*, [1999] 1 SCR 497 at para 2.

[96] Carol Thomas, "Disability and Gender: Reflections on Theory and Research" (2006) 8:2–3 Scandinavian Journal of Disability Research 177 at 177.

original model (which has been subject to revisions and contestation[97]) suggests that limitations on activity experienced by disabled people are social in origin (not attributable to impairment such as blindness or deafness) and constitute a form of oppression (i.e., disablism). Thus, limits on activity imposed by disablism can be removed through social change.[98] In other words, the social model stands for the proposition that structural barriers – physical as well as attitudinal – lie at the root of the marginalization of disabled people.[99] For that reason, "the focus of analysis and action is on the state and ruling practices rather than solely or even primarily on individuals with disabilities and their families."[100]

But for the purpose of my case study, I take a different path to interpret the meaning and significance of disability. The main reason for not putting the social model at the centre of my theorization of LTC is that for many LTC residents, the health dimension of disability[101] is an important part of their lived experience at their stage of the life course. As well, removal of barriers (especially those identified and emphasized by early activists) will not be enough for LTC residents in order to address their disadvantages and difficulties. Oppression is not the sole explanation for all of the policy, financial and legal choices that created the current legal framework for LTC. It is more fruitful to engage the subsequent debates in disability that do not focus exclusively on barriers and oppression. I will present some of the concepts used in the disability scholarship that will guide my understanding of the debates about "care" in LTC, which will be presented later in this chapter. The interactional model of disability as proposed by Tom Shakespeare is used in this dissertation. I will make the case for connecting this approach with insights from feminist disability studies. This connection will lead us to the debate about care, which will be further linked to the feminist political economy literature (see chapter 4). Earlier scholars such as Jenny Morris, Adrienne Asch and Michele Fine brought forward some of the issues that most affected disabled women who were often at a relative disadvantage to both

---

[97] Mårten Söder, "Tensions, Perspectives and Themes in Disability studies" (2009) 11:2 Scandinavian Journal of Disability Research 67 at 71; Lisa Schur, Douglas Kruse & Peter David Blanck, *People with Disabilities: Sidelined or Mainstreamed?* (New York: Cambridge University Press, 2013) at 9–12; Mark C Weber, "Disability Rights, Welfare Law" (2010) 32 Cardozo L Rev 2483 at 2490–2491.

[98] Thomas, *supra* note 96 at 178..

[99] Ravi Malhotra & Morgan Rowe, *Exploring Disability Identity and Disability Rights Through Narratives: Finding a Voice of Their Own* (London; Routledge, 2014) at 2.

[100] Michael J Prince, "Canadian Disability Policy: Still a Hit-and-Miss Affair" (2004) 29:1 The Canadian Journal of Sociology 59 at 62.

[101] Shakespeare, *supra* note 4.

disabled men and non-disabled women, and that their specific issues and experiences remained invisible. These scholars direct our attention to the fact that historically, disabled women have had difficulty having their points of view acknowledged – both in the mainstream feminist movement and in the disabled people's movement.[102]

2.2.2.1 Impairment, disability and impairment effects

For disability activists and scholars, the distinction between impairment and disability has been crucial in the debate about transforming disabilities as private problems to public issues.[103] The term impairment refers to those variations in body and mind that biomedicine has classified as degrees of abnormality, whether life-long or acquired.[104] It follows that impairment is not the same as disability. For Carol Thomas, this distinction means "disability is first and foremost about the disadvantaged social status and inequitable life opportunities experienced by people whose bodies and minds are designated impaired by representatives of scientific medicine and other professions."[105] This definition reveals a key premise in the social model: disability is oppression.[106] Although Shakespeare does not agree that disability is oppression, he accepts the contextual nature of impairment. The key point is that impairments are never experienced abstractly; it is the social context - particular environments, value systems, and social relations - that can turn impairment into disadvantage.[107] I will return to the definition of disability later.

An important insight for my case study is the recognition that impairments often contribute to the disadvantage and difficulties experienced by persons with disabilities.[108] The significance of the personal and the experiential is a major contribution of Thomas. In particular, Thomas coins the term impairment effect to illustrate manifestation of impairment and

---

[102] Ana Bê, "Feminism and Disability: A Cartography of Multiplicity" in Nick Watson, Alan Roulstone & Carol Thomas, eds, *Routledge Handbook of Disability Studies* (Milton Park, Abingdon, Oxon: Routledge, 2012) 363 at 363–364.

[103] Simo Vehmas & Tom Shakespeare, "Disability, Harm, and the Origins of Limited Opportunities" (2014) 23 Cambridge Quarterly of Healthcare Ethics 41 at 44.

[104] Carol Thomas, "Disability and Diversity" in Steven Vertovec, ed, *The Routledge International Handbook of Diversity Studies* (London: Routledge, 2015) 43 at 43.

[105] *Ibid*.

[106] Tom Shakespeare, *Disability: The Basics* (Abingdon, Oxon; New York, NY : Routledge, 2018) at 13.

[107] Vehmas & Shakespeare, *supra* note 103 at 45; Tom Shakespeare, "Can Disabled People Be Healthy?" in Christopher Riddle, ed, *From Disability Theory to Practice: Essays in Honor of Jerome E Bickenbach* (Landham: Rowman and Littlefield, 2018) 61 at 64.

[108] Shakespeare, *supra* note 4 at 131.

embodiment: “the direct and unavoidable impacts that 'impairments' (physical, sensory, intellectual, emotional) have on individuals' embodied functioning in the social world. Impairments and impairment effects are always bio-social and culturally constructed in character, and may occur at any stage in the life course.”[109] She remarks that it is a hopeless quest to attempt to eclipse impairment effects by arguing that all restrictions of activity associated with being impaired have 'nothing to do with the body'.[110] However, she cautions not to mistake impairment effects for what are, in fact, disabilities.[111] Recognition of impairment and impairment effect has implications for theorizing supports and accommodations for disabled people. Although the provision of social support may mitigate the effects of many disabilities, it is impossible to completely eradicate the impact of serious disabilities, whatever services are provided.[112] Accordingly, the disability phenomenon cannot simply be reduced to barriers and oppression.[113] Furthermore, it is argued that it is often impossible to separate the impact of physical or mental impairments from the impact of disabilities caused by social barriers in real life.[114] Their impairments mean disabled people are to some extent, always already disadvantaged.[115] This poses a challenge for any theory of citizenship if the disadvantages of disabled people are to be removed at the structural level in order to achieve their full inclusion in all realms of our society.

2.2.2.2 Citizenship, Equality and Disablism

The notion of ‘citizenship’ or ‘citizen’ is frequently invoked in studies about public policy issues relevant to disabled people to illustrate how exclusion and the quest for inclusion in the social, economic and political realms of our society are constructed.[116] My research builds on

---

[109] Thomas, *supra* note 104 at 45.
[110] Carol Thomas, *Female Forms: Experiencing and Understanding Disability*, Disability, human rights, and society (Philadelphia, Pa: Open University Press, 1999) at 37–38.
[111] *Ibid* at 38.
[112] Jonathan Herring, *Caring and the Law* (Oxford: Hart Pub., 2013) at 28.
[113] Shakespeare, *supra* note 4 at 131.
[114] Schur, Kruse & Blanck, *supra* note 97 at 11.
[115] Tom Shakespeare & Nick Watson, “Disability and Social Justice” in Gary Craig, ed, *Handbook on Global Social Justice* (Cheltenham, UK: Edward Elgar, 2018) 201 at 202.
[116] For example see Ruth Bartlett, “Citizenship in Action: The Lived Experiences of Citizens with Dementia Who Campaign for Social Change” (2014) 29:8 Disability & Society 1291; Hughes, *supra* note 18; Michael Prince, *Absent Citizens* (Toronto: University of Toronto Press, 2009); Karen Soldatic & Helen Meekosha, “Disability and Neoliberal State Formations” in Nick Watson, Alan Roulstone & Carol Thomas, eds, *Routledge Handbook of Disability Studies* (Milton Park, Abingdon, Oxon: Routledge, 2013) 195; Gøril Ursin & Ann Therese Lotherington, “Citizenship as Distributed Achievement: Shaping New Conditions for an Everyday Life with Dementia” (2018)

Michael Prince's insights into the concepts of citizenship, inclusion and participation, as explained in *Absent Citizens: Disability Politics and Policy in Canada*. By way of background, citizenship is a leading discourse and a central target of policy reform in contemporary disability politics. Disability groups seek to achieve equality of status through full citizenship as well as to alter the language of the social policy community and wider society.[117] Framing disability in terms of citizenship is intended to accomplish the following:

> It offers a normative benchmark for evaluating existing services and benefits in terms of enabling or restricting the dignity and self-determination of persons with disabilities, and thus, by extension, advocating for reforms. It places responsibility on governments to respond to claims for equal status in the democratic community by committing public resources for promoting and protecting human rights. It argues for consulting with persons with disabilities as citizens on a host of policy areas, and for supporting a vibrant network of disability organizations at the national and local levels. It can draw these issues to the attention of wider publics and connect them to other equality seeking groups.[118]

Within Canadian disability policy and politics, the following elements of citizenship are particularly significant: the discourse of citizenship; legal and equality rights; democratic and political rights; fiscal and social entitlements; and economic integration.[119] Of particular interest to this project are legal rights, which are the first generation of citizenship rights in that they were the initial ones enacted by governments.[120] In law, substantive equality (as opposed to formal equality) continues to be the guarantee under s.15 of the *Canadian Charter of Rights and Freedoms*.[121] According to Carissima Mathen, formal equality requires that similar cases be treated according to similar principles. The formal aspect of equality incorporates the rule of law requirement against arbitrary treatment and is paramount in a just society.[122] In contrast, substantive equality requires taking into account of the social and economic context in which a

---

20:1 Scandinavian Journal of Disability Research; Ruth Bartlett et al, "Gender, Citizenship and Dementia Care: A Scoping Review of Studies to Inform Policy and Future Research" (2018) 26:1 Health Soc Care Community 14; Richard Devlin & Dianne Pothier, "Introduction: Toward a Critical Theory of Dis-Citizenship" in Richard Devlin & Dianne Pothier, eds, *Critical Disability Theory: Essays in Philosophy, Politics, Policy, and Law* (Vancouver: UBC Press, 2006) 1.

[117] Prince, *supra* note 116 at 15.

[118] *Ibid* at 17.

[119] *Ibid*.

[120] *Ibid* at 19.

[121] *Canadian Charter of Rights and Freedoms, Part I of the Constitution Act, 1982,* being Schedule B to the Canada Act 1982 (UK), 1982, c.11 [*Charter*].

[122] Carissima Mathen, "The Upside of Dissent in Equality Jurisprudence" (2013) 63:1 SCLR (2d) 111 at 123.

claim of inequality arises and the outcomes of a challenged law or action.[123] Thus, the concept of substantive equality calls for tailoring of institutional supports and resources to the different needs of individuals and groups.[124] Equality and inclusion are principles frequently invoked to legitimize claims for human rights, social acceptance, public participation, and an array of material benefits.[125] Later in this chapter, I will expand on the meanings of participation and inclusion in the literature.

The struggle for full citizenship can be linked to another concept deployed in disability studies: disablism. If disabled citizens remain outside of social, political and economic realms, it follows that an important line of inquiry in disability research is how restrictions or barriers are imposed on those categorized as disabled. The concept of disablism is closely associated with the relational nature of disability. The focus is on "the existence of relationships (at individual and institutional scales) between those designated normal and those designated disabled in any social arena. The non-disabled occupy positions of relative power and authority, for example within family settings, health and social services, workplaces, institutions of governance, or leisure arenas."[126] Accordingly, disablism refers to the social imposition of avoidable restrictions on the life activities, aspirations and psycho-emotional well-being of people categorised as 'impaired' by those deemed 'normal'. Disablism constitutes a form of social oppression in contemporary society - alongside sexism, racism, ageism, and homophobia.[127] Finally, disablism operates in numerous ways in the realms of ''the private'' and ''the personal'', not just in the public sphere ''out there'' in employment, education, housing, transport, and so on.[128]

2.2.2.3 Interactional or multi-factorial approach to disability

Disability's significance is in the "interactions between bodies and their social and material environments".[129] Few scholars would reject the relational nature of disability but they differ in how to reconcile it with the social model. Shakespeare rejects the social model and instead looks for ways to overcome such a strong emphasis on the structural aspects of

---

[123] *Ibid*. See also Lynn Smith & William Black, "The Equality Rights" (2013) 62 SCLR(2d) 301 at paras 9–11.
[124] Camilla Kong, *Mental Capacity in Relationship* (Cambridge: Cambridge University Press, 2017) at 24.
[125] Prince, *supra* note 116 at vii.
[126] Thomas, *supra* note 104 at 45.
[127] *Ibid* at 43.
[128] Thomas, *supra* note 96 at 182.
[129] Rosemarie Garland-Thomson, "Feminist Disability Studies" (2005) 30:2 Signs 1557 at 1557.

restrictions and exclusions experienced by disabled people. An interactional approach (also known as a relational understanding of or multi-factorial approach) to disability acknowledges the importance of environments and contexts, including discrimination and prejudice, but does not simply define disability as the external disabling barriers or oppression as proposed by the social model.[130] Shakespeare asserts that the experience of a disabled person results from the relationship between factors intrinsic to the individual (e.g., nature of impairment, personality, motivation, and attitudes) and extrinsic factors (e.g., environment, support system, and oppression). Contextual factors will also influence these intrinsic factors. He is careful to point out that contextual factors will influence these intrinsic factors: "impairment may be caused by poverty or war; personality may be caused by upbringing and culture etc".[131] One of the key strengths of the interactional model is that it highlights the various ways in which improvements to the situation of disabled people can be made, from medical interventions that restore functioning to anti-discrimination and attitudinal changes.[132] The issue is which approach is the most appropriate or cost effective for different impairments or specific individuals.[133]

The relevance of the interactional approach for understanding disability, gender and aging is that this approach pushes us to see that the term disability covers a multitude of conditions and states of being within those conditions.[134] And this approach will be even more powerful if it is linked with insights from feminist disability studies[135] (or feminist disability theory)[136], as termed by Rosemarie Garland-Thompson. Sources of human variations include but are not limited to different impairments, gender, sexuality, social class and stages of life.[137] The challenge is to account for the range and diversity of disability experience[138] but at the same time, not to treat differences such as gender in simple, additive terms.[139] Garland-Thompson

---

[130] Tom Shakespeare, *Disability Rights and Wrongs Revisited* (Abingdon, Oxon; New York: Routledge, 2013).
[131] *Ibid* at 75–76.
[132] *Ibid* at 82.
[133] *Ibid* at 83.
[134] Lennard Davis, Book Review of *Disability Rights and Wrongs Revisited* by Tom Shakespeare, (2015) 17:1 Scandinavian Journal of Disability Research 95 at 95.
[135] Garland-Thomson, *supra* note 129.
[136] Rosemarie Garland-Thomson, "Integrating Disability, Transforming Feminist Theory" (2002) 14:3 NWSA Journal 1.
[137] Rannveig Traustadottir, "Disability and Gender: Introduction to the Special Issue" (2006) 8:2–3 Scandinavian Journal of Disability Research 81 at 81.
[138] Shakespeare, *supra* note 130 at 80.
[139] Traustadottir, *supra* note 137 at 82.

challenges us to scrutinize differences: social labels such as "disabled" and "people of colour" capture the single, reductive, exclusionary social category that conflates and stigmatizes a range of differences.[140] Thomas argues that the social forces and processes that construct and give shape to both gender and disability are closely intermeshed.[141] She points out the complexity of "intermeshing":

> Of course, when we add other dimensions of social exclusion and ‘‘difference’’ into the equation ‘‘race’’ and ethnicity, sexuality, age and class then the picture becomes more complex. Disablism intersects with racism, homophobia, ageism and socio-economic stratification to generate intricate webs of disadvantage and exclusion. This gives rise to multiple and intertwined strands in our identities, and warns against bracketing disabled women or men into undifferentiated or fixed social groupings.[142]

One way to probe "intermeshing" is through the issue of health / illnesses and aging. This is important because as we will see in Chapter 4, the acuity of LTC residents has increased year-over-year and there is a need to theorize the health needs of residents using concepts in disability scholarship. This is challenging because the health needs of disabled people are rarely taken into consideration in disability studies.[143] Failure to meet general or impairment-related health needs is itself a disabling barrier; enabling better access to healthcare will enable individuals with impairments to be less excluded and have better quality of life.[144] One explanation of downplaying the health dimension of disability is that the field has tended to uncritically accept dualistic and opposing notions of health and illness.[145] There are exceptions to this tendency; one promising trend is research on theorizing chronic illnesses as disability.[146] But addressing the issue of health clearly requires careful consideration of gender and age. The conflation of impairment, age, and disability in late life occurs through attention to the biological realities of aging, and the socio-cultural narratives of decline and dependence.[147] Such conflation is resisted by scholars such as Ruth Bartlett and colleagues. Bartlett *et al* take up the issue of health by

---

[140] Garland-Thomson, *supra* note 129 at 1558.
[141] Thomas, *supra* note 96 at 178.
[142] *Ibid* at 179.
[143] Shakespeare, *supra* note 130 at 83; Shakespeare, *supra* note 4.
[144] Shakespeare, *supra* note 130 at 83.
[145] Bê, *supra* note 102 at 368.
[146] Carol Thomas, *Sociologies of Disability and Illness: Contested Ideas in Disability Studies and Medical Sociology* (Basingstoke [England]: Palgrave Macmillan, 2007); Sasha Scambler, "Long-Term Disabling Conditions and Disability Theory" in Nick Watson, Alan Roulstone & Carol Thomas, eds, *Routledge Handbook of Disability Studies* (Milton Park, Abingdon, Oxon: Routledge, 2012) 136.
[147] Grenier, Griffin & McGrath, *supra* note 23 at 13.

considering the gendered nature of lived experiences of dementia.[148] Gender, as well as age, will inevitably be a factor in structuring the lives of those living with dementia.[149] They argue that while there is increased critical attention on older women, gender is a neglected dimension in public discourse about dementia.[150] They also emphasize that one social identity can intersect with another to create disadvantage.[151] Their critical review of existing research shows that most of the existing work fails to address the marginalisation of people living with dementia. Questions about how to address inequalities and promote citizenship remain unanswered.[152]

2.2.3 **Summary**

The terms ‘regulation’ and ‘governance’ have become widely used in disciplines such as law and political science as well as in public discourses. From a legal research and analysis perspective, the concepts of regulation, governance, the regulatory state, co-regulation, risk-based regulation and social regulation provide a solid foundation for describing the subjects of my case study. The concepts used in the disability scholarship - impairment, disability and impairment effects, citizen and disablism - will guide my understanding of the debates about “care” in LTC. The interactional model of disability provides the language to discuss a particular place where care happens in relation to impairment and other differences such as gender and age. Thinking through disability as a multi-factorial concept brings out important questions about impairment, gender and health. The debate about ‘care’ is illustrative of the tensions around these concepts. The debates about care offer valuable concepts relevant to explaining LTC within a broader dialogue between disability scholars and care scholars.

2.3 Reconceptualization of care

At first blush, incorporating a disability perspective into the study of LTC homes seems to be improbable. As Lisa Schur *et al* argue, one of the most blatant forms of social exclusion is to segregate disabled people by putting them into institutions such as asylums and nursing homes.[153] Disability activists have argued that living in institutions threatens their fundamental

---

[148] Bartlett et al, *supra* note 116.
[149] *Ibid* at 15.
[150] *Ibid* at 14.
[151] *Ibid* at 24.
[152] *Ibid* at 25.
[153] Schur, Kruse & Blanck, *supra* note 97 at 121.

right to autonomy.[154] As a concept, "care" is frequently positioned as a complex form of oppression[155] and rejected by critical disability researchers.[156] As well, institutionalization invokes painful memories and reminds us of the potential for abuse of people with disabilities.[157] Further, impairments experienced by LTC residents are the result of illnesses frequently associated with aging, and therefore LTC research is suspect for "conflating disability with illness".[158] In this section, I propose that although LTC today is in many ways different from large institutions such as Huronia, Rideau and Southwestern, it is imperative to situate LTC research within debates about care. We cannot make complete sense of the debate about care without understanding the past and current resistance to institutionalization (or "incarceration" as some disability studies scholar would argue[159]). To this end, I will first explain the legacy of institutionalization and then more recent debates about deinstitutionalization. Then I will briefly introduce care research as the opposite of disability studies. The criticisms of feminist disability scholars such as Carol Thomas and Jenny Morris will inform our understanding of why care is so problematic but also illustrate why there is a pressing need to continue to study care. In essence, I do not believe that the obvious tension between the aspirations of the disability movement and care is so great that a scholarly dialogue about law reform of care is not possible. To bridge the disability perspective on the one side and the reality of older women in need of institutional care and the (younger) women who care for them on the other, I suggest the emphasis should be on caring relationships and the law. This section will conclude with remarks about the possibility of restructuring bureaucratic decision-making to better achieve the promotion of autonomy.

---

[154] Geraldine Boyle, "Autonomy in Long-Term Care: A Need, a Right or a Luxury" (2008) 23:4 Disability and Society 299 at 300.

[155] Christine Kelly, "Making 'care' Accessible: Personal Assistance for Disabled People and the Politics of Language" (2011) 31:4 Critical Social Policy 562 at 563 [Kelly, "Making 'Care' Accessible"]; Christine Kelly, *Disability Politics and Care: The Challenge of Direct Funding* (Vancouver : UBC Press, 2016) [Kelly, *Disability Politics*]; Christine Kelly, "Care and Violence Through the Lens of Personal Support Workers" (2017) 1:1 International Journal of Care and Caring 97 [Kelly, "Care and Violence"].

[156] Teppo Kröger, "Care Research and Disability Studies: Nothing in Common?" (2009) 29:3 Critical Social Policy 398.

[157] Kelly, "Making 'Care' Accessible", *supra* note 155 at 563; Kelly, *Disability Politics*, *supra* note 155.

[158] Marcia Rioux & Tamara Daly, "Constructing Disability and Illness" in Bryant Toba, Dennis Raphael & Marcia Rioux, eds, *Staying Alive: Critical Perspectives on Health, Illness, and Health Care*, 2nd ed (Toronto: Canadian Scholars Press, 2010) 347 at 352.

[159] L Ben-Moshe et al, *Disability Incarcerated: Imprisonment and Disability in the United States and Canada* (New York: Palgrave Macmillan US, 2014).

2.3.1 Legacy of institutionalization and more recent debates about deinstitutionalization

To understand objections to "caring" within institutions such as LTC homes, Erving Goffman's concept of "total institution" is a good starting point. In *Asylums*, a total institution is defined as a "place of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life".[160] One type of total institution is for those who are considered incapable and harmless e.g., nursing homes.[161] Despite the differences across the five types of institutions identified by Goffman, the common characteristics of a total institution are: "(1) the daily round now entirely transpires 'in the same place and under the same authority'; (2) activities are carried out in the company of a batch of like-situated others; (3) activities are timetabled and sequenced by clear rules and a class of officials; and (4) all of the scheduled activities are part of a plan designed to realize the goals of the institution".[162] As the feminist political literature (see Chapter 4) will show, LTC homes today still retain some of the characteristics of the "total institution", as reflected in the high degree of regimentation in terms of organization of frontline personal care within homes.[163]

For over a century, institutions would figure prominently in many governments' response to disability.[164] Many institutions would eventually close permanently in the period between the 1970s and the 1990s.[165] Since 1830s, "mental retardation policy" (as used at that time) in Ontario has tried to achieve four major objectives: 1) to provide asylum for "mentally retarded" people who could not physically survive in the community without government help 2) to educate "mentally retarded" people defined as being educable 3) to impose some kind of social control

---

[160] Erving Goffman, *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*, 1st ed (Garden City, N.Y: Anchor Books, 1961) at xiii.

[161] Michel Richard, "Goffman revisited: Relatives vs. administrators in nursing homes" (1986) 9:4 Qualitative Sociology 321.

[162] Gregory W H Smith, *Erving Goffman* (Abingdon, Oxon: Routledge, 2006) at 71.

[163] Pat Armstrong, Hugh Armstrong & Tamara Daly, "The Thin Blue Line: Long-Term Care as an Indicator of Equity in Welfare States" (2012) 29:3 Canadian Woman Studies 49; Pat Armstrong & Tamara Daly, "Introduction" in Pat Armstrong & Tamara Daly, eds, *Exercising Choice in Long-Term Residential Care* (Toronto: Canadian Centre for Policy Alternatives, 2017) 11.

[164] Griffiths, Owen, & Condillac, *supra* note 17.

[165] Doug Surtees, "Chapter 7 What can Elder Law Learn from Disability Law?" in Israel Doron, ed, *Theories on Law and Aging: The Jurisprudence of Elder Law* (Berlin: Springer, 2009) 93 at 95; Schur, Kruse & Blanck, *supra* note 97 at 122.

on “mentally retarded” people who are defined (or labeled) as delinquent or immoral 4) to provide social welfare for “mentally retarded” people who have been physically capable of surviving in the community but could not do so because of lack of employment, because they had personality or behavioural traits which led the community to reject them, or because of the absence of a social service infrastructure appropriate to their needs.[166] The first large-scale residential institution built for individuals with developmental disabilities opened in Orillia, Ontario in 1876.[167] In the 1950s and 1960s, concerns emerged over the overcrowded and deteriorated conditions in Ontario’s residential institutions. The “community living” movement was also spreading across North America.[168] In 1977, the Ontario government launched its first multi-year plan to increase community supports and decrease reliance on institutional care. In 1987, the Ministry of Community and Social Services announced that within 25 years, it planned to shutter all of the remaining residential facilities. The last provincially-operated residential facility for individuals with developmental disabilities was closed in 2009.[169]

Although the last institutions were formally closed, their legal consequences continue to unfold. The two class actions, *Dolmage v. HMQ*, and *McKillop and Bechard v. HMQ*,[170] relate to Huronia Regional Centre (“Huronia”), Rideau Regional Centre (“Rideau”) and Southwestern Regional Centre (“Southwestern”). In each action, the plaintiffs alleged that the defendant (the “Crown”) was negligent and breached its fiduciary duties in the funding, operation, management, administration, supervision and control of the facility. The parties settled the actions. These actions are useful reminders that scholarly research on institutions and institutionalization will continue to be necessary.

It is probably not controversial to suggest that the potential for legal challenges against homes and the provincial government is very limited. As I will explain in Chapter 7, “Inclusion and Participation”, residents and/or their substitute decision-makers may decide to challenge the decisions of their respective homes and/or the provincial government. The small number of judicial and tribunal decisions is indicative of the practical difficulties of using litigation to

---

[166] Simmons, *supra* note 17 at xiii.
[167] Ontario Ombudsman, *supra* note 7 at 12.
[168] *Ibid* at 14.
[169] *Ibid* at 13.
[170] *Dolmage v Ontario*, 2012 ONSC 4329, [2012] O.J. No. 3575; *McKillop and Bechard v HMQ*, 2014 ONSC 1282.

influence the delivery and receipt of care in institutions (see chapter 9 "Discussion and Analysis"). It is important to remember that these cases do not necessarily mean the plaintiffs reject institutional care.

Deinstitutionalization is often presented as an 'ideal' policy strategy that benefits all: it is intended to promote the self-determination of service users and to reduce care costs.[171] Scholars are now reviewing the current directions of deinstitutionalization.[172] One theme is how deinstitutionalization does not equal inclusion[173] and how some disabled people still have to confront isolation and exclusion from "real" community life.[174] This may be due to a variety of barriers to accessing home and community-based services in place of institutional care[175] and in some cases, even exposure to hate crimes and violence.[176] Others examine institutionalization as incarceration and explore abolition as a useful strategy for resistance to all forms of incarceration.[177] Another strand of research is to investigate the impact of the deinstitutionalization process and what constitutes a good quality of life in the community.[178] The more recent research related to deinstitutionalization draws our attention to how exclusion can be experienced in all types of settings – even in the community.[179] Unpacking the care practices that undermine individual autonomy and self-determination in different settings can be a shared ground for inquiry to both care research and disability studies.

My research also contributes to the debate about institutionalization and deinstitutionalization in three principle ways. The focus here is how the law including substantive and procedural protections shapes the experiences of those living in institutions. First of all, my research includes empirical evidence on how a small group of younger disabled people

---

[171] Sue Yeandle, Teppo Kröger & Bettina Cass, "Voice and choice for users and carers? Developments in patterns of care for older people in Australia, England and Finland" (2012) 22:4 Journal of European Social Policy 432 at 434; Pat Armstrong et al, "Structural Violence in Long-term Residential Care" (2011) 10:1 Women's Health & Urban Life 111 at 125.

[172] For example see Johnson & Traustadottir, *supra* note 17.

[173] Jihan Abbas & Jijian Voronka, "Remembering Institutional Erasures: The Meaning of Histories of Disability Incarceration in Ontario" in Liat Ben-Moshe et al, eds, *Disability Incarcerated : Imprisonment and Disability in the United States and Canada* (New York: Palgrave Macmillan).

[174] Johnson & Traustadottir, *supra* note 17 at 25; Watchman, *supra* note 17 at 249.

[175] Schur, Kruse & Blanck, *supra* note 97 at 125.

[176] Shakespeare & Watson, *supra* note 115 at 207–208.

[177] Ben-Moshe et al, *supra* note 159.

[178] Griffiths, Owen, & Condillac, *supra* note 17.

[179] Eilionóir Flynn et al, *Global Perspectives on Legal Capacity Reform: Our Voices, Our Stories*, Routledge research in human rights law (Abingdon, Oxon ; Routledge, 2019).

become institutionalized or re-institutionalized. I extend the debate by considering how aging affects the relationships of younger disabled people's 'choices' in the context of our existing laws on consent and capacity. Second, the variations in institutions today including LTC call for a more nuanced exploration of the living circumstances of those living in institutions and an explanation why such variations exist. My research shows how a group of younger disabled people become mismatched in a particular institutional setting. Third, the increasing demand for LTC in aging societies such as Canada presents a theoretical dilemma to the ideal of deinstitutionalization. The care required by those who experience multiple impairments and have extremely high needs is only available in institutional settings at this juncture. Despite the rhetoric of "aging at home" or "aging in place" (see Chapter 4), institutional care is the reality of many individuals with cognitive and other impairments. I extend the debate by drawing on the critiques of disability scholarship to analyze the enabling as well as disabling relationships in LTC care today in order to shed light on the lived experience of older disabled people in institutions.

2.3.2 "We do not need care": Feminist disability scholars' criticisms of care

One strand of disability scholarship is devoted to theorizing the experience of disabled women. Earlier in this chapter, I described feminist disabled scholars' concerns and viewpoints about how the intersection of different categories influence the lives of disabled women. Their powerful criticisms of the concept of care are still relevant for our understanding of LTC. At the heart of the debate is the strong emphasis on the demands of care on (non-disabled) women as carers while disregarding the perspectives and needs of care recipients. The debate about "care" highlighted some feminist scholars' uncritical acceptance of constructions that "disability equals dependency" and thus made disabled women invisible / needy as they were simply a "burden of care" or mere "passive recipients of care".[180] This lack of acknowledgement of disabled women could be traced to the perception of disabled women as childlike, helpless, and victimized.[181] To

---

[180] Bê, *supra* note 102 at 365.

[181] *Ibid* at 363–364. citing Michelle Fine & Adrienne Asch, 'Disabled Women: Sexism without the Pedestal" in Mary Jo Deegan, Nancy A. Brocks, eds, *Women and Disability: The Double Handicap* (New Brunswick: Transaction Books, 1985) 6.

advance more powerful, competent, and appealing female icons, non-disabled feminists have disconnected disabled women from the sisterhood.[182]

2.3.2.1 Objections to "care" and "caring for"

To understand the contested nature of "care", it is necessary to take a step back and briefly explain the field of care research. The discussion here is intended to contextualize the issues to which disability scholars have been reacting. Teppo Kröger notes that care research continues to expand as care is becoming a burning policy issue in almost every society.[183] The sudden interest in care, as Jonathan Herring suggests, is largely driven by economics: the cost of care on the state and on individuals are huge.[184] But even in its early days, care research was more than "just about personal relationships" or emotions. In a 1993 article that explores the problematic nature of the concept of care in sociological research, Thomas helpfully points out the significance of care research in relation to policy-related and academic agendas: "Care research is also a route to the politics of welfare and to sociological/policy analysis of the welfare state, its ideologies and systems."[185] In essence, care research has highlighted that care is ultimately gendered due to the fact that care - both unpaid and paid - is performed overwhelmingly by women. As well, since traditionally caring has been understood to be a 'natural female activity', social esteem and remuneration levels of caring have remained low.[186] Evidently, the nature and impact of care on the lives of women also vary due to race, class and sexuality[187] – a recurrent theme in the feminist political economy literature to be explored further in Chapter 4.

A key concept in care research is the "ethics of care", which is advanced by scholars such as Joan Tronto and Selma Sevenhuijsen.[188] Feminists are divided on the value of an ethics of care; the issue of contention is about the connection between care and women's oppression.[189]

---

[182] *Ibid*. citing Michelle Fine & Adrienne Asch eds. *Women with Disabilities: Essays in Psychology, Culture and Politics* (Philadelphia: Temple University Press, 1988).

[183] Kröger, *supra* note 156 at 399.

[184] Herring, *supra* note 112 at 8.

[185] Carol Thomas, "De-Constructing Concepts of Care" (1993) 27:4 Sociology 649 at 651.

[186] Kröger, *supra* note 156 at 400; Bill Hughes et al, "Love's Labours Lost? Feminism, the Disabled People's Movement and an Ethic of Care" (2005) 39:2 Sociology 259 at 261.

[187] Herring, *supra* note 112 at 37.

[188] Kröger, *supra* note 156 at 402; Söder, *supra* note 97 at 77.

[189] Grace Clement, *Care, Autonomy, and Justice: Feminism and the Ethic of Care* (Boulder, Colo: Westview Press, 1996) at 21, 95–96.

To make a case for legal reform based on an ethics of care, Herring summarizes the six themes in ethics of care. First, care is part of being human: we are either being cared for by or caring for another at every point in life - often both at the same time.[190] Second, care is a good part of life.[191] Third, emotions are central to good care.[192] Fourth, the ethics of care is based on the belief that people understand themselves in terms of their relationships.[193] Fifth, the ethics of care emphasizes the importance of responsibilities within caring relationships. Supporters are wary of the danger that rights are used in an individualistic way. Instead, the law should enable people to fulfil their responsibilities.[194] Sixth, an ethics of care approach starts with the context and concrete reality of a particular situation and the individuals in it and their relationships and characteristics. In other words, supporters reject abstract moral rules.[195]

Not surprisingly, disability scholars have raised objections to the assumptions and more importantly, the intended and unintended implications of care research for disabled people. Here is a summary of critiques relevant to my case study. First, care is defined in relation to dependency in many cases, especially in earlier studies. People who need and get support in their everyday lives are regularly referred to as ‘the cared-for’, ‘care-takers’ or ‘care receivers’.[196] In a frequently cited 1997 article about a care researcher’s analysis of direct payments legislation in the UK, Morris advances the position of “throw[ing] off the ideology of caring which is a form of oppression and an expression of prejudice.”[197] She explains that in the second half of the twentieth century, care “has come to mean not caring about someone but caring for in the sense of taking responsibility for.”[198] In many studies of “informal carers” and the role of “caring”, the rights of disabled and older people to adequate support has been obscured.[199] The conclusion is

---

[190] Jonathan Herring, “The Disability Critique of Care” (2014) 8 Elder L Rev 1 at 2.
[191] *Ibid*.
[192] *Ibid* at 3.
[193] *Ibid*.
[194] *Ibid*.
[195] *Ibid* at 4.
[196] Kröger, *supra* note 156 at 401. See also Nick Watson et al, “(Inter)Dependence, Needs and Care: The Potential for Disability and Feminist Theorists to Develop an Emancipatory Model” (2004) 38:2 Sociology 331; Hughes et al, *supra* note 186 at 261.
[197] Jenny Morris, “Care or Empowerment? A Disability Rights Perspective” (1997) 31:1 Social Policy & Administration 54 at 54.
[198] *Ibid*.
[199] *Ibid*.

that "[o]ne cannot, therefore, have care and empowerment, for it is the ideology and the practice of caring which has led to the perception of disabled people as powerless."[200]

Second, the focus on formal and informal carer presents another set of knotty questions for disability scholars. It is argued that references to the interests or rights of carers negate the rights and needs of disabled people, either at the individual level or as a collective. For Geraldine Boyle, whilst feminist debate on caregiving has highlighted the need for the autonomy of carers, little attention has been paid in such debate to older care recipients' needs for autonomy.[201] The attention on carers can be seen as an attack on disabled people's hard-won struggle for adequate support. As Herring explains, a common strategy of organisations promoting the interests of carers is to emphasise the burdens and disadvantages that carers suffer because of their work. This unintentionally paints the disabled person as the cause of disadvantages: disability is 'a problem', which carers pay the cost of solving.[202] Similarly, Karen Soldatic and Helen Meekosha are also critical of the carers' rights movement, which has a predominantly female membership and leadership, in many Western liberal democratic countries.[203] The range of supports and legislative measures of informal carers' of disabled people have largely been incorporated in state plans to reduce public expenditure on disability social provisioning measures. Such measures would absolve the state of its responsibilities to a class of citizens because these measures attempt to privatize the right of disabled people to personal support assistance. This results in reinforcement of disabled people's historical oppression and stigmatization of disabled people's subjective experience of the self and the body.[204]

Third, and closely related to the previous criticism, most of this (early) research on informal caregivers explicitly separates out nondisabled women from disabled women.[205] One manifestation of this separation is particularly relevant to us. Some early feminist researchers take the position that residential care for older and disabled people is preferred on the grounds that this is the only way to prevent the exploitation of women as informal carers.[206] For Morris,

---

[200] *Ibid*.
[201] Boyle, *supra* note 154 at 299.
[202] Herring, *supra* note 190 at 5.
[203] Soldatic & Meekosha, *supra* note 116 at 205.
[204] *Ibid*.
[205] Jenny Morris, "Feminism and Disability" (1993) 43 Feminist Review 57 at 61.
[206] *Ibid* at 62.

such position is indicative of the failure of feminist researchers to include the subjective experience of disabled and older people and consider their opposition to institutional care.[207] To put it bluntly, these feminist researchers completely ignore the interests of disabled and older women who actually made up the majority of the so-called ‘‘cared for”.[208]

The last group of criticisms concern the “dark side of care”. The harmful effects of care on disabled people are frequently in the background (if not foreground) of almost any disability research. For Christine Kelly, “Care is positioned as a layered form of oppression that includes abuse, coercion, a history of physical and metaphorical institutionalization, and a denial of agency often signified by excluding disabled people from research. The potential for daily practices of care to veer into pain and oppression is high.”[209] It should be noted that the harm of care can occur inside and outside of institutions.[210] However, scholars continue to advance the right of living in the community and identify barriers to community living, such as accessing primary care.[211] The case for living in the community is supported by research on harms in institutional care. One of the harms is lack of autonomy in LTC.[212]

To conclude the discussion on care, I will briefly explain the significance of the concepts of independence, choice and control from a disability perspective. These concepts are conceived as the opposite of care. For earlier scholars such as Barnes and Oliver, there is a lack of control over the disabled individuals’ own lives and a lack of opportunity to participate in family and social life in a way that other people take for granted. It is argued that as a result, the civil and human rights of disabled people are being violated.[213] Accordingly, independence does not refer to self-sufficiency or to the capability to do everything themselves. Rather, independence refers to having choice and control over how the necessary help is provided.[214] Mark C. Weber captures the significance of “having control one’s life” well: “Paternalism is a particularly acute

---

[207] *Ibid*.
[208] *Ibid*; Bê, *supra* note 102 at 183.
[209] Kelly, *Disability Politics*, *supra* note 155 at 29.
[210] For example, see Morris, *supra* note 205 at 65–66.
[211] John A Ford et al, “Access to Primary Care for Socio-Economically Disadvantaged Older People in Rural Areas: A Qualitative Study” (2018) 13:3 PLOS ONE e0193952.
[212] For example, see Boyle, *supra* note 154; Geraldine Boyle, “Social Policy for People with Dementia in England: Promoting Human Rights?” (2010) 18:5 Health & Social Care in the Community 511.
[213] Kröger, *supra* note 156 at 405.
[214] *Ibid*.

problem for people with disabilities, but no man or woman is or should aspire to be an island. Independence should be less important than control over one's life, something that is not necessarily incompatible with dependence on others for a range of activities."[215] Thus, an important strand in the disability research is to examine how disabled people's control (or lack of it) over their own lives (including their bodies) is manifested in government policies and law, such as direct payment,[216] contractual capacity,[217] medicine and female bodies,[218] and administration of social programs.[219]

This understanding of independence in disability studies stands in contrast to how independence is portrayed in public discourses. Independence and self-sufficiency, Bernhard Weicht argues, are constructed as ideals for human existence.[220] It follows that "those being dependent on others are constructed as morally inferior to the idealized independent person."[221] One site where the dominance of independence is produced and reproduced is in discourse on care and older people.[222] Care is established as a dichotomy between the young, active, independent actor and the old, passive, dependent non-actor.[223] And the (old, vulnerable) body is the physical expression of dependency, both representing the absence of individual choice and autonomy.[224] Choices and decisions taken by oneself are often presented in opposition to an image of old age, in which older people are dependent, passive, infantilized and vulnerable to abuse and neglect.[225] I now turn to scholarly work that examines older people, especially older women, in the context of care.

---

[215] Mark C Weber, "Law and the Contradictions of the Disability Rights Movement Book Review Essay" (2010) 31:2 J Legal Med 241 at 246.
[216] Kelly, *Disability Politics*, *supra* note 155.
[217] Flynn et al, *supra* note 179.
[218] Linda Steele, Macarena Iribarne & Rachel Carr, "Medical Bodies: Gender, Justice and Medicine" (2016) 31:88 Australian Feminist Studies 117.
[219] Kari Krogh & Jon Johnson, "A Life without Living: Challenging Medical and Economic Reductionism in Home Support Policy for People with Disabilities" in Dianne Pothier & Richard Devlin, eds, *Critical Disability Theory: Essays in Philosophy, Politics, Policy and Law* (Vancouver: UBC Press, 2005) 151.
[220] Bernhard Weicht, "Embracing Dependency: Rethinking (in)Dependence in the Discourse of Care" (2010) 58:2_suppl The Sociological Review 205 at 206–207.
[221] *Ibid* at 207.
[222] *Ibid*.
[223] *Ibid* at 209.
[224] *Ibid* at 210.
[225] *Ibid* at 211.

2.3.2.2 Locating "older women" in our language

Any study about a gendered space such as a LTC facility should address the question of how this group of residents is described. A common characteristics is the chronological age of residents. In other words, they are old. Age is not just a number. I adopt Margaret Hall's position that it is important to see the difference of old age, and the social impact of that difference.[226] I have decided to use the comparative term "older" rather than old, recognizing that it is not without difficulties. As Isabel Grant and Janine Benedet point out, "older" defines those who are old only in comparison to those who are not, and one could be seen as implying that "younger" is the norm.[227] Hall observes that old age happens at different times for different people. And it is experienced on the corporal and social levels.[228] Indeed, what constitutes older is highly gendered, and women are constructed as older at a younger age than men.[229] The point at which one is labelled as older will vary depending on other intersecting inequalities, such as disability, gender, class, and race[230] and disadvantages and privileges accumulated over a lifetime. For instance, disabled persons are more likely to be labelled as older at a younger age than those without an identifiable disability.[231] If we borrow chronological age as a lens to describe aging, then in the LTC context, female residents are in general older compared to the general population (the life expectancy of a Canadian woman is 83) and older compared to the male residents. I am using the term "older" to acknowledge that this group of women may be impacted by different kinds of inequality over the life course, and how they arrive at LTC and how they experience LTC may be shaped by those inequalities.

The challenge is to put older women at the centre of the analysis of social policies such as LTC without reducing them to mere "objects of care" or "recipients of other people's responsibilities".[232] In a paper about older care recipients' needs for autonomy in LTC (in community or institution), Boyle argues that recent debate has been dominated by the need for equality by younger disabled people and by women as carers, rather than by older people with

---

[226] Hall, *supra* note 23 at 2.
[227] Isabel Grant & Janine Benedet, "The Sexual Assault of Older Women: Criminal Justice Responses in Canada" (2016) 62:1 McGill L J 41 at 47.
[228] Hall, *supra* note 23 at 5.
[229] Grant & Benedet, *supra* note 227 at 48.
[230] *Ibid* at 49.
[231] *Ibid*.
[232] Boyle, *supra* note 154 at 305.

support needs.[233] For instance, although constraints associated with caregiving on the autonomy of women have been a key emphasis in feminist debate, there has been little regard to the possible constraints on the autonomy of older people associated with receiving care. Likewise, although research has pointed to the negative mental health effects associated with caring (and with constraints on carers' autonomy), little consideration has been given to the possible mental ill health experienced by older people as a result of receiving care which constrains their autonomy.[234]

Jane Aronson's work is an example that takes gender, age, and disability into account. She observes that political decisions to make health and social services scarcer and to ration them meagerly are often accompanied and justified by talks of enhancing customer satisfaction and the choice of service consumers. The rhetoric of consumer participation associated with the new managerialism conceals the fundamental disempowerment of being managed. Elderly people being managed are subject to thin definitions of need (as used by Nancy Fraser[235]) determined by professionals through standardized assessment procedures.[236] Aronson explores possible interpretations and images of elderly women as care recipients in their own homes or in the vaguely defined community: being managed, managing, and making demands.[237] These images present very different practical possibilities. They also lead to differences in LTC policies and service providers' practices. For example, the managerial framing of frail elderly women and their needs, which dominates LTC policies, leads to the meager allocation of resources and service practices that objectify and isolate recipients.[238]

It would be a mistake to assume that common theoretical ground between disabilities and care research is impossible. Disability scholars continue to look for bridges that connect the concerns of both fields. Scholars such as Sally Chivers continue to engage the concept of care

---

[233] *Ibid*.

[234] *Ibid*.

[235] Nancy Fraser, "Talking about Needs: Interpretive Contests as Political Conflicts in Welfare-State Societies" (1989) 99:2 Ethics 291.

[236] Jane Aronson, "Conflicting Images of Older People Receiving Care: Challenges for Reflexive Practice and Research" in Sheila M Neysmith, ed, *Critical Issues for Future Social Work Practice with Aging Persons* (New York: Columbia University Press, 1999) 47 at 49–51.

[237] Jane Aronson, "Restructuring Older Women's Needs: Care Receiving as a Site of Struggle and Resistance" in Sheila M Neysmith, ed, *Restructuring Caring Labour: Discourse, State Practice, and Everyday Life* (Toronto: Oxford University Press, 2000).

[238] *Ibid* at 54.

critically[239] by exploring LTC from multiple perspectives. In *Care Home Stories: Aging, Disability, and Long-Term Residential Care,* Sally Chivers and Ulla Kriebernegg consider various kinds of stories told about institutional care for older adults.[240] The contributors in that volume write about many different ways in which LTC in late life could become something desirable rather than necessary.[241] Some scholars look for common policy issues that affect disabled people and those who provide care, such as decent wages and working conditions for personal assistants.[242] Others look for concepts or models that can address the tensions of both fields, such as conceptualization of 'needscapes' which incorporate interdependence and needs interpretation.[243] At the heart of these attempts is a rejection of binary categorization such as helper / helped. Next I will turn to the idea of "caring relationships" in order to draw attention of the complexities of caring and care.

2.3.3 Explaining the reality of older women in need of institutional care and the women who care for them

Disability scholars such as Carol Thomas and Jenny Morris have proposed powerful critiques of care. I do not claim to be able to resolve the tensions in these scholarly debates. However, I build on existing work that sees the potential to reconcile the tensions and offer suggestions here to bridge these perspectives in order to avoid a binary understanding of "helper/helped" and "carer / recipient". While many scholars have utilized the concept of caring relationship, this dissertation is concerned with law and how it shapes the caring relationship. It is not possible to talk about relationships without exploring law's assumptions about individuals. A good place to start is to explain how the notion of self is reflected in law.

2.3.3.1 The legal conception of the self

Unpacking the challenges of allowing caring relationships to flourish requires a brief explanation about the 'isolated individual' in law. The "traditional liberal self" is seen as

---

[239] For example, see Sally Chivers, "Care, Culture, and Creativity: A Disability Perspective on Long-Term Care" in Pat Armstrong & Susan Braedley, eds, *Troubling Care: Critical Perspectives on Research and Practices* (Toronto : Canadian Scholars' Press Inc., 2013) 47. The more recent work from Sally Chivers is discussed in Chapter 4.

[240] Sally Chivers & Ulla Kriebernegg, eds, *Care Home Stories: Aging, Disability, and Long-Term Residential Care* (Transcript-Verlag, 2018).

[241] Sally Chivers & Ulla Kriebernegg, "Introduction" in Sally Chivers & Ulla Kriebernegg, eds, *Care Home Stories: Aging, Disability, and Long-Term Residential Care* (Transcript-Verlag, 2018) 17 at 19.

[242] Kröger, *supra* note 156 at 409.

[243] Watson et al, *supra* note 196.

"rational, self-maximizing, economic man, plucked out of his social context, abstracted from his social relations, implausibly independent, intent on pursuing his personal preferences".[244] This image of self is reflected in law and has great significance to what kind of law we have:

> The law is built around the ideal of legal personhood: a man who is autonomous, self-sufficient, in control, capacitous, and independent. For such a man the law gives the legal tools he needs to maintain his status: the rights of autonomy, privacy, liberty, and freedom from state interference. For him, legal rights are designed to keep him free from intrusion. Rights are designed to keep people apart, to give people their space.[245]

With respect to how the law protects the 'able, autonomous and unattached adult',[246] Jennifer Nedelsky provides an insightful account in *Law's Relations: A Relational Theory of Self, Autonomy and Law*.[247] More specifically, within the Anglo-American liberal tradition, one of the most important functions of rights has been to define the legitimate scope of the state.[248] The image (or metaphor) of protective boundaries as essential to the integrity and autonomy of the self is deep and pervasive in Western culture.[249] Nedelsky discusses the pervasiveness of the boundary metaphor not only in law (with specific examples in the areas of property and privacy)[250] but in other domains as well (such as sexual relations).[251] The boundary metaphor "invites us to imagine that the self to be protected is, in some crucial sense, insular and that what is most important to the preservation of such a self is drawing boundaries around it that will protect it from invasion (or at least that is the most crucial thing the law can do)."[252] In other words, the most autonomous person is the one with the strongest right to exclude others from one's person (including body) and property (i.e., to secure separation from others).[253] Not surprisingly the centrality of boundary is rejected by Nedelsky but she is also careful to point out

---

[244] Ngaire Naffine, "Review Essay: The Liberal Legal Individual Accused: The Relational Case" (2014) 29:01 Canadian Journal of Law and Society 123 at 128; Jennifer J Llewellyn & Jocelyn Grant Downie, "Introduction" in Jennifer J Llewellyn & Jocelyn Grant Downie, eds, *Being Relational: Reflections on Relational Theory and Health Law* (Vancouver, BC: UBC Press, 2012) 1 at 7.

[245] Jonathan Herring, *Vulnerable Adults and the Law* (Oxford : Oxford University Press, 2016) at 1.

[246] Herring, *supra* note 112 at 2.

[247] I thank Prof. Nedelsky for a discussion about some of the ideas in her book.

[248] Jennifer Nedelsky, *Law's relations: a relational theory of self, autonomy, and law* (New York: Oxford University Press, 2011) at 91.

[249] *Ibid* at 98.

[250] *Ibid* at 95–98.

[251] *Ibid* at 101.

[252] *Ibid* at 98.

[253] Naffine, *supra* note 244 at 124.

that boundaries do protect people from certain kinds of threats.[254] Law (in its ideal liberal form) in turn protects the autonomous selves from harm by each other and by the state.[255] But crucially the boundary metaphor "consistently misdirects attention away from the relationships actually necessary to achieve values such as freedom and autonomy."[256] Nedelsky's criticisms of the metaphor of boundary paves the way for an alternative language for the self, autonomy, and the rights that are designed to protect them.[257]

2.3.3.2 Relational conception of rights and autonomy in the context of law

The alternative to the traditionally individualistic conception of the self starts with a basic assumption which is that each individual is constituted by networks of relationships of which they are a part, such as intimate relationships, being participants in a global economy, and so forth.[258] Relationships are not always enabling or even benign: Nedelsky's conception of human selfhood as constituted by relationship "has nothing warm, mushy, or romantic about it."[259] One of Nedelsky's claims – and there are many in the book - is that rights, self, and autonomy should be framed in relational terms.[260]

It is hard to disagree with Nedelsky's observation that "rights structure relations of power, trust, responsibility, and care."[261] Nedelsky begins with a commitment to equality and makes a compelling claim that a relational approach helps us determine ways to ensure that inevitable hierarchies of power (and the advantages of unequal strengths and talents) do not become relations of domination. Law and rights should be understood in terms of the relations they structure and how those relations can foster core values, such as autonomy.[262] A relational approach always directs attention to the difference that context makes, and to how the law affects different people in different circumstances.[263] Further, relations structured by law often serve to

---

[254] Nedelsky, *supra* note 248 at 116.
[255] *Ibid* at 5.
[256] *Ibid* at 91.
[257] *Ibid* at 14.
[258] *Ibid* at 19.
[259] *Ibid* at 32 and 201. Nedelsky refers to the contribution of feminism to her work. In particular, Nedelsky agrees that relationships are not necessarily benign, as feminists know very well the destructive power of bad structures of relationship.
[260] *Ibid* at 7.
[261] *Ibid* at 74.
[262] *Ibid* at 65.
[263] *Ibid* at 221; Llewellyn & Downie, *supra* note 244.

hide power and the role of the state in that power. An example is the “market” where the role of the law in constructing the basic terms (property and contract) is also often invisible, allowing “the market” to be presented as a “nonstate” alternative to state regulation.[264] It is important to note that although law can restructure relations of power and responsibility, this approach does not always call for more law or state power.[265]

Nedelsky holds the view that rights can be rescued from their long association with individualistic theory and practice.[266] The key is to recognize the relational nature of rights and to ensure that their relational nature becomes a regular tool of analysis in rights debates.[267] To summarize, the relational approach to rights invites us to ask the following questions in examining rights disputes: 1) What is structuring the relations that have generated the problem? In a legal case, how is law structuring the relevant relations, and how is that structuring related to the conflict? 2) What are the values at stake? 3) What kinds of relationships would foster those values? 4) How would competing versions of a right structure relations differently?[268]

The value that is important for my project is autonomy, which is a key concept in disability studies. Nedelsky’s inquiry into the meaning of autonomy is relevant for my project because it is guided by both feminist objectives and the challenges of the modern welfare state and regulatory state.[269] In Nedelsky’s view, autonomy is not to be equated with independence.[270] Equally important, she rejects the language of control as a synonym for choice: “our lives involve other people, and control is not a respectful relation to other autonomous beings. . . The effort at control almost always involves some form of domination.”[271] Further, autonomy is made possible by constructive relationships. The purpose of a relational approach is to understand all the different dimensions of human relationships—including their interaction with ideas, institutions and personal practices—that foster autonomy. It is not to yield simplistic conclusions that people in destructive relationships—whether intimate, institutional, or

---

[264] Nedelsky, *supra* note 248 at 72.
[265] *Ibid* at 71.
[266] *Ibid* at 248.
[267] *Ibid*.
[268] *Ibid* at 236.
[269] *Ibid* at 119.
[270] *Ibid*.
[271] *Ibid* at 46.

cultural—must be without autonomy.[272] In other words, for Nedelsky both selves and autonomy are constitutively relational.[273]

Nedelsky's work influences my research and analysis in the following ways. It provides a foundation through which to analyze the current rights and entitlements of those in LTC and points to possible ways to move forward with explaining why those rights do not always help advance values such as autonomy in real life. Further, the relational approach to autonomy allows me to probe more deeply into the relationships that impact residents' autonomy and to consider what autonomy means in LTC. Next, I bring Nedelsky's relational approach together with Herring's work on caring relationships in order to propose a way to analyze care in LTC. My approach of integrating the work of Nedelsky and Herring is similar to some of the recent care-related research in socio-legal studies such as examining the role of relationships in fostering or undermining mental capacity[274] and the impact of legal and regulatory regimes on the everyday lives of carers of people with dementia.[275]

2.3.3.3 Caring relationships and the law

One way to illustrate the complex ways in which power relations may be exhibited in relationships (not just in a dichotomous and unidirectional sense) is to interrogate the "care" relationship. As discussed earlier, I have chosen the care relationship in part to avoid replicating the dichotomy between people with and without disabilities and attempt to attend to the debates about "care" in the feminist and disability scholarship. My starting point is that the role of law, as Ngaire Naffine states, is not to ward relations off: law is intended to ensure that relations run smoothly and that they neither oppress nor harm us.[276] In his book *Caring and the Law*, Jonathan Herring builds on the debates about ethics of care and objections from disability scholars, advancing the idea of making caring the principle of the law.[277] In a more recent book, *Vulnerable Adults and the Law*, Herring builds on some of his ideas about our relational self and

---

[272] *Ibid* at 137.

[273] Marilyn Friedman, "Relational Autonomy and Individuality" (2013) 63:2 UTLJ 327 at 331.

[274] Kong, *supra* note 124.

[275] Rosie Harding, *Duties to Care: Dementia, Relationality, and Law* (Cambridge, United Kingdom; Cambridge University Press, 2017).

[276] Naffine, *supra* note 244 at 123.

[277] Herring, *supra* note 112 at 10.

considers how vulnerability operates within specific areas of law and how a vulnerability analysis might improve our understanding of those areas.[278]

Care is an act and should not be treated simply as a series of tasks.[279] Instead of adopting a simple definition of care, Herring proposes that there are four key markers of care: meeting needs, respect, responsibility and relationality. These markers may be exhibited in various degrees and indicate the extent to which an activity is or is not care.[280] Of particular relevance to this research is relationality. He explains that caring is about relationships and that individual acts of care can only be understood in the context of the relationship between the parties.[281] In a caring relationship, the interests and identities of the two people become intermingled. Thus, it becomes impossible to consider the welfare or rights of any one party in isolation. The focus must be on the relationship, rather than the individuals.[282] Further, the values of autonomy, freedom, and justice need to be used to enable and support caring of dependents.[283] In this vein, our identities, values, and well-being are tied up with our relationships and the responsibilities that come with them.[284] Accordingly, the main argument is that rather than promoting 'care', we should promote 'caring relationships'. By using this terminology of ‘caring relationships’, it is argued that the contributions of both parties would be recognised.[285]

Having established that our society should encourage and promote caring relationships, Herring argues that we need a legal system that acknowledges our responsibilities to those we are in relationships with and others in our society.[286] Traditionally, our legal and ethical tools have been built on an individualistic model.[287] Herring’s vision for radical change is as follows: “A legal system that is designed around relational people, dependent on others to meet their needs and one whose key values are not autonomy, freedom, and privacy but mutuality,

---

[278] Herring, *supra* note 245; Jamie Lindsey, Book Review of *Vulnerable Adults and the Law* by Jonathan Herring, (2018) 27:2 Social & Legal Studies 273.
[279] Herring, *supra* note 112 at 323.
[280] *Ibid* at 14.
[281] *Ibid* at 2.
[282] *Ibid* at 4.
[283] *Ibid* at 2.
[284] *Ibid*.
[285] Herring, *supra* note 190 at 8.
[286] Herring, *supra* note 245 at 2.
[287] Herring, *supra* note 112 at 43.

interdependence, and relational responsibilities."[288] In a nutshell, legal rights should be designed to enable us to undertake our caring relationships.[289] Equally important, it is argued that a responsibility to ensure we do not exploit each other's vulnerability should govern our interactions with each other.[290]

This dissertation adopts Herring's categorization of care and the claim that the identities and interests of those in caring relationships are inter-mingled. My approach to analyzing care in LTC is informed by Herring's contributions in the following specific ways. First, although a strong emphasis on relationships is not new in the literature about care, the clear connection made between key concepts such as dependency and relationality on the one hand and law on the other is a major step forward. But Charles Foster and Jonathan Herring are also careful to emphasize that the law can play only a small part in promoting and protecting a care-valuing ethos. Nonetheless, law can send important messages about the standards of behaviours expected.[291] Herring's contribution is that he provides specific examples of how caring relationships are accommodated (or not) in law.[292] For example, in the chapter about caring and medical law, he advances the claim that medical law is grounded in highly individualized concepts of what are people, what are bodies and what our rights are.[293] His questions about the place of carers in medical law will guide my own questions about the role and responsibilities of families and friends of LTC residents. Equally important, his work acknowledges the dark side of caring, including abuse, and makes the case for the need for protection of those in caring relationships in the form of legal response.[294]

Herring is correct to argue that the legal and social responses to different caring relationships should not be the same.[295] I extend the debate in two ways. First, this research will extend the debate by examining concrete legal interventions that support or regulate different caring relationships in LTC homes. My analysis looks at interventions at the macro level

---

[288] Herring, *supra* note 245 at 2.
[289] Herring, *supra* note 112 at 323.
[290] Charles Foster & Jonathan Herring, *Human Thriving and the Law* (Cham, Switzerland: Springer, 2018) at 54.
[291] *Ibid*.
[292] Herring, *supra* note 112 at 9.
[293] *Ibid* at 186.
[294] *Ibid* at 10; Herring, *supra* note 245 at 136–181.
[295] Herring, *supra* note 112 at 26.

(structural issues in the sector such as the system's capacity to meet the demands for care) as well as at the micro level (such as how care relationships are defined in the home). Looking at how the state is accountable for its support for (or neglect of) care is an important part of this dissertation. In Chapter 4, I will explain in more detail how the provincial government is involved in LTC, mainly by provision of funding, licensing and regulation of homes. If its involvement has expanded over time, one could ask how the provincial government is held accountable for its involvement. Secondly, similar to Herring, I attend to the responsibilities that public authorities have towards those who may be considered vulnerable[296] by looking at the state's responsibility towards its citizens. in the context of compliance and enforcement. Herring remarks since we are profoundly dependent on others and on a range of social provisions, it follows that compliance with legal norms (or the cost of complying with them) very much depends on the particular circumstances an individual is in. Thus, it requires a sensitivity to the individual's circumstances – something which is often lacking in our current legal system.[297] This point will be investigated further in my study as I consider how those in caring relationships in LTC – residents, care providers, homes – interpret and comply with legal rules.

My approach is also different from Herring's in the sense that unlike Herring I have not completely abandoned concepts such as autonomy. Drawing on feminist critiques of the ideal of autonomy, Susan Sherwin provides a thoughtful summary of the linkage between uncritical acceptance of complete independence and autonomy.[298] I share Sherwin's view that "autonomy often appears to be a goal that is primarily of interest to – and accessible by – those with privilege and power."[299] However, Sherwin has not abandoned the concept entirely. For some feminist health activists, appealing to the ideal of autonomy allows them to secure greater power for women to determine the course of their health care and, especially, their reproductive lives.[300] For me, the importance of the concept of autonomy in the disability scholarship (to be discussed below) and activism is the main reason why I have not abandoned it. Autonomy is still an

---

[296] Herring, *supra* note 245 at 136–181.
[297] *Ibid* at 265–266.
[298] Susan Sherwin & Susan Sherwin, "Relational Autonomy and Global Threats" in Jocelyn Grant Downie & Jennifer J Llewellyn, eds, *Being Relational: Reflections on Relational Theory and Health Law* (Vancouver, BC: UBC Press, 2012) 13 at 13–15.
[299] *Ibid* at 14.
[300] *Ibid* at 15.

important concept in our legal system and it is more fruitful to use Nedelsky's approach in the context of decision-making and to try to place autonomy in an appropriate place in relation to other values.

2.3.4 **Autonomy and dependence in the modern state**

In the context of care, the role of the state is an important area of contention.[301] Of particular relevance for my research is the relationship between public benefit scheme recipients and the state. Jennifer Nedelsky's work on the concept of relational autonomy and bureaucratic state is particularly helpful in illuminating this relationship. In *Law's Relations: a Relational Theory of Self, Autonomy, and Law*, Nedelsky argues that the characteristic problem of autonomy in the modern state is to ensure the autonomy of individuals when they are within the many spheres of collective power.[302] For many people, their most direct encounter with state power is as recipients of state services or benefits (public education, health care, pensions, employment insurance and so forth) and subjects of regulation (licenses, health and safety regulation, zoning, securities regulations). "Dependence is a reality, and will be a reality in any society based on collective responsibility for the material well-being of some or all of its members. The problem is to avoid making autonomy a casualty of such collective responsibility."[303] Thus, the problem of interdependence, individual autonomy, and collective power assumes its current form in the relations between administrative bodies and those subject to their decisions.[304] Accordingly, the nature of people's interactions with bureaucratic decision making may be just as important as legislative policy-making in determining whether people are autonomous members of a democratic society or dependent objects of collective control. The task is to render autonomy compatible with the interdependence that collective power (properly used) expresses.[305]

Earlier in this section, I outline the relational approach to rights and autonomy. Adopting Nedelsky's relational approach, autonomy requires constructive relationships throughout a

---

[301] Albert Banerjee, "Chapter 6 The Regulatory Trap: Reflections on the Vicious Cycle of Regulation in Canadian Residential Care" in Gabrielle Meagher & Marta Szebehely, eds, *Marketisation in Nordic Eldercare: a Research Report on Legislation, Oversight, Extent and Consequences* (Stockholm: Department of Social Work, Stockholm University, 2013) 203 at 213. See also Armstrong, Armstrong & Daly, *supra* note 163 at 50.

[302] Nedelsky, *supra* note 248 at 118 and 125.

[303] *Ibid* at 140.

[304] *Ibid* at 125.

[305] *Ibid*.

person's life. Autonomy can thrive or wither in adults depending on the structures of relationship they are embedded in. Even relations of dependence and hierarchies of power can be structured in ways that foster rather than undermine autonomy. Understanding how to structure such dependence is essential to the protection of autonomy.[306] In framing autonomy and dependency this way, there is recognition that power imbalances are not necessarily incompatible with autonomy. This suggests that there is possibility of contributing to the on-going discussion about restructuring bureaucratic decision-making to better achieve the promotion of autonomy. This provides an additional dimension i.e., autonomy, by which to evaluate the implication of changes to regulation and governance in the LTC home sector.

Therefore, this research provides an opportunity to generate new questions about how dependence on the state is exemplified in processes established by the state around different types of decisions related to a public benefit scheme. One could argue that the protection of individual autonomy is a responsibility of the state in terms of making available the necessary mechanisms to challenge decisions made by others when an individual is deemed incapable. Recall that professionals' control over disabled people's lives is a theme in disability studies. The legal processes around capacity for decision-making such as LTC admission are concrete expressions of how autonomy is interpreted legally and, on the ground, as well as how autonomy is (or is not) protected. In particular, I will analyze health care consent decisions, supplemented by data from the Consent and Capacity Board and key informant interviews. This approach allows me to explore the power dynamics within the context of bureaucratic decision-making. Not all relationships are enabling – whether it is between a health care provider and a resident or between a home and resident – and bureaucratic decision-making can be a venue to sever those disabling relationships.

2.3.5 **Summary**

This research responds to the call in the more recent literature for developing a more nuanced theoretical understanding of those involved in caring relationships. Of particular relevance to this research is the attitude towards care in disability studies. The legacy of institutionalization is always in the background (if not the foreground) of scholarly work on care

---

[306] *Ibid* at 39.

– in institutions or in the community. There is a real danger of care conceptualized as an activity done by one person to another (passive) person. However, the literature surveyed shows that it is not necessary to reject care and still incorporate the criticisms of disability studies. Here I push back a little against scholars who reject care completely and avoid discussions about reforming institutional care altogether. The result of a lack of disability perspective on law reform in the LTC sector is that critical analysis is left to other disciplines (such as gerontology and sociology) which may not see the variety of ways in which disablism operates in the legal and other realms. I make the claim that the emphasis on caring relationships allows us to move beyond binary understanding of caregiver / recipient and helper/ helped while attending to the objections to care articulated by disability scholars.

The idea that the interests and identities of the two or more people in a caring relationship become intermingled is crucial to my research. In Chapter 4, I will pick up this theme again when I explore the themes of LTC research in the feminist political economy literature. For now, it suffice to say that caring relationships in turn are shaped by, among other political and market forces, the legal and administrative structure of a benefit scheme or regulatory regime. I now turn to the negotiation of tensions and contradictions in public benefit schemes as a way to link the debate about care with the regulation and governance literature.

2.4 Negotiating Tensions and Contradictions in Public Benefit Schemes

The purpose here is to identify the key issues that are pertinent to explaining the changes to regulation and governance in LTC, which in turn shape care and caring relationships. The claim here is that many of the regulation and governance changes are best described as a hybrid of a more flexible, informal approach with command-and-control regulation. Providing an empirical account of the changes is important for the theorization of care and caring relationships because care is a public or collective responsibility although many activities associated with care may occur in private and individuals assume responsibilities for such activities. Such an account will provide insights into the state / citizen relationships. In doing so, I will introduce the New Governance literature. As a school of legal thought, the New Governance literature is used primarily to gain insight into the techniques and instruments of regulating and governing – both on empirical and normative bases[307] – the care, treatments and living circumstances provided in LTC homes. I choose to explore the New Governance literature because the issues in the LTC home sector do not fit into the "oppositional orthodoxies of regulation and deregulation."[308] Some scholars present New Governance as a third-way approach.[309] I will first present the tensions and contradictions in public benefit schemes.

2.4.1 **Tensions and Contradictions in Public Benefit Schemes**

I will first map out the inherent tensions and contradictions in public benefit schemes: medical versus social model of disability, formal equality versus recognition of complexity of disability in everyday life, physical survival versus exercise of citizenship and deserving versus undeserving. Then the discussion will shift to the negotiation of tensions and contradictions as an on-going problem-solving process, followed by a brief overview of New Governance approaches. As I will explain, these New Governance approaches co-exist with more traditional forms of legal regulation and there is a debate about traditional law / New Governance hybrids.

A common theme in the analysis of public benefit schemes in the literature is the presence of tensions and contradictions in the foundations of such schemes. In a study of American welfare programs for people with disabilities, Weber argues that the civil rights approach, when thoughtfully applied, supports continued disability-specific welfare programs, and various improvements in the law of public welfare.[310] For Weber, disability-related welfare relies heavily on medical model ideas and may conjure images of charity and pity,[311] which is inconsistent with a social model or civil rights approach to disability. Through an in-depth review of the Federal Court of Appeal decision *Harris v Canada (Minister of Human Resources and Skills Development)*, Nancy Hansen and Lorna Turnbull argue that the Canada Pension Plan (CPP) rules made Harris (a woman who became unable to work because of multiple sclerosis) invisible. Similar to Weber, Hansen and Turnbull identify a tension in the CPP: its formalistic

---

[307] Orly Lobel, "New Governance as Regulatory Governance" in David Levi-Faur, ed, *The Oxford Handbook of Governance* (Oxford: Oxford University Press, 2012) 65 at 69. Lobel argues that New Governance brings together two academic literatures: empirical studies of regulation and normative thinking about the role of the state.

[308] Orly Lobel, "Setting the Agenda for New Governance Research Surreply" (2004) 89 Minn L Rev 498 at 499.

[309] Jason M Solomon, "New Governance, Preemptive Self-Regulation, and the Blurring of Boundaries in Regulatory Theory and Practice Symposium: New Governance and the Transformation of Law" (2010) 2010 Wis L Rev 591.

[310] Weber, *supra* note 97 at 2483.

[311] *Ibid* at 2500–2501..

approach to equality is in contrast to a broad and contextual approach which recognizes the diversity and complexity of disability in everyday life[312]. In a qualitative study of home support services in British Columbia, Kari Krogh and Jon Johnson examine the negative effects changes to services have had on the lives of people with disabilities.[313] Their findings point to the home support administrators' view that home support should focus on providing services that are essential to the physical survival of users.[314] This view competes with the notion of home support as a citizenship service, which advances the stance that home support services can enable individuals with disabilities to live their lives as full and active citizens.[315] Finally, Bill Hughes examines how the disabled identity has been transformed from deserving citizens into scroungers by right-wing 'workfare' discourse.[316] Austerity has made disabled people its scapegoat: disabled people are being represented as parasites by a populist politics of resentment.[317] There is a tension between the 'deserving' and the 'undeserving' (counterfeit citizenship) implied in modern welfare systems.[318]

The four sets of tensions and contradictions identified here - medical versus social models of disability, formal equality versus recognition of complexity of disability in everyday life, physical survival versus exercise of citizenship and deserving vs. undeserving - are helpful for contextualizing my study within the broader debates concerning assumptions about and objectives of public benefit schemes, especially those schemes grounded in a medical model of disability. This is important for the purpose of locating my case study within a body of work that questions current conceptions of public benefit schemes from a disability perspective. These authors' recognition of the tensions in the respective benefit schemes opens up a new question: how is the co-existence of theoretical and/or doctrinal tensions reflected in the on-going regulation and governance of a benefit scheme? My study also involves the identification of the underlying tensions that are specific to the LTC home scheme, such as safety versus autonomy and medical versus social care, and I extend this analysis by illustrating how these tensions are

---

[312] Nancy Hansen & Lorna Turnbull, "Disability and Care: Still Not 'Getting It'" (2013) 25:1 Canadian Journal of Women and the Law 111 at 125.
[313] Krogh & Johnson, *supra* note 219 at 152.
[314] *Ibid* at 160.
[315] *Ibid* at 168.
[316] Hughes, *supra* note 18 at 992.
[317] *Ibid* at 991.
[318] *Ibid* at 1001–1002.

negotiated when program changes are contemplated, contested and implemented. Understanding program changes requires an analysis of the substance of the changes (in law, for example) as well as the deliberations and decisions that led to those changes. This analysis will contribute to critical assessment of New Governance's claim that it is an entirely "new" regime that will have the built-in ability to innovate and constantly reinvent itself.[319]

2.4.2 **Law Conceptualized as Problem-Solving**

The negotiation of tensions and contradictions in the LTC home sector is conceptualized as an on-going problem-solving process. For the purpose of this dissertation, I adopt the New Governance's approach to law as "problem-solving involving institutional experimentation in a pragmatist sense."[320] In an article that explains the pragmatist approach with a discussion of two case studies - one of drug courts and one of employment discrimination remedies,[321] William H. Simon asserts that Pragmatism resists approaches to legal issues that rely primarily on abstract analytical schemes and methods.[322] The Pragmatist objects to the liberal idea of rights enforcement as the elaboration of a pre-existing moral consensus.[323] More specifically, "rights are analytical, individualistic, categorical, judicially enforceable, and corrective. Rights are derived analytically by the application of legal reasoning to authoritative sources."[324] In sum, solutions to public problems cannot be derived analytically, therefore, instead of relying on abstract analytical schemes and methods, these solutions are best derived deliberatively and experimentally.[325]

---

[319] Orly Lobel, "The Renew Deal: The Fall of Regulation and the Rise of Governance in Contemporary Legal Thought" (2004) 89 Minn L Rev 342 at 2714.

[320] Victoria Nourse & Gregory Shaffer, "Varieties of New Legal Realism: Can a New World Order Prompt a New Legal Theory" (2009) 95 Cornell L Rev 61 at 88. The idea of problem-solving has also been considered by Julia Black in the context of de-centred understanding of regulation. She asserts that in the de-centred understanding of regulation, it does not assume that any one actor has all the information necessary to solve policy problems. Not only is knowledge fragmented but that information is socially constructed: there is no such thing as objective truth. See Black, *supra* note 6 at 107.

[321] William H Simon, "Solving Problems vs. Claiming Rights: The Pragmatist Challenge to Legal Liberalism" (2004) 46:1 William & Mary Law Review 127. The studies refer to are: Michael C. Doff & Charles F. Sabel, "Drug Treatment Courts and Emergent Experimentalist Government" (2000) 53 Vand L Rev 831 and Susan Sturm, "Second Generation Employment Discrimination: A Structural Approach" (2001)101 Colum L Rev 458.

[322] *Ibid* at 131.

[323] *Ibid* at 178.

[324] *Ibid* at 136.

[325] *Ibid* at 131.

Simon further explains that pragmatist practice is problem solving[326] and elaborates the concept of problem-solving as follows:

> The rhetoric of problems and solutions suggests common interests, rather than the notion connoted by the idea of rights of individual interests competing with group interests. Problem solving connotes the possibility of mutually beneficial outcomes. It treats issues as neither purely distributive nor involving categorical choices between mutually exclusive positions.[327]

Simon is careful to point out that this approach "does not ignore conflicting interests or value dissensus."[328] However, neither the individual nor the community can know what their interests are prior to entering a properly designed process. As all parties may learn things in the process about the possibilities for realizing their own goals, the conceptions of those goals may change in the course of the process.[329] Every discussion needs starting points; however, these starting points are usually indeterminate, and should be regarded as provisional.[330] Finally, problem-solving is a continuous or recursive activity: every resolution is provisional and incorporates assumptions about its evolution and potential transformation.[331]

Before addressing the approaches used within the context of New Governance, it is necessary to scrutinize some of the assumptions implicit in the concept of problem-solving. An implicit underlying assumption is that all parties are autonomous and are capable of sharing and processing information and engaging in problem-solving. This may be attributed to the fact that pragmatism distinguishes itself from legal liberalism. One of the basic premises of legal liberalism is victimhood, which connotes weakness, passivity, and self-absorption.[332] In contrast to victimhood, "citizenship connotes interest in and capacity for active participation in decision making and at least moderate sensitivity to public values."[333] For the LTC home sector, would some residents, for example those with cognitive impairments, need support in order to participate in any problem-solving process? This is an important question to ask if we want a

---

[326] *Ibid* at 178.
[327] *Ibid*.
[328] *Ibid* at 179.
[329] *Ibid*.
[330] *Ibid*.
[331] *Ibid*; Christine Overdevest & Jonathan Zeitlin, "Experimentalism in Transnational Forest Governance: Implementing European Union Forest Law Enforcement, Governance and Trade (FLEGT) Voluntary Partnership Agreements in Indonesia and Ghana" (2018) 12:1 Regulation & Governance 64 at 65.
[332] Simon, *supra* note 321 at 133–135, 173.
[333] *Ibid* at 173.

truly inclusive process that can accommodate different capabilities and needs of residents. I will return to the matter of participation in the next section. As well, Simon's appeal to "mutually beneficial outcomes" partly depends on the assumption that at the very least, all parties can agree to the definition of the problem at some point and there are indeed possibilities for realizing their goals. This ignores how lived experiences are shaped by constructions of gender, disability and other factors and such experiences affect problem definition and resolution. These questions will guide my own construction of the problem-solving process within the LTC sector by identifying some of the assumptions used in the literature which may be speculative and require critical assessment.

New Governance covers a wide variety of processes being used to establish norms and standards, regulate behavior, solve problems, and resolve disputes. These governance innovations include a family of approaches such as public-private partnership, devolution, decentralization, enforced self-regulation, and stakeholder collaboration and proponents offer a variety of definitions of these approaches.[334] According to Grainne de Burca, the rise of New Governance can be viewed as a response to two kinds of impetus or background conditions: strategic uncertainty and interdependence.[335] The former refers to "the need to address complex policy problems which have not shown themselves to be readily amenable to resolution whether through hierarchy, market, or otherwise."[336] The latter refers to "the need to manage interdependence where divergent regulatory regimes affect one other to varying degrees, creating externalities, giving rise to conflict, or hindering transactional or personal mobility."[337]

The common thread in these diverse approaches in New Governance is that they all differ in some significant way from conventional legal institutions and procedures yet at the same time

---

[334] Bradley C Karkkainen, "New Governance in Legal Thought and in the World: Some Splitting as Antidote to Overzealous Lumping Reply" (2004) 89 Minn L Rev 471; Lobel, *supra* note 319; Lobel, *supra* note 308; Lisa T Alexander, "Reflections on Success and Failure in New Governance and the Role of the Lawyer Symposium: New Governance and the Transformation of Law - Wisconsin Law Review Symposium Afterword: Part III" (2010) 2010 Wis L Rev 737 at 739.

[335] Grainne de Burca, "New Governance and Experimentalism: An Introduction Symposium: New Governance and the Transformation of Law" (2010) 2010 Wis L Rev 227 at 232.

[336] *Ibid*.

[337] *Ibid*.

appear to be playing roles similar to those notionally performed by the law.[338] A commonality is that they all differ to some degree from top-down, rule-based, command-and-control regulation.[339] The critiques to the 'old' system are numerous[340] but can be summarized as follows. It is argued that the old model of regulation was ineffective and failed to promote broad public participation. In particular, regulatory laws could not easily respond to uncertainty or adapt to change. Regulatory solutions were also ineffective because they were devised with limited information and generated by bureaucratic experts or technocrats, rather than by individuals and institutions involved in implementation on the ground.[341] Scholars emphasize the need for 'third-way' approaches between market and state in complex modern economies.[342] In fact, New Governance scholars also accept the role of an active state in a democracy: "In their willingness to synthesize an emerging social vision, progressive reformers can move beyond entrenched and failed government structures while resisting flat attacks on the affirmative state."[343]

At the heart of New Governance scholarship is the notion of experimentalism. According to New Governance scholars, such as Charles Sable and William Simon, experimentalism aims to "accommodate the continuous change and variation that we see as the most pervasive challenge of current public problems."[344] Experimentalism can be defined "as a recursive process of provisional goal-setting and revision, based on learning from review of implementation experience in different settings."[345] The appeal of experimentalism is its capacity for learning and adaptation. The basic architecture involves a "center", which could be the national government, and a set of "local units", which could be states or municipalities. In experimentalist regimes, central institutions explicitly give autonomy to local ones to pursue framework goals

---

[338] David Trubek & Louise Trubek, "The World Turned upside Down: Reflections on New Governance and the Transformation of Law Symposium: New Governance and the Transformation of Law - Wisconsin Law Review Symposium Afterword: Part I" (2010) 2010 Wis L Rev 719 at 721.

[339] "Symposium: New Governance and the Transformation of Law - Foreword" (2010) 2010 Wis L Rev [iii]; Lisa T Alexander, "Stakeholder Participation in New Governance: Lessons from Chicago's Public Housing Reform Experiment" (2009) 16 Geo J on Poverty L & Pol'y 117.

[340] Lobel, *supra* note 319.

[341] Alexander, *supra* note 339 at 125.

[342] Lobel, *supra* note 308 at 504.

[343] *Ibid* at 502.

[344] Charles Sabel & William Simon, "Minimalism and Experimentalism in the Administrative State" (2011) 100 Georgetown Law Journal 53 at 78.

[345] Overdevest & Zeitlin, *supra* note 331 at 65.

(such as “adequate education”). The centre then monitors local performance, pools information in disciplined comparisons, and creates services and inducements that facilitate this disciplined comparison. The achievement of learning and coordination is through deliberative engagement among officials and stakeholders.[346] Instead of being a centralized rule-maker, the government acts as a facilitator of the experimentalist enterprise.[347] Finally, the framework goals, performance measures, and decision-making procedures are also regularly revised, and the cycle repeats.[348]

There is much debate about the nature and desirability of the changes that are occurring.[349] New Governance experiments have occurred in a variety of policy areas, such as public housing, poverty law, post- secondary education, financial services, food safety, drugs, health care, environment and social policy co-ordination.[350] For some, the impact of New Governance is a positive development, expanding law's capacities and enhancing its legitimacy. Accordingly, one strand of the New Governance scholarship is to investigate the success stories of New Governance.[351] For others, these developments may undermine law and the values associated with it. Therefore, another strand of the literature seeks to investigate the failures of New Governance.[352] Lisa Alexander observes that scholars view a New Governance experiment as promising or troubling because it either enhances or diminishes participation and redistribution.[353] New Governance proponents are interested in exploring the conditions that are necessary for the successful implementation of New Governance approaches. Equally important, the failures also expose the weaknesses and limitations of these approaches. A theme that emerges in critiques of New Governance approaches is the practical difficulties of stakeholder

---

[346] Sabel & Simon, *supra* note 344 at 55, 79.
[347] Wendy A Bach, “Mobilization and Poverty Law: Searching for Participatory Democracy Amid the Ashes of the War on Poverty” (2012) 20 Va J Soc Pol’y & L 96 at 110.
[348] Sabel & Simon, *supra* note 344 at 79.
[349] de Burca, *supra* note 335.
[350] Mark Dawson, “New Governance and the Displacement of Social Europe: The Case of the European Semester” (2018) 14:1 European Constitutional Law Review 191; Alexander, *supra* note 339; Alexia Brunet Marks, “A New Governance Recipe for Food Safety Regulation” (2016) 47 Loy U Chi LJ 907; Bach, *supra* note 347; Simon, *supra* note 321; Overdevest & Zeitlin, *supra* note 331; Lobel, *supra* note 319; Gráinne De Búrca & Joanne Scott, eds, *Law and New Governance in the EU and the US* (Oxford: Hart, 2006).
[351] Lobel, *supra* note 319; Susan Sturm, “The Architecture of Inclusion: Advancing Workplace Equity in Higher Education” (2006) 29 Harv JL & Gender 247; Sabel & Simon, *supra* note 344; Marks, *supra* note 350.
[352] Bach, *supra* note 347; Douglas NeJaime, “When New Governance Fails” (2009) 70 Ohio St LJ 323; Alexander, *supra* note 339; Alexander, *supra* note 334.
[353] Alexander, *supra* note 334 at 740.

collaboration under conditions of intense social conflicts that originated from power dynamics of race, class, gender, religion and sexual orientation.[354] This point will be explored further in section 2.5.2 “Theorizing Participation in New Governance”. But the policy prescription is not necessarily a return to a ‘command-and-control’ approach. Rather, the debate is about how to create a hybrid of some of the elements of the old, such as a healthy balance between traditional public law protections and New Governance.[355] In the next section, I will elaborate on the debate about the relationship between law and New Governance in order to address the question of whether we can harness the promise of New Governance approaches and incorporate traditional legal values into those concepts in the regulation of care.

2.4.3 **Co-existence of Legal Regulation and New Governance Approaches**

One of the debates in the literature is the actual as well as the potential nature and role of law in New Governance.[356] There is a shared concern within the literature about how New Governance transforms how we think of law. Of particular relevance to my case study is how law and legal processes are implicated in the operation of new regulatory approaches.[357] Drawing from examples from the European Union and the U.S., David Trubek and Louise Trubek describe three varieties of co-existence of New Governance and “law”: 1) complementarity (two systems working for common goals); 2) rivalry (two systems competing for dominance); and 3) transformation or hybridity (systems merge into new hybrid process).[358] Three factors have been proposed to help explain the success of efforts to yoke New Governance processes and traditional legal regulation in areas that have previously been regulated by command and control systems.[359] These are: inclusion of key stakeholders in new participatory mechanisms, genuine and effective commitment to social objectives, and maintenance of legal remedies as a default position.[360] Finally, proponents argue that the most interesting area of co-existence is when law is transformed by its relationship with New Governance. Such

---

[354] NeJaime, *supra* note 352; Bach, *supra* note 347.

[355] Alexander, *supra* note 339 at 175.

[356] Grainne De Búrca & Joanne Scott, “Introduction: New Governance, Law and Constitutionalism” in Grainne De Búrca & Joanne Scott, eds, *Law and New Governance in the EU and the US* (Oxford: Hart, 2006) 1 at 4.

[357] *Ibid* at 2.

[358] David M Trubek & Louise G Trubek, “New Governance & Legal Regulation: Complementarity, Rivalry, and Transformation” (2006) 13 Colum J Eur L 539 at 543–544.

[359] *Ibid* at 562.

[360] *Ibid* at 562–563.

constellations may happen when law creates New Governance procedures and mandates parameters. This is linked to a shift to "proceduralism" in which law simply creates procedures for conflict resolution and problem-solving.[361] This transformation thesis can be summarized as follows: "Law, as a social phenomenon, is necessarily shaped and informed by the practices and characteristics of New Governance, and New Governance both generates and operates within the context of a normative order of law."[362]

Scholars respond to hybridity with some understandable anxiety.[363]For some, it is important to carefully discern the power dynamics among participants in a New Governance experiment.[364] Alexander argues that approaches which give primacy to traditional legal elements such as legal rights and entitlements should be used in New Governance experiments involving traditionally marginalized groups. More specifically, for any participating lawyer to advance an equitable distribution of the benefits of reform, a robust role for both procedural and substantive rights may be necessary in New Governance regimes that involve traditionally marginalized groups.[365] On the other hand, when similarly situated professionals are participating, or when parties are equally dependent upon one another, legal rules are applicable only when the reform experiment fails to conform to its stated demands and goals so that meaningful and equal deliberation is possible.[366]

This leads to a broader question of the role of a hybrid model in implementing changes in order to respond to problems that are "uncertain and interdependent", as explained by de Burca. The transformation thesis is a promising line of inquiry to follow up on in my own research. As I will argue in subsequent chapters, many of the New Governance approaches in the LTC sector are created and sustained by law but at the same time, for practical and conceptual purposes, the nature of law may be understood differently in the shadow of New Governance. In my view, there is little dispute that we need a more thorough understanding of this transformed legal order as New Governance approaches will only be more common in the future if the New Governance scholars are correct.

---

[361] *Ibid* at 548.

[362] De Búrca & Scott, *supra* note 356 at 9.

[363] Trubek & Trubek, *supra* note 338 at 725.

[364] Alexander, *supra* note 339; NeJaime, *supra* note 352; Bach, *supra* note 347.

[365] Alexander, *supra* note 334 at 744.

[366] *Ibid* at 744–745.

This study seeks to further our understanding of the co-existence of the more traditional forms of legal regulation and New Governance approaches by focusing on a small sub-set of legal concepts and norms relevant to the LTC home sector. For example, is it possible to seek to combine elements of a rights model with New Governance approaches? The current legal framework provides recourses for residents and their families, as well as homes, through reviews and appeals to the Consent and Capacity Board and Health Services Appeal and Review Board.[367] As well, the *Human Rights Code* and the *Charter* guarantee equality rights to be free from discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability. These mechanisms are believed to be critical to protecting the rights and entitlement of LTC residents. The question that needs to be asked is whether we can harness the promises of New Governance approaches and incorporate traditional legal values into them. Alternatively, we can look at the ways in which the substantive content of certain legal norms or concepts is transformed by New Governance approaches.[368]

2.4.4 **Summary**

How the tensions and contradictions inherent in the LTC sector are negotiated using New Governance approaches may be the most challenging type of problem-solving, as these tensions and contradictions are intertwined with normative issues. My research will highlight the New Governance approaches that can be observed in the changes to legislation and governance and link them to those tensions and contradictions. I will also summarize changes that cannot be explained by New Governance in order to raise questions about the explanatory power of New Governance scholarship. In other words, this analysis is a systematic way to begin to theorize the changes to legislation and governance that are procedural in nature but may have significant impact for how problems in the LTC home sector are solved in the future. The debate about a hybrid approach that gives primacy to some traditional and substantive rights-claiming strategies points to the potential perils of New Governance experiments in some contexts. In sum, the debates referenced above provide a language that I can use to articulate the transformation of the

---

[367] The Consent and Capacity Board holds hearings about consent to treatment, admission to a care facility or personal assistance service. The Health Services Appeal and Review Board can review orders and decisions of the Director (appointed by the Minister of MOHLTC) under the *Long Term Care Homes Act, 2007* (e.g. licensing decisions).

[368] For example, see Louise Trubek, "New Governance Practices in US Health Care" in Grainne De Búrca & Joanne Scott, eds, *Law and New Governance in the EU and the US* (Oxford: Hart, 2006) 245.

nature of law and New Governance in the LTC home sector.

2.5 Inclusion and Meaningful Participation Opportunities for Persons with Disabilities

In my earlier discussion about Prince's work on disability politics in Canada, recall that citizenship places responsibility on the government to consult with persons with disabilities as citizens on a host of policy areas. As well, the criticisms about care bring forward the claim that without adequate support disabled people are not able to participate in different aspects of life that other people have taken for granted. It follows that debates about inclusion and opportunities for meaningful participation for disabled people are important issues in disability research. In modern welfare states, inevitably care is mingled with health and social policies. Administration of social policies such as different types of social security and support programs has attracted intense scholarly attention. These programs (and the ways in which they operate) can indeed be disabling.[369] I make the case for an empirical study of processes and procedures – many of them mandated by law - that purport to promote inclusion and participation of disabled people and their families and friends. This dissertation's contribution is expanding our understanding of the meaning of participation outside of the employment setting. Here I argue that participation can be analyzed at the individual and collective levels. I apply theories about participation from the New Governance literature in order to examine techniques purported to promote inclusion and participation in the LTC sector. This analysis is intended to extend the debate in the disability studies literature by attending to the regulation aspects of participation.

2.5.1 "Nothing about us without us" in Social Policies

The principle of user involvement is fundamental in disability advocacy and resistance.[370] To put it simply, disabled people should, wherever possible, decide for themselves.[371] This principle is important in social services. Hearing from the people directly affected should mean services are more appropriate and effective. People should use their own lived experience to determine the shape of service provision i.e., expertise by experience. While specialist expertise

---

[369] JoNel Newman, "Identity and Narrative: Turning Oppression into Client Empowerment in Social Security Disability Cases" (2015) 79 Alb L Rev 373.

[370] Shakespeare, *supra* note 106 at 159.

[371] *Ibid*.

is still required, this should not mean professionals have all the powers while disabled people have none.[372]

It follows that social programs can be constructed in an enabling way: by designing social programs to achieve larger objectives such as inclusion and equality on the one hand, and by building in mechanisms for participation in program administration or operation on the other. It is a policy, legal, and fiscal choice and therefore requires close study. The seemingly broad acceptance of the notion of participation in policy discourses[373] does not always correspond to the reality of disabled people. Weber as well as Hansen and Turnbull argue persuasively for participation and inclusion for persons with disabilities. In particular, these scholars assess how persons with disabilities participate in the benefits of various programs and draw the link between such participation and paid employment. For example, Turnbull and Hansen write:

> Lack of assistance with basic domestic labour often prevents disabled women from accessing the paid labour market. In addition, to be able to function fully, disabled women rely upon the assistance of personal attendants or carers. Cynthia Harris might well have been able to function in the workplace with such assistance and with similar assistance at home or in the school to help meet Bradley's needs. The fit between the world of work and the world of care is poor for women, and it is poor for persons with a disability.[374]

In some regard, one view is that paid employment is a form of participation and inclusion. In an article about the collective goals, working assumptions, and points of view of the Canadian disability movement, Prince explains the Canadian disability movement’s recognition of the importance of access to paid labour as one of the dimensions of citizenship: “Disability activists recognize the importance of work incentives in social policy and condemn the work disincentives embedded in various income programs and public services.”[375] Further, the Canadian disability movement strives for greater participation of individuals with physical and mental impairments in the mainstream paid labour market.[376] This recognition exists in parallel with the policy priority given by governments to the employability of adults with disabilities,

---

[372] *Ibid* at 160.

[373] For example see Prince, *supra* note 116 at 94–95. There is no shortage of government reports about promoting inclusion of disabled people.

[374] Hansen & Turnbull, *supra* note 312 at 124.

[375] Michael Prince, “Canadian Disability Activism and Political Ideas: In and Between Neo-Liberalism and Social Liberalism” (2012) 1:1 Canadian Journal of Disability Studies 1 at 11.

[376] *Ibid*.

which is tied to the discourse of economy.[377]

This begs the question: what do "participation" and "inclusion" mean for persons with disabilities who cannot participate in paid employment, for example, due to advanced age and illness? This is an important area of research because according to Émilie Raymond and Amanda Grenier, recent discourses on aging emphasize the value of older people's social participation.[378] Although various definitions and interpretations of participation exist in social gerontology, the most common appears to be that of participation as a daily and social activity.[379] Results from a critical discourse analysis on aging policy conducted in Quebec between 2005 and 2011 indicate that over time, participation increasingly came to be defined as productivity. The participation context also changed from collective responsibility to community adjustment and personal choice. Further, policy texts reflected a polarization between activity and a loss of autonomy that linked participation with health status: "With participation and health portrayed as intricately linked features of the new aging lifestyle, participation is considered to produce health, and health to generate participation – impairment and disability become relegated to the margins, invisible, or unvoiced."[380] This draws our attention to the danger of uncritical acceptance of "participation" as it can exclude those who are deemed outside of the new aging lifestyle.

A gap in the literature surveyed is that it is short on prescriptions for participation techniques. Hansen and Turnbull did not elaborate concepts such as participation or explain precisely how to move forward: "Inclusion requires the ability to see the ways in which our current social structures contribute to excluding some individuals among us and the creativity to imagine ways to challenge those structures through the participation of all people."[381] Even if there is increased participation, would such increased participation "correct or simply reinforce existing imbalance of power"[382]? This is a promising direction for further research but the

---

[377] Prince, *supra* note 116 at 78. Prince discusses the discourse of resource scarcity or, even in times of budgetary surplus, of fiscal prudence to avoid government deficits again.
[378] Émilie Raymond & Amanda Grenier, "Participation in Policy Discourse: New Form of Exclusion for Seniors with Disabilities?" (2013) 32:2 Canadian Journal on Aging 117 at 118.
[379] *Ibid* at 119.
[380] *Ibid* at 125.
[381] Hansen & Turnbull, *supra* note 312 at 126–127.
[382] Louise G Trubek et al, "Health Care and New Governance: The Quest for Effective Regulation" (2008) 2:1 Regulation & Governance 1 at 4.

analyses will need to be framed with explicit acknowledgement to the "struggle for full citizenship" (as termed by Prince) in order to give sufficient attention to the normative aspects of participation.

In particular, this inquiry should be situated within a broader discussion about disability organizations engaging in policy development processes.[383] This is an important area for close examination because fiscal and social benefits are especially critical for overcoming obstacles in achieving full membership and participation within Canadian society. In other words, they can be concrete expressions of social citizenship.[384] Regrettably, disabled people have often found that they lack authority over and within welfare programs and have little control of the predominantly nondisabled personnel who manage and operate those programs. It is argued that in any helper-helped relationship, the "helpers" by dint of their super-ordinate position, are able to exercise greater influence over defining the problem to be solved.[385] In the Krogh and Johnson study of home care, it is argued that a community coalition (Home Support Action Group) had limited success in influencing home support policy and administration.[386] This study draws attention to the perils of the appearance of "increased user participation" and "work in collaboration"[387] – the policy outcome (inadequate home support) remains the same for people with disabilities.

Thus, there is a case for close examination of the techniques used to promote inclusion and participation as well as the purposes of and meanings attributed to such techniques. This in turn calls for greater attention to the theoretical justifications for and empirical assessments of participation. Accordingly, I will further the scholarly debate by considering whether there are meaningful opportunities for persons with disabilities to participate in making decisions – individually and collectively – within a benefit scheme or regulatory regime. My research will borrow the techniques and instruments referenced in the New Governance literature, in particular the principles of stakeholder participation, decentralization and collaborative process, to analyze opportunities for residents in the LTC home sector setting. This is not an attempt to argue that

---

[383] Prince, *supra* note 116 at 155–176.
[384] *Ibid* at 21.
[385] Robert F. Drake, "Welfare States and Disabled People" in Gary L. Albrecht, K.D. Seelman, & M. Bury, eds., *Handbook of Disability Studies* (Thousand Oaks, CA: Sage Publications Inc., 2001) 412 at 417.
[386] Krogh & Johnson, *supra* note 219 at 170–172.
[387] *Ibid* at 171.

New Governance is the only possible theoretical approach to explain participation mechanisms in the LTC sector or to relate these mechanisms to other health sector reforms. For example, there is a rich and growing body of literature about public and patient engagement.[388] The New Governance literature provides a useful way to describe how changes in hard and soft law relate to participation mechanisms and support required (such as legal representation). The analyses will also be informed by Prince's discussion of social inclusion in order to properly contextualize my case study within the broader struggles of the Canadian disability movement.

2.5.2 **Theorizing Participation in New Governance**

Participation is an important theme in the New Governance literature. "The goal of New Governance theory is to get a broad range of stakeholders involved, including regulated entities, private interest groups, government enforcement agencies, and the class of people that the law is intended to benefit."[389] As I indicated earlier, one branch of the literature can be described as success stories of New Governance, with an emphasis on illustrating the instrumentality of participation and other New Governance techniques.[390] Scholars envision two crucial roles for democratic participation. First, participation results in better, more responsive programs. Second, beyond its instrumental value, participation deepens democracy by conceptualizing a far more robust role for stakeholders in the creation of public policy.[391] New Governance scholarship emphasizes increased participation of non-state actors because it challenges conventional assumptions that the regulatory policymaking powers of administrative agencies are based on their superior knowledge, information, and expertise.[392] New Governance

---

[388] Julia Abelson, "Patient Engagement in Health Technology Assessment: What Constitutes 'meaningful' and How We Might Get There" (2018) 23:2 J Health Serv Res Policy 69; Julia Abelson et al, "Supporting Quality Public and Patient Engagement in Health System Organizations: Development and Usability Testing of the Public and Patient Engagement Evaluation Tool" (2016) 19:4 Health Expect 817; Julia Abelson et al, "Assessing the Impacts of Citizen Deliberations on the Health Technology Process" (2013) 29:3 International Journal of Technology Assessment in Health Care 282; Kathy K Li et al, "Conceptualizing the Use of Public Involvement in Health Policy Decision-Making" (2015) 138 Social Science & Medicine 14.

[389] Michael Waterstone, "A New Vision of Public Enforcement" (2007) 92 Minn L Rev 434 at 482 cited in Nourse & Shaffer, *supra* note 320 at 88.

[390] For example see Lobel, *supra* note 319. [Occupational Health and Safety, Employment Discrimination, Environment and Internet]; Susan Sturm, "Gender Equity Regimes and the Architecture of Learning" in Gráinne De Búrca & Joanne Scott, eds, *Law and New Governance in the EU and the US* (Oxford: Hart, 2006) 323. [Women's under-participation in academic science and engineering careers]; Louise G Trubek, "New Governance and Soft Law in Health Care Reform" (2006) 3 Ind Health L Rev 139.[Health care reforms].

[391] Bach, *supra* note 347 at 111; Lobel, *supra* note 319.

[392] Lobel, *supra* note 307 at 66.

diversifies the types of expertise and experience that new actors bring to the table.[393] Participation has included sharing tasks and responsibilities with the private sector, which creates more interdependence between government and the market. As a result, the boundaries between private and public become more fluid and permeable.[394]

While there are strong theoretical arguments for participation, one of the debates within New Governance scholarship is about the realization of the above-mentioned participatory ideals. The point of contention in the literature is the limits of participation in practice from the perspective of outsiders. Even scholars who advocate forcefully New Governance approaches recognize criticisms about grassroot and outsider participation. A common theme in this debate is the conditions necessary for New Governance approaches to be effective. This theme is closely related to my earlier discussion about the role of law in New Governance.

In an article about advancing workplace equity through institutional transformation, Susan Sturm summarizes the skepticism about legitimacy and feasibility of grass roots participation in New Governance deliberations.[395] One of the challenges is developing outsider groups' capacity to engage effectively and thus participate as "equals" in the deliberative process.[396] Also, it is said that there is the challenge of constructing effective processes that enable meaningful participation by disempowered groups, and that do not simply privilege experts.[397] Further, reliance on grass roots organizations in third party monitoring depends on strategies for enabling these groups to participate effectively, which are still lacking in the literature. Without attention to these questions, grass roots organizations find it difficult to sustain their involvement over time. They also are limited to the relatively rare situations where outsiders have already organized sufficiently to engage in effective collective action.[398]

In this regard, empirical studies of New Governance approaches in social policies are particularly relevant. Instead of examining success stories, scholars such as Lisa T. Alexander, Douglas NeJaime and Wendy Bach critically evaluate instances where New Governance

---

[393] Lobel, *supra* note 319 at 373.
[394] *Ibid* at 373–374.
[395] Sturm, *supra* note 351 at 269.
[396] *Ibid*.
[397] *Ibid*.
[398] *Ibid*.

approaches could not deliver concrete outcomes for outsiders. They challenge the claims made by Orly Lobel, Simon, Trubek and other New Governance scholars. They provide a set of questions concerning the potential negative impact of participation in governance that will be a useful guide to my analysis of the LTC home sector.

In a study about implementation of participatory democracy mechanisms in the context of poverty law, Wendy Bach suggests that participatory structures, as currently constituted, are likely to lead to little more than tokenism.[399] More specifically, she acknowledges that the legal structures mandating and implementing participation played a crucial role in rendering participatory governance endeavors more robust.[400] As well, administrative discretion in the implementation of the legal mandate was also important.[401] However, she raises the issue of whether New Governance programs that focus only on participation inside a governing structure would be ineffective in achieving robust participation. She concludes that New Governance must allow for additional means to augment and support participation, for example, by providing support to independent organizations.[402]

NeJaime's work contributes to our understanding of the limitations of New Governance by challenging the New Governance scholarship's faith in process to engage stakeholders in collaborative deliberation in situations lacking strong shared substantive commitments.[403] He observes that much of the collaborative governance scholarship has been applied in situations where some shared ground and commitments exist instead of those characterized by diametrically opposed views and constituencies.[404] In gender-based advocacy and other identity-based projects, divergent commitments and intense disagreement regarding baseline norms are most likely.[405] In a case study about sex education curriculum in Maryland, he illustrates that intensely adversarial legal and political relationship between the Christian Right and gay rights movements poses an insurmountable challenge to the consensus norm that New Governance trusts to defuse adversarial interactions and to expose win-win solutions. The community indeed

---

[399] Bach, *supra* note 347 at 96..
[400] *Ibid* at 153.
[401] *Ibid* at 154.
[402] *Ibid* at 155–156.
[403] NeJaime, *supra* note 352 at 356–357.
[404] *Ibid* at 357.
[405] *Ibid* at 357–358.

attempted a New Governance strategy, using stakeholder participation to revise the curriculum in a collaborative process but the parties returned to litigation.[406]

Finally, NeJaime contends that effective participation in New Governance collaboration means participation that has real implications for process and outcomes and requires a meaningful seat at the proverbial table. Access by outsider groups must be meaningful in the sense that such groups can actually affect decision making.[407] He illustrates how a sham process failed to instigate changes in an employment equity context. The now-dissolved international law firm Heller Ehrman LLP sought to address the under-representation of women in partnership through the Opt-In Project, which purported to include stakeholders and offer solutions. Heller's effort, however, produced little change on the ground and largely ignored the unique situation of women of colour.[408] In sum, attempts at New Governance participatory structures may *rhetorically* include disempowered stakeholders but actually *cede* little or no power.[409]

2.5.3 **New Governance and Health Care**

While there are many articles about the various tools of governance in the health care setting,[410] I will focus on the issue of participation. The notion of patient / consumer participation has been studied in the New Governance literature. For example, in an article about three health care reforms in the U.S. — achieving universal coverage, embedding technology into health care delivery and attaining high quality care for all —Louise Trubek describes the processes used to tackle these reforms.[411] Trubek discussed how stakeholder groups - physicians, health care providers, business, government, consumers/patients, and technology experts and entrepreneurs – become reformers of the health care system. Here I will focus on

---

[406] *Ibid* at 330.

[407] *Ibid* at 363.

[408] *Ibid* at 396. For example, Heller's Gender Diversity Committee produced lengthy reports and recommendations detailing the issues of women's low rates of retention and promotion in Heller and other large law firms. Rather than vesting authority in the Committee, though, Heller understood the Committee's role as "provid[ing] input to management on best practices in these areas."

[409] *Ibid* at 362.

[410] Examples include: Yolanda Campbell, “New Governance in Action: Community Health Centers and the Public Health Service Act” (2010-2011) 4 St. Louis U. J. Health L. & Pol'y 397; John D. Blum, “New Governance and Health Care Regulation” (2007) 2 Asian J. WTO & Int'l Health L & Pol'y 125; John D. Blum, “A Revisionist Model of Hospital Licensure” (2008) 2 Regulation & Governance 48.

[411] Trubek, *supra* note 390 at 139.

consumers.[412] Trubek associates the rise of consumers as key players in health care to the use of markets in health care to controlling costs and the increase in patient involvement to control chronic disease.[413] Consider New Governance's portrait of the patient / consumer: "The patient and consumer are envisioned as independent actors who can influence outcomes at the clinical and policy level."[414] Justification for participation seems to originate from what consumers can do for the health care system: if consumers and patients are provided information or economic incentives, they can influence the system as well as obtain better, less expensive care.[415] Trubek's discussion puts an emphasis on consumer and patient participation in health care reform:

> The consumers are considered essential to the functioning health care improvement processes; the voice of consumers and patients is essential for deliberation. The voices of the consumers and patients can be provided through groups of consumers, such as disease groups, and lawyers who represent disadvantaged groups, including racial and ethnic minorities.[416]

Trubek's assumption seems to ignore the information imbalance between consumer / patient and health care providers. At the same time, Trubek seems to recognize the limitation of the independent consumer / patient: "While educated patients can be effective at the patient-physician level, representatives of the interests of the disadvantaged groups are essential at the institutional and policy level."[417] Further, "on the institutional and policy level, the knowledge required for intervention is often sophisticated and requires skills such as accessing institutional policies, locating statutes and court cases, and discovering the places where intervention will be useful."[418] This begs the question as to why some consumers are better represented than others.

Yet my study differs from Trubek's work in the sense that disability and gender will be integrated into my analysis of patient / consumer participation. A limitation of Trubek's work is that the casting of patient / consumer participation as "consumerist" or "market-oriented" assumes a market solution to an equality problem without much substantiation. To be clear,

---

[412] *Ibid* at 141.
[413] *Ibid* at 157.
[414] *Ibid* at 156.
[415] *Ibid* at 158.
[416] *Ibid* at 157.
[417] *Ibid* at 158.
[418] *Ibid* at 159.

Trubek's work originates in part from an interest in eliminating racial and ethnic disparities in health care treatment. It is said that civil rights litigation model has not been successful in eliminating such disparities.[419] Trubek acknowledges that in order to be legitimate, the governance process must include participation of the underrepresented and under-organized groups.[420] She makes a few helpful suggestions about the techniques of including those groups, including explicit measurement of the participation of disadvantaged groups, provision of a process where groups who view themselves as excluded can challenge the transparency and effectiveness of the governance scheme, and sanctions for those actors who refuse to collaborate in new alliances.[421] A gap in the literature is that there is little elaboration concerning how gender, disability, race, class and other differences are factored into explaining the causality between New Governance participatory approaches and their outcomes. This gap will be addressed in my study in two ways.

First of all, the conversation about patient / consumer participation needs to be extended beyond questions about techniques to ask whether user participation could actually influence how problems and solutions are defined. More precisely, New Governance is at best vague at explaining how problems may be defined differently by health care consumers due to gender, age, race, class and other differences. It should be clear from the gendered disability perspective that women may define health system outcomes differently from dominant policy discourses. For example, in a series of focus groups across Canada, Pat Armstrong *et al* asked how women defined quality in health care and concluded that the women interviewed said time in and for care are critical components of quality.[422] This understanding of quality may not be reflected in themes in research literature and policy fields: quality is defined in terms of hospitalization rates and of patients' satisfaction with services.[423] The point is that much remains to be studied about neglected aspects of consumer / patient participation, such as the lived experience of female users of the health care systems. The gap in the New Governance literature is that increased participation of non-state actors appears to be gender-neutral, and it is not clear how gender

---

[419] *Ibid* at 140 and 149; Trubek, *supra* note 368 at 255–256.

[420] Trubek, *supra* note 390 at 169.

[421] *Ibid*.

[422] Pat Armstrong et al, "Women-Defined Quality Care" in Pat Armstrong et al, eds, *Thinking Women and Health Care Reform in Canada* (Toronto: Women's Press, 2012) 215 at 230.

[423] *Ibid* at 215.

might mediate the effect of its realization. More empirical research is needed to demonstrate whether user participation could actually influence how problems and solutions are defined in specific contexts.

Secondly, to push this line of thought further, Prince's observation about placing individuals within a larger societal context is particularly useful in avoiding the pitfall of reducing consumers / patients to unconnected and undifferentiated individuals. "Disability groups often focus on individuals and their needs, but the general emphasis is not individualistic; individuals are interdependent and interconnected through myriad networks of roles, structures, and relationships, some of which are enabling, and many others, over the life-course, disabling."[424] This research project is intended to move beyond an "individualistic" understanding of participation by examining how the law creates and maintains mechanisms for individuals as well as groups to participate on an on-going basis. In particular, one possible line of inquiry is to examine participation of LTC residents and their families in influencing the operation of the homes through legally mandated participatory mechanisms, for example, through Residents' Councils and Family Councils.[425] The literature has not provided many examples of on-going collective participation mechanisms that allow consumers/patients and families to access decision-making in health facilities. This line of inquiry addresses the gap in the New Governance literature by interrogating participation in decision-making at the LTC home level.

2.5.4 **Summary**

Having established that the concept of hybridity (more flexible, informal approach combined with traditional law) is a promising way to describe and explain many of the regulation and governance changes, here I concentrate on one of the "new" approaches: participation. In light of the significance assigned to the concept of "inclusion" from a disability perspective, this research aims to better understand participation outside of employment context and more specifically, in decision-making opportunities – individually or collectively - in public benefit schemes and regulatory regimes. The New Governance literature informs my own theorization of participation and provides a set of issues to consider in my case study: means to

---

[424] Prince, *supra* note 375 at 13.
[425] *Long-Term Care Homes Act, 2007,* SO 2007, c 8. See Part IV Councils.

augment and support participation, lack of strong shared substantive commitments, access by outsider groups to decision-making power, and individualistic understanding of patient / consumer participation. A gap in the literature is that there is little elaboration concerning how gender, disability, race, class and differences are factored into explaining the causality between New Governance participatory approaches and their outcomes. My study will extend existing analysis by focusing on whether participation could actually influence how problems and solutions are defined, based on the assumption that gender needs to be taken into account. My case study could be used to compare with other examples of inclusion and participation in the social and political realm in order to contribute to debates about the disconnect between theoretical justifications of participation mechanisms and empirical realities of disempowered groups and outsiders in social policy.

2.6 Summary of theoretical contributions of the research and conclusion

To conclude, I will briefly summarize the theoretical contributions of my research. First, care, in particular institutional care, is not a new problem in disability studies but I am offering new ways of studying the problem. To this end, I build on more recent research that attends to the possibility of being inclusive of the disability studies' critiques of care and the gendered nature of care. What this research adds to the conversation about care is a more comprehensive analysis of the legal aspects of institutional care today. Drawing on insights from feminist disability scholars such as Jenny Morris and Carol Thomas about why care is so problematic for disabled women, I theorize on the one hand, how law, including substantive and procedural protections offered by law, has shaped the lived experience of those living in institutions today; on the other hand, how law reflects meanings of and assumptions about disability. The linkage between disability critique of care and the gendered nature of care is made by Herring's work on care and caring relationships. To extend debate about the caring relationship, my analysis will incorporate the work of Nedelsky on relational approach to law, rights and autonomy. Following Nedelsky, I will turn my attention to the difference context makes (in my case, disability, gender and age) and ask how existing laws and rights may have helped to construct the current problems in LTC and justifications for solutions as proposed by the government. This will lead to a broader discussion about state support for care and what such discussion can tell us about state / citizen relationship.

Secondly, I apply concepts in the New Governance scholarship in order to provide an empirical account of changes to the regulation and governance in the LTC sector, which in turn shape care and care relationships. New Governance scholars argue persuasively that law is problem-solving involving institutional experimentation in a pragmatist sense. I incorporate the notion of problem-solving and delve into the tensions inherent in the LTC sector and ask how such tensions are negotiated using New Governance approaches. The analysis will include an assessment of the regulation and governance changes in terms of how they measure up to New Governance approaches. I will also provide an account of changes that do not fit into New Governance. This will fill a gap in the New Governance scholarship because there are relatively fewer studies devoted to social policies and in the Canadian context. The "care" relationships provide a novel context through which to study the implementation of New Governance approaches in parallel with so-called command-and-control regulation. My research also differs from many of the existing studies because it will yield a deeper understanding of how disability, gender and age mediate the impact of New Governance.

Thirdly, my research will further the scholarly debate about participation and inclusion of persons with disabilities by considering whether there are meaningful opportunities for users to participate in making decisions – individually and collectively – within a benefit scheme or regulatory regime. If we accept that care, including care that is provided as part of a government scheme, must be understood in its relational context, it follows that measures that influence the interactions of those involved in caring relationships such as participation mechanisms, are worthy of critical inquiry. In doing so, New Governance's work on the normative and instrumental value of different forms of participation complement theorization about exclusion of disabled people in different settings. I seek to contribute to the literature by moving beyond an "individualistic" understanding of participation by examining how the law creates mechanisms for individuals as well as groups to participate on an on-going basis. Again, since the scope of my research includes different parties in a caring relationship, I will also consider participation of families and friends in the operation of LTC homes. The conditions necessary for meaningful participation, not just law, will be explored in order to articulate theoretical justifications for support to those who may not be able to participate in more conventional ways. My research could be used to compare with other examples of participation and inclusion in the social and political realms.

3 Research Methodology

3.1 Introduction

The following research methods were employed in this dissertation: 1) detailed examination of the contents of publicly available government reports; 2) legislation (statutes, regulation and "soft law") and case law; and 3) key informant interviews. Informed by the literature review, I combined these methods to create a more comprehensive and reliable account of the changes to the legislation and governance of treatment, care and living circumstances within long-term care homes in Ontario between 2004 and June 2018.[426] This chapter describes each method and its respective justification in the order that the methods were carried out.

But before proceeding to the discussion of research methods, I want to take a step back and consider the question of "who legal research is done for".[427] Desmond Manderson and Richard Mohr argue that legal research is informed by understandings of the question and role of law in society.[428] As a process of debating between outcomes, law offers a language for articulating issues of morality and justice.[429] In explaining the inherent tension between legal practice and legal scholarship, they maintain that an ethics of law understands legal argument as a way of helping us to differentiate between alternative outcomes rather than simply dictate the shortest way to a predetermined goal. Further, to move to an ethically prudent approach - which recognises alternative outcomes - is to recognise alternative reference groups. Hence, legal research needs to be comprehended and approached as continuous with the purposes of law, in other words, with legal ethics.[430] According to Manderson and Mohr:

> . . . we first recognised that 'discovering the law' was inadequate for any but the most limited view of vocational legal research. Broadening our perspective, we now propose that research is defined not only by its objects of inquiry (statutes or society), but also the interests it serves. To recognise this is not simply to take different sides in a traditional

---

[426] There was a change in government in June 2018. From October 2003 to June 2018, the Ontario Liberal Party was the governing party.

[427] Desmond Manderson & Richard Mohr, "From Oxymoron to Intersection: An Epidemiology of Legal Research" (2002) 6 Law Text Culture 159 at 166.

[428] *Ibid*.

[429] *Ibid* at 167.

[430] *Ibid* at 168.

> adversarial contest, but to identify new sources guiding our inquiries and their purposes. Legal research must refresh itself not by a divorce from interests (or advocacy) but by a diversification of and problematising of those interests.[431]

By identifying alternative interest groups – in this case, people with disabilities and older women – I hope to find "alternative standpoints from which to take a fresh look at the social and moral world"[432] (or at least the world of regulation and governance). To put it differently, the incorporation of disability and gender into this research can also be justified from a methodological perspective.

3.2 Review of Government Documents

Review of government documents was the first phase of my research in part to reflect the "law in context" tradition.[433] More specifically, the starting point is not law but rather problems in society which are likely to be generalized or generalizable. Thus, law becomes problematic in two ways: it may be a contributor or cause of a problem and may provide a solution or be part of a solution. Of the latter, other non-law solutions, including social and political arrangements, are not precluded and may indeed be preferred.[434] Accordingly, the primary purpose of document review for this study was to ascertain how public bodies (units of government) and their relationships with the LTC system shaped the specific policy questions about health, illness, disability and health care that were being asked in that period. The assumption here was that identifying the key concepts or ideas embedded in these public documents would reveal the perceptions or understanding of problems regarding long-term care homes. The content of some of these documents helped me to contextualize and explain the legislative and regulatory changes (the next research phase).

The first task was to locate the relevant public bodies and to determine their respective significance in this study. To reflect the multiple locations of the exercise of power and control

---

[431] *Ibid*.

[432] *Ibid* at 167.

[433] The other tradition is "black letter law", focusing mainly if not exclusively upon the law as an internally consistent set of principles which can be accessed through reading court judgements and statutes with little reference to the world outside of the law. See Wing Hong Chui & Mike McConville, "Introduction and Overview" in Mike McConville & Wing Hong Chui, eds, *Research Methods for Law*, 2nd ed (Edinburgh: Edinburgh University Press Ltd, 2017) 1 at 1.

[434] *Ibid*.

in the sector, it is imperative to consider “where and how deliberations and decision making occurs.” Below is a list of provincial public bodies whose documents I reviewed as these are the bodies that carry out deliberations and /or make decisions about long-term care home issues in Ontario:

- Auditor General
- Ombudsman
- Standing Committee on Social Policy
- Standing Committee on Public Account
- Ontario Ministry of Health and Long-Term Care (MOHLTC)
- Chief Coroner for Ontario
- Geriatric and Long Term Care Review Committee (Chief Coroner)
- Local Health System Integration Networks (LHINs)
- Health Quality Ontario (HQO)

The decision to examine only publicly available documents was based on the following considerations. The potential costs and time required to submit Freedom of Information requests make it impractical to include internal documents. As well, such requests are unlikely to generate useful documents because internal documents are likely to be subject to various exemptions and privileges such as solicitor-client privilege and Advice to Cabinet. Further, even if documents are released, they are most likely to be early drafts of publicly available documents or internal decision documents that confirm decisions that would be announced later.

To locate publicly available documents, I visited the website of each of these bodies and searched for reports that are related to long-term care homes. More specifically, I looked for reports, plans and documents under the headings of “seniors”, “Ministry of Health and Long-Term Care”, “long-term care homes”, “health care” or “long-term care”. This search also included news releases and other communication materials that accompany the release of these documents. Last but not least, I also contacted the clerks of the Standing Committees to request documents that are relevant to my case study, such as the government’s responses to recommendations of Standing Committees. These are the core documents. The documents used in this dissertation were published between 2004 and 2018.

I also reviewed government documents that could inform me of policy directions that are relevant to my case study (the supplementary documents). The first set of documents concern background about the health care sector generally and funding information including government investment in the LTC sector, such as the annual provincial budget, mandate letters and strategy documents. The second set of documents concern policy areas that are related to my topic, such as consultation papers related to the *Accessibility of Ontarians with Disabilities Act* (AODA), and reports about income security issued by Statistics Canada. The third group of documents that I consulted are documents that illuminate the complex formal and informal relationships among these bodies as well as with groups that are active in the sector. These documents included memorandum of understanding, annual reports, strategic plans and so forth. I chose Health Quality Ontario and one of the LHINs (Toronto Central) because they both have accountability relationships with LTC homes and these documents help me to understand the context in which the LHINs and Health Quality Ontario attempt to influence the behaviours of homes.

My analysis of government documents (the core documents) was mostly inductive as this was done at the beginning of the research project where I was in the exploratory and discovery stage. The purpose was to allow understanding of critical themes and issues to emerge from close study of texts.[435] The review of government reports was done in two stages: each report was reviewed and analyzed separately and then all the analyses were summarized to identify common themes. To ensure the document review was done consistently, I undertook a preliminary review of a sample of documents, for example, one document from each body, and then developed a template for tracking my analysis. The template specified the key issues, concepts, approaches, and official positions. I then conducted a comprehensive review of all of the documents using the template. In other words, I continually wrote down my thoughts about what I was reading and these thoughts and observations became analysis about how the themes

---

[435] H Russell Bernard, *Social Research Methods: Qualitative and Quantitative Approaches*, 2nd ed (Los Angeles: SAGE Publications, 2013) at 524–525. Bernard discusses two epistemological approaches for all research: induction and deduction. All research is ultimately a combination of inductive and deductive efforts. He argues that the work is mostly inductive when the researcher is in the exploratory and discovery stage of any research project. In contrast, the work is mostly deductive when the researcher is in the confirmatory stage of any research project.

are connected to each other in a theoretical way.[436] As well, I identified and recorded any other official reports that were released during this period but missed during the initial search. These reports were reviewed following the same process.

3.3 Legislation (statutes, regulation, "soft law") and case law

While this dissertation draws on theories from outside of legal scholarship (particularly from the fields of disability studies and feminist political economy) in order to tease out the meanings of the changes, the bulk of my analysis is fundamentally rooted in a study of law. But the question of "what is the law" is not a straightforward question. Health law, where regulation of LTC homes belongs, covers a variety of provincial and federal statutes, interwoven with common law and constitutional law principles. This is complicated by the existence of a variety of guidelines of various degrees of legal formality applicable to the sector. In other words, the health law researcher inevitably has to make choices about which law is the most relevant to the subject i.e., LTC homes.

3.3.1 **Hard Law**

According to Mike McConville and Wing Hong Chui, doctrinal research (or the "black-letter" law approach) relies heavily on using court judgements and statutes to explain law. This type of research aims to systematize, rectify and clarify the law on any particular topic through a distinctive mode of analysis of authoritative texts that include primary and secondary sources. [437] One of its assumptions is that the character of legal scholarship is derived from the law itself.[438] In recent years, pure doctrinal analysis has been criticised for its intellectually rigid, inflexible and inward-looking approach to understanding the law and the operation of the legal system.[439] Ian Dobinson and Francis Johns argue that doctrinal research is a process of selecting and

---

[436] *Ibid* at 530. Bernard discusses "memoing": the researcher continually writes down his / her thoughts about what he / she is reading. These thoughts become information on which to develop theories. Memoing is taking "field notes" on observations about texts. The observations can be about the themes emerging or ideas about how the themes are connected.

[437] Chui & McConville, *supra* note 433 at 3–4.

[438] *Ibid* at 4.

[439] *Ibid*.

weighting materials taking into account hierarchy and authority as well as understanding social context and interpretation.[440]

This study does include typical doctrinal research as described by McConville and Chui. For this study, the purpose of doctrinal research is to identify legislation that is applicable to the circumstances around treatment, care and living circumstances within LTC homes. [441] The typology of "hard law" and "soft law" is useful here.[442] In addition to the statutes and regulations, guidelines and agreements that impose requirements on LTC homes or offer guidance on compliance are also within the scope of my research. For those guidelines that are referenced in statutes or published by the government, I consider them to be part of the formal legal regime. To identify the relevant statutes, regulations and "soft law", I reviewed the web content of MOHLTC. In particular, I reviewed the list of statutes introduced or amended during the period of 2004 and 2018 (under the heading of "Legislation" on MOHLTC's website). I also reviewed the Legislative Assembly's website for omnibus bills such as budget bills and good government bills (which may include amendments to statutes administered by the Minister of Health). As well, I identified changes to regulations made by the Lieutenant-Governor-in-Council (Cabinet) or the Minister of Health by reviewing the web content of Ontario's Regulatory Registry[443] and E-Law.

Since my research question ("what are the changes") encompasses a comparison of the current and previous legal regimes governing the LTC sector, I used the implementation of the LTCHA as the beginning of the current regime. The previous regime was composed of three statutes: *Nursing Homes Act*, *Homes for the Aged and Rest Homes Act* and the *Charitable Institutions Act.* The three previous statutes were similar but not identical. In terms of structure, all three statutes covered important topics such as Residents' Councils, Residents' Bill of Rights,

---

[440] Ian Dobson & Francis Johns, "Qualitative Legal Research" in Mike McConville & Wing Hong Chui, eds, *Research Methods for Law* (Edinburgh: Edinburgh University Press Ltd, 2017) 18 at 21–22.

[441] *Ibid* at 22–23. Dobinson and Johns note that law is reasoned and not found. Law cannot be objectively isolated and the aim is to establish a doctrinal legal research methodology which takes into account of the nature of law.

[442] Robin Creyke & John McMillan, "Soft Law v Hard Law" in Linda Pearson, Carol Harlow & Mark Tushnet, eds, *Administrative Law in a Changing State: Essays in Honour of Mark Aronson* (Oxford; Portland, OR: Hart Publishing, 2008) 377.

[443] ServiceOntario, "Ontario's Regulatory Registry", (Toronto: Government of Ontario, 2018), online: <http://www.ontariocanada.com/registry/>. The Registry is a source for information on new proposed regulatory initiatives that could affect Ontario businesses as well as recently approved regulations that affect businesses.

Admission and Eligibility requirements and Inspection. There were also some key differences among these statutes. However, a comparison of all three previous statutes with the new LTCHA would be repetitive. The *Nursing Homes Act* was chosen because, at the time of transition to the new legal framework (2010), more than half of the LTC beds were operated by the private sector (see Chapter 4) and were subject to the *Nursing Homes Act*. The *Homes for the Aged and Rest Homes Act* was applicable to municipal homes while the *Charitable Institutions Act* was applicable to non-profit homes. The table in Appendix A illustrates the current and previous regulatory regimes specific to LTC in Ontario.

On February 26, 2019, the Ontario government introduced *The People's Health Care Act, 2019* (Bill 74). The Bill received Royal Assent on April 18, 2019.[444] The Bill would consolidate multiple health care agencies and organizations within a single agency - Ontario Health.[445] Once the relevant provisions of Bill 74 become effective, the *Local Health System Integration Act* and its regulations would be repealed in stages. The 14 local health integration networks and their functions would be reorganized.[446] Bill 74 would make consequential amendments to a number of statutes, including the *Excellent Care for All Act, 2010* and *Long-Term Care Homes Act, 2007*.[447] These statutes are within the scope of my doctrinal research. The legislative changes provided for by Bill 74 would come into effect at different dates.[448] However, at the time of writing, the changes are not in effect yet. Therefore, the comparison of the previous and current regulatory regimes described in Chapters 5 to 8 is still relevant. This dissertation does not address the Bill 74 changes.

Another important legislative development is Bill 100, *Protecting What Matters Most Act (Budget Measures), 2019*.[449] Introduced for First Reading on April 11, 2019, Bill 100 affects statutes within the scope of this research (such as the *Excellent Care for All Act* and *Substitute Decisions Act*) and introduces a new statute. Schedule 17 of Bill 100 repealed the *Proceedings*

---

[444] Bill 74, *The People's Health Care Act, 2019*, 1st session, 42nd Leg, Ontario, 2019 (assented to 18 April 2019), SO 2019, c.5.

[445] Bill 74 would enact the *Connecting Care Act, 2019,* SO 2019, c.5, Sched 1.

[446] Ministry of Health and Long-Term Care, *Building a Connected Public Health Care System for the Patient* (Toronto: Ministry of Health and Long-Term Care, 2019).

[447] *The People's Health Care Act, 2019*, *supra* note 444. See schedule 3.

[448] *Ibid*, s 2.

[449] Bill 100, *Protecting What Matters Most Act (Budget Measures), 2019,* 1st session, 42nd Leg, Ontario, 2019 (assented to 29 May 2019), SO 2019, c.7.

Against the Crown Act and replaced it with the *Crown Liability and Proceedings Act, 2019*.[450] The new Act came into force on July 1, 2019 with retroactive effects. It addresses Crown liability, including the limits on it, and sets out the procedural rules that apply in proceedings against the Crown and, in some cases, proceedings to which the Crown is a party. The new Act could affect the ability of residents and/or their family members to bring forward certain types of actions (e.g. tort) against the provincial government and transfer payment recipients such as LTC homes. This act is excluded from the scope of my review.

Other laws of general application are relevant to the regulation and governance of LTC sector in Ontario and are included in the review. However, changes to these laws are best described as incremental in nature rather than a complete "overhaul". Table 1 lists the laws of general application included in my review.

Table 1: Laws of General Application

Constitutional and quasi-constitutional	*Canadian Charter of Rights and Freedoms, Part I of the Constitution Act, 1982*, being Schedule B to the Canada Act 1982 (UK), 1982, c.11. Human Rights Code, RSO 1990, c H.19
Disability	*Accessibility for Ontarians with Disabilities Act, 2005*, SO 2005, c 11. O Reg 191/11
Health care related	*Health Care Consent Act, 1996,* SO 1996, c 2. O Reg 104/96 *Substitute Decisions Act,* SO 1992, c 30. O Reg 460/05 *Guidelines for Conducting Assessments of Capacity* (incorporated by reference in O Reg 460/05)

To ensure the consistency of the review, a template was developed to summarize the comparison. The template tracked my close textual reading of the statutes listed above, the legislative intent and nature of the changes, linkages to government documents, and deliberations

---

[450] *Crown Liability and Proceedings Act, 2019,* SO 2019, c. 7, Sched. 17.

and decisions associated with the changes. The comparison of old and new was informed by the key issues identified in the document review. The headings in a statute also helped me to tease out the key topics. However, the comparison was not exhaustive (i.e., not a section by section comparison). For example, consequential amendments (e.g. updating the French version of a statute) were excluded. Also, issues that are not "live" are excluded. For example, I did not address smoking in LTC homes because of the passing of the *Smoke Free Ontario Act*. A synthesis of all of the material I collected allowed me to make statements about what the law is on primary authority.

3.3.2 **Soft law**

According to Robin Creyke and John McMillian, a distinguishing feature of soft law is that it is intended to influence behaviour.[451] This intention is supported by some of the legal enforceability mechanisms.[452] It is argued that businesses, individuals and governments are willing to trade off the certainty and authoritative effect of legal rules for more flexible and adaptable soft law regulation.[453]

In the health sector, there are many guidelines issued by various bodies. Some are explicitly linked to formal law (for example, a regulatory college's code of practice) while some are completely voluntary (for example, guideline issued by a research institute). It is not possible to include all guidelines applicable to LTC in Ontario in this research, so I included a sample. Only a small number of organizations (nine) were included but they represented a diverse range of soft law applicable to the LTC sector (specifically those of regulatory colleges, professional associations, established knowledge transfer organizations and an accreditation agency). Some organizations also issued a considerable number of guidelines, however not all of them are relevant. By way of example, the College of Physicians and Surgeons of Ontario (CPSO) has guidelines pertaining to the operation of independent health facilities. Such guidelines were excluded from my review. I included guidelines that explicitly mention long-term care, or care for illnesses that are prevalent in the sector such as dementia, or issues known to require further guidance such as use of physical restraints. I also sought out guidelines that could illuminate

---

[451] Creyke & McMillan, *supra* note 442 at 379.
[452] *Ibid*.
[453] *Ibid* at 404.

concepts in statutes, such as “consent” and “patient-centred care”. Finally, since my project is about changes, I included guidelines that were introduced or amended during this period.

Table 2: Soft Law

Organization	**Number of documents reviewed**
College of Physicians and Surgeons and Ontario (CPSO)	9
College of Nurses of Ontario (CNO)	6
College of Dietitians of Ontario	1
Ministry of the Attorney General (MAG)	1
Health Quality Ontario	1
Registered Nurses’ Association of Ontario (RNAO)	12
Canadian Patient Safety Institute (CPSI)	2
Accreditation Canada	1
Choose Wisely Canada	1

This study is not only about “finding the law”. It also concerns the question of law as a contributor to and/or solution to social problems. Therefore, this research also attempts to attend to decisions and deliberations that may lead us to ask “how things get to be called law, or how they are experienced as such, and with what effects.”[454] To this end, I focused on the Standing Committees that considered LTCHA and other health-related statutes. In particular, I reviewed compendia, stakeholder submissions to Standing Committees, research products of the Legislative Assembly Library Services and clause-by-clause debates. They were useful for understanding the government’s interpretation of the LTCHA including its legislative intent.

---

[454] Manderson & Mohr, *supra* note 427 at 160.

3.3.3 **Case law**

It is also essential to check judicial consideration of the statutes and regulations I was reviewing against my own assumptions about interpretation or application.[455] The difficulty is that the LTCHA is a relatively new statute (effective July 2010) and there are very few cases that cite the LTCHA (outside of proceedings pursuant to the *Labour Relations Act* such as disciplinary decisions concerning long-term care home employees). Since the Health Services Appeal and Review Board (HSARB) hears appeals related to matters pursuant to the LTCHA, a search of these cases was undertaken on CanLII. I also checked whether any of these cases was appealed to the Superior Court.

The next group of cases was those brought under the *Health Care Consent Act*. The Consent and Capacity Board (CCB) hears appeals about incapacity findings regarding treatment, LTC admission and personal assistance. A search of these cases was done on CanLII.[456] I also checked whether any of these cases were appealed to the Superior Court, the Court of Appeal and then the Supreme Court of Canada. For CCB cases, I concentrated on cases where the appellants were deemed to be incapable of making decisions about LTC admission or where family members made applications to be appointed as representatives of incapable persons for LTC admission purpose.

The Human Rights Tribunal of Ontario is another forum where residents or applicants may assert their rights under the Ontario Human Rights Code. A search was done on CanLII to determine if any cases were brought forward by LTC residents or applicants or their family members (or litigation guardian).

The AODA is different from the statutes mentioned above in the sense that it is not a right conferring statute. There is no appeal mechanism for those who feel that an organization has not met the accessibility standards established under the AODA when they receive services. Rather, the AODA allows for appeals to the Licence Appeal Tribunal related to enforcement actions, such as administrative penalties imposed by the Director of the Accessibility Directorate of Ontario for non-compliance of filing requirements. I found only four cases when I performed

---

[455] Dobson & Johns, *supra* note 440 at 27.

[456] The CCB does not publish all decisions, only those decisions with written reasons. Any party of a particular case can request written reasons.

my search and they could not tell us very much about the interpretation of the AODA. I also searched for court cases that refer to the AODA in order to get a sense of how the AODA is interpreted by the courts and the context in which disability issues may come up. These cases are not related to LTC.

Regarding equality cases, I started by reviewing the recent issues of leading journals, including the Supreme Court Law Review, Review of Constitutional Studies and National Journal of Constitutional Law. I also consulted the Canadian Journal of Disability Studies and Canadian Journal of Women and Law for articles about relevant cases that are related disability and gender. This literature review helped me to identify three leading cases: *Withler v. Canada (Attorney General)*, 2011 SCC 12, [2011] 1 SCR 396, *Quebec (Attorney General) v A*, 2013 SCC 5, and *R. v. Kapp*, 2008 SCC 41, [2008] 2 SCR 483.

I also reviewed cases that engage care issues that may come up in the LTC home sector. I relied on my knowledge about the health care system. These are well-known cases. The cases are purposely chosen because they can inform me of matters that are relevant to the case study. For example, I reviewed the class actions related to Huronia, Rideau and Southwestern[457] because although they were settled, they still provide a glimpse of the harms of institutional care and give a sense of the arguments advanced by the government about state responsibility (or the lack thereof) towards those being "cared for" in institutions operated by the government.

Table 3: Summary of Judicial Decisions Reviewed

Type of decisions	**Forum**	**# of cases**
Appeals related to the LTCHA	HSARB	4
	Superior Court	1
Consent – LTC admission	CCB	10
	Superior Court	3
Consent – personal assistance services	CCB	4

---

[457] *Dolmage v. Ontario*, *supra* note 170; *McKillop and Bechard v. HMQ*, *supra* note 170.

Type of decisions	Forum	# of cases
Consent – treatment	CCB Superior Court	7 5
AODA	LAT	4
AODA – other	small claims court, Superior Court, law society discipline hearings, WSIAT etc.	8
Human Rights	Human Rights Tribunal of Ontario	3 (but each case has multiple decisions)
Equality	Supreme Court of Canada	3
Other care cases	Federal Court, Supreme Court of Canada and Superior Court	8 (each may have multiple decisions)

3.4 Key informant Interviews

Although this project is predominantly based on legal analysis, I contend that the themes in the interviews assist in filling the gaps in the research.

In the final stage of my research, I identified and interviewed key informants. The key informant interview is a research method commonly used by ethnographers and is a type of individual interview that involves forming a relationship over time.[458] Key informants are individuals who possess special knowledge, position in a culture or status, or communication skills. They have access to perspectives and or observations that would otherwise be denied to

---

[458] Valerie J Gilchrist & Robert L Williams, "Key Informant Interviews" in Benjamin F Crabtree & William L Miller, eds, *Doing Qualitative Research*, 2nd ed (Thousand Oaks, Calif: SAGE Publications, 1999) 71 at 71.

the researcher. Most importantly, they are willing to share their knowledge and skills with the researcher.[459] The selection of key informants is not based on a random sampling; rather, it represents a non-probability sampling, known as purposeful, strategic or information rich sampling.[460] Two sets of criteria can be used in finding key informants: 1) the type of information being sought, either based on a theoretical perspective or is data driven; 2) compatibility for on-going relationship.[461] This results in a small number of informants who are willing and able to work with the researcher.[462]

I used multiple methods to select potential interviewees. To identify which advocacy groups may have been able to assist with filling in the information gaps, my first step was be to identify groups that had presented at public hearings when the LTCHA was at the Standing Committee Stage in 2007. In addition, I reviewed official reports (identified in phase one) to locate advocacy groups that had participated in advisory groups, committees, taskforces or roundtables. As well, I checked the agendas of industry conferences, lists of researchers for projects commissioned by the Law Commission of Ontario[463] and faculty lists for professional development sessions. I reviewed the methodology sections of articles regarding LTC to identify groups that had been involved in previous relevant research projects.[464] The groups I identified had participated in multiple consultations, or maintained on-going relationships with the Ministry or have on-going involvement in LTC issues. The selection of potential respondents was also informed by reviewing the literature on Canadian disability movement and other social movements. Over the course of my research, I developed contacts with various organizations associated or familiar with various disability issues. Finally, as a former employee of the MOHLTC, I drew on my own understanding of stakeholders in the health care sector.

The Human Participants Review Sub-Committee reviewed and approved this project (STU 2015 – 154). The last approval was for the period November 2017 to November 2018.

---

[459] *Ibid* at 72.
[460] *Ibid* at 75–76.
[461] *Ibid* at 76.
[462] *Ibid* at 77.
[463] The Law Commission of Ontario had completed a number of projects that are relevant to my research: Legal Capacity, Decision-Making and Guardianship, The Law as it Affects Persons with Disabilities and the Law as it Affects Older Adults.
[464] For example see Rachel Barken & Pat Armstrong, “Skills of Workers in Long-Term Residential Care: Exploring Complexities, Challenges, and Opportunities” (2018) 43:1 Ageing Int 110.

A total of 15 interviews were conducted with 18 individuals. Five interviews were conducted on a "with attribution" basis and ten were conducted on a "without attribution" (anonymous) basis. The small number of interviews is justified by the diversity of perspectives represented: residents and families, homes and unions. Of the 18 interviewees, the four lawyers provided insights from a legal perspective that are not always present in recent social science and health policy research on LTC. One notable perspective missing here is the provincial government's perspective. I was not able to secure an interview with any representative from the Long-Term Care Home Division of the MOHLTC or Health Quality Ontario. The extensive document review partially compensated for the lack of provincial interviewees. Below is a list of the organizations and individuals interviewed:

Table 4: Interviewees

Interviewee	Description
1	Health Law lawyer (anonymous)
2	Lorraine Purdon, Executive Director, Family Councils Ontario
3	Samantha Peck, Director, Communications and Education, Family Councils Ontario
4	Dr. Fred Mather, President, Ontario Long-Term Care Clinicians
5	Lois Dent, Board Member, Concerned Friends of Ontario Citizens in Care Facilities
6	Jordanne Holland, Board Member, Concerned Friends of Ontario Citizens in Care Facilities
7	Keith Dee, Director of Membership, Community Living Ontario
8	Gord Kyle, Director of Policy, Community Living Ontario
9	Union representative (anonymous)
10	Industry association representative (anonymous)
11	Beverly Mathers, Chief Executive Officer, Ontario Nurses' Association
12	Judith Wahl, Elder Law Lawyer
13	Disability Rights Lawyer (anonymous)
14	Dee Lender, Executive Director, Ontario Association of Residents' Councils
15	Andy Savela, Director of Health Care, Unifor
16	Industry association representative (anonymous)
17	Michael Jacek, Senior Advisor, Association of Municipalities of Ontario
18	Lisa Corrente, Partner, Torkin Manes LLP

Interviewees were asked different types of questions because each possessed specific area of knowledge or experience in relation to the research topic (with some overlap if they were positioned to address similar concerns). The interview questions were developed after my analysis of government reports and legislation was complete. Prior to and during the interview stage of the research, I reviewed the more recent research in the feminist political economy literature in order to re-visit emerging issues in the literature. Prior to the interviews, I had also reviewed publicly available 'grey literature' such as technical reports, position papers, background briefings and written submissions to government produced by these groups to gather as much background information as possible. If there was not enough information about a particular interviewee or organization, a newspaper search was conducted using names of the interviewees or their organizations. I did not collect detailed demographic information about participants. The list of topics for each interviewee is in Appendix B.

Key informant interviews were conducted between September 2017 and February 2018 and then in August 2018. All interviews were conducted in Toronto. The interviews – either by phone or in person - ranged between 45 minutes to almost two hours in length, with the majority of the interviews being completed in approximately one hour. In advance of the interviews, I drafted and forwarded to participants a list of broad topics in advance, and if requested by an interviewee, I provided more detailed questions, however, ultimately I structured each interview as a conversation, rather than as a series of carefully worded questions. In some cases, interviewees introduced additional topics or issues that they believed to be relevant to my project. Fourteen interviews were taped with the permission of the interviewees and then transcribed. The transcripts were then uploaded into the qualitative analysis software package NVivo (http://www.qsrinternational.com/product) for the purpose of managing and coding the data.

The analysis of text in the transcript is based on thematic analysis. "Thematic analysis is a data reduction and analysis strategy by which qualitative data are segmented, categorized, summarized, and reconstructed in a way that captures the important concepts within the data set."[465] The first stage of the analysis involved closely reading a total of 14 interview transcripts by reading each transcript twice.[466] As Catherine Marshall and Gretchen Rossman state, "Reading, re-reading and reading once more forces the researcher to become intimately familiar

---

[465] Lioness Ayres, "Thematic Coding and Analysis" in Lisa Given, ed, *The SAGE Encyclopedia of Qualitative Research Methods* (Thousand Oaks California: SAGE Publications, Inc., 2008) 868.
[466] Gery Ryan & H Bernard, "Techniques to Identify Themes" (2003) 15:1 Field Methods 85 at 89. One interview was not recorded and transcribed at the request of the interviewee.

with those data."[467] The next phase is generating categories and themes.[468] Categories may be theory-driven or data-driven, derived from research literature, or based on intuition.[469] My analysis is informed by Gery Ryan and H Russell Bernard's observation that themes come both from the data (an inductive approach) and from the investigator's prior theoretical understanding of the phenomenon under study (an a priori approach).[470] Some themes would be anticipated in the text due to the topics or questions that I asked the interviewees. The first attempt at generating themes often comes from the interview questions.[471] But of course, one cannot anticipate all the themes that will arise before analyzing the data and therefore themes are partly empirical.[472] Ryan and Bernard suggest that themes and subthemes may be discovered using a number of techniques. Repetition is one of the easiest ways to identify themes.[473] An example of code is "caring conditions", which is a theme in the feminist political economy literature to describe conditions necessary for good care, such as working conditions (see Chapter 4). Using the "node" function of NVivo, I created nodes and then child nodes to represent the themes and sub-themes. An example of a child node under "caring conditions" is "violence and safety", which is a much debated issue in the literature and covers matters such as assaults experienced by workers and theoretical accounts of such assaults. The nodes and child nodes I generated are listed in Appendix C. Then I coded the transcripts according to the child nodes and read the text in each child node. A short summary of the content of each child node was prepared as the "analytic memo".

My final comment is about the trustworthiness and rigour of the data collection. For Paulette Rothbauer, triangulation means a multi-method approach to data collection and data analysis. The underpinning idea of triangulation is that the phenomena under study can be understood best when approached with a variety or a combination of research methods.[474]

---

[467] Catherine Marshall & Gretchen B Rossman, *Designing Qualitative Research* (Thousand Oaks, California: SAGE Publications, 2014) at 158.
[468] *Ibid* at 156.
[469] Sharon Lockyer, "Coding Qualitative Data" in Michael Lewis-Beck, Alan Bryman & Tim Futing Liao, eds, *The SAGE Encyclopedia of Social Science Research Methods* (Thousand Oaks, California: SAGE Publications, 2004) 138.
[470] Ryan & Bernard, *supra* note 466 at 88.
[471] *Ibid*; Ayres, *supra* note 465.
[472] Ryan & Bernard, *supra* note 466 at 88.
[473] *Ibid* at 89.
[474] Paulette M Rothbauer, "Triangulation" in Lisa Given, ed, *The SAGE Encyclopedia of Qualitative Research Methods* (Thousand Oaks California: SAGE Publications, 2008) 893.

Where possible, I used two or more methods to confirm my understanding of a particular issue. For example, to understand workplace violence issues in LTC, I relied on document review and interviews with union representatives. For this project, triangulation is also made possible when the same question was asked of more than one interviewee who could speak knowledgeably about a particular topic. But this was not always feasible. For example, there was only one provincial association representing the Residents' Councils. I could not find another provincial organization that could speak from the perspective of Residents' Councils to triangulate multiple perspectives.

3.5 Conclusion

This dissertation adopted multiple methods of data collection and analysis to investigate the implications of the changes to the regulation and governance of the LTC sector in Ontario between 2004 and 2018. This is a dissertation primarily rooted in law, therefore includes details of the relevant legislation, case law and materials for interpreting law that inform this research question. But it also expands beyond doctrinal analysis and includes the methods of document review and key informant interviews. In the next chapter, I will shift from a theoretical perspective to an empirical account of regulation and governance of LTC in Ontario.

4 Background and Themes in LTC Research

4.1 Introduction

This chapter will set the scene for an empirical account of the regulatory changes in the sector in subsequent chapters. As I set out in Chapter 2, the concept of care is fraught with tension and some disability studies scholars have tried to create new paths forward in order to be inclusive of the perspectives of those in caring relationships. Since the state has a critical role to play in shaping caring relationships, I sketch out some of the tensions and contradictions inherent to public benefit schemes and regulatory regimes when considered through a disability studies lens. Here, the negotiation of tensions and contradictions in the long-term care home sector is conceptualized as an on-going problem-solving process. In Chapter 3, I explained the methodology I used in order to paint a more comprehensive picture of changes to regulation and governance relevant to the LTC sector in Ontario from 2004 to 2018. This chapter will show, in practical terms, how care is provided in a contemporary institutional setting constructed by law. I will explore how the evolution of the regulatory framework is the result of a combination of factors inside and outside of LTC.

The chapter will begin by situating LTC policy within health and social policies. It will then provide background information on the sector in Ontario: what are these homes (e.g. ownership structures, funding arrangements, industry associations and advocacy groups in the sector), what types of care / services are provided in the homes and who lives in the homes. Although my focus is the period between 2004 and 2018, a brief regulatory history (from post-war to early 2000s) will be included. I will also explain the context in which the new legal framework was developed and implemented. In the final section, I will outline the key themes of debates in the feminist political economy literature and explain how this research fills some of the gaps in our knowledge base.

4.2 Situating LTC policy in health and social policies

The emphasis of this section is on situating this inquiry of the LTC home sector in Ontario within the broader context of the functions of the welfare state, and law’s gate-keeping functions in social policy. In Chapter 2, law is defined as a system of rules to govern behaviour enforced through institutions created for that purpose.[475] This discussion provides a foundation for understanding the legal specifics of the LTC home sector. I intend to show that to make sense of LTC today, it is necessary to think of the LTC as being part of a basket of entitlements offered by the welfare state. The governance and regulation of LTC inevitably is part of a long-term trend of greater complexity of law governing a variety of programs and schemes offered by the welfare state.

4.2.1 **LTC as a late comer to the welfare state**

Care of children, the elderly, and people with disabilities is frequently associated with one of the typical functions of the welfare state, which is to: "support a reasonable level of social reproduction".[476] LTC is a latecomer to the welfare state.[477] In general, LTC includes a range of personal care services, as well as basic medical services, nursing care, prevention, rehabilitation, or palliative care. It may also include housekeeping and assistance with administrative tasks.[478] In many OECD countries (other than some Nordic countries) into the 1980s and beyond, LTC was characterized by fragmentation and residualism. Limited support was found in diverse policy areas, including health, pension, disability, or housing. Over the past 20 years, welfare states have begun to implement, or at least to consider, more comprehensive policy approaches in response to factors such as growing care needs, changes in the socio-economic context and in understanding of individual, family, and public responsibility.[479]

There are significant variations in whether and how people's needs are met across OECD countries.[480] The sharing of responsibilities regarding care for dependent older adults between the state, the market and the family depends on a combination of factors such as tradition, legal responsibilities, health and social policy, and the economic context.[481] In care regimes characterized by mixed public / private responsibilities, the state provides limited access to

---

[475] Windholz, *supra* note 50 at 8–10.
[476] Marjorie Griffin Cohen, "The Strange Career of Regulation in the Welfare State" (2015) 12:1 Econ Journal Watch 28 at 30.
[477] August Österle & Heinz Rothgang, "Long-Term Care" in Francis G Castles et al, eds, *The Oxford Handbook of the Welfare State* (Oxford: Oxford University Press, 2010) 378 at 378.
[478] OECD / EU, *A Good Life in Old Age? - Monitoring and Improving Quality in Long-term Care* (Paris: OECD Publishing, 2013) at 10.
[479] Österle & Rothgang, *supra* note 477 at 379–380.
[480] Tim Muir, *Measuring Social Protection for Long-Term Care* (Paris: OECD Publishing, 2017) at 9.
[481] Ulrike Schneider et al, "Polices to Support Informal Care" in Cristiano Gori, Jose-Luis Fernández & Raphael Wittenberg, eds, *Long-Term Care Reforms in OECD Countries* (Bristol: Policy Press, 2016) 219 at 221.

formal care, with no intention of completely substituting formal for informal care provisions.[482] Demands for publicly funded care also depend on the eligibility criteria for public support including any means test.[483] Relatively less generous public funding for care in turn is likely to encourage greater reliance on private purchase of care and support for those able to afford it, or greater use of unpaid informal care for those with family carers.[484]

Ontario is best described as a mixed public / private LTC regime. In Ontario, institutional care for older adults (and in some cases younger disabled adults) is called LTC homes in law, so for the purposes of consistency, I will use the term LTC to describe Ontario's institutional care throughout the dissertation. Services provided in the community such as private dwellings are generally called home care. LTC and home care are regulated under separate statutes.[485]

Since Ontario's LTC regime is partially supported by public funding, issues about affordability, access and eligibility need to be addressed in the program design. Obviously funding level plays an important role in determining who can access LTC, how and when. In social policies, the program design reflects a host of financial as well as legal considerations. Law also plays a critical part in creating and maintaining social policies (such as LTC). Law is used to allow or deny individuals access to benefits and entitlements and to describe the conditions necessary for such access. In other words, law plays several gate-keeping functions in social policies.

4.2.2 Law's gate-keeping functions in social policies

To Deborah Mabbett, regulatory techniques shape how social policy problems are defined, in particular, by emphasizing efficiency goals, and also through the international dissemination of norms, including rights.[486] Here I will simply highlight three perspectives related to law's gate-keeping functions in social policies, recognizing that other public law topics are also relevant but are excluded from the discussion here due to space considerations.[487] First

---

[482] *Ibid* at 222.
[483] Raphael Wittenberg, "Demand for Care and Support for Older People" in Cristiano Gori, José Fernández & Raphael Wittenberg, eds, *Long-Term Care Reforms in OECD Countries* (Bristol : Policy Press, 2016) 9 at 22.
[484] *Ibid* at 19.
[485] *Home Care and Community Services Act, 1994,* SO 1994, c. 26.
[486] Deborah Mabbett, "The Regulatory Rescue of the Welfare State" in David Levi-Faur, ed, *Handbook on the Politics of Regulation* (Cheltenham, UK: Edward Elgar, 2011) 215 at 216.
[487] For example, polycentricity and justiciability (see Jeff A. King, "The Pervasiveness of Polycentricity" (Spring

of all, law can invoke a standard or paradigm for categorizing people as "disabled" for a particular purpose, such as to determine eligibility for services.[488] As I will show later in the dissertation, an important function of the regulatory framework is to determine who is "disabled enough" to be eligible for admission. Secondly, law may determine eligibility or ineligibility for certain functions and roles,[489] for example the *Health Care Consent Act, 1996*[490] (HCCA) governs consent to treatment for capable and incapable persons in all settings. Finally, law can also remove barriers to accessing services provided by public benefit schemes, or at least mitigate the effects of those barriers. For example, in *Eldridge v. British Columbia (Attorney General)*,[491] the question was whether the BC government's lack of funding for sign language interpreters in a hospital setting violated s. 15(1) of the *Charter*.[492] A brief account of s.15 jurisprudence on disability will be provided. I will also examine the *Ontario Human Rights Code*[493] requirements pertaining to disability and gender. The significance of the *Convention of the Rights of Persons with Disabilities*[494] will be briefly noted because Canada has signed and ratified the Convention, however, the details of the Convention are beyond the scope of this dissertation.

4.2.3 **Legal complexity and the modern welfare state**

Using the concept of complexity provides an alternative lens with which to view the regulatory regime in the LTC sector. The work that I rely on deals with the issue of complexity more generally and in relation to the welfare state. The topic of legal complexity (which will be defined shortly) has generated interest from practicing lawyers as well as legal scholars.

2008) PL 101); discretion (See Laura Pottie, and Lorne Sossin, "Demystifying the Boundaries of Public Law: Policy, Discretion, and Social Welfare" (2005) UBC L Rev 147 (LegalTrac); remedies (see Ranjan K. Agarwal, "The Road to the Promised Land Runs Past Conway: Administrative Tribunals and Charter Remedies" (2011) Alta L Rev 783 LegalTrac)).

[488] Anita Silvers, "An Essay on Modeling: The Social Model of Disability" in D.C. Ralston & J. Ho eds., Philosophical Reflections on Disability, Philosophy and Medicine (Dordrecht, New York: Springer Verlag, 2009) at 22. I borrow from the discussion on models of disability, where Silvers explains that sometimes appeals to models of disability are meant to invoke a standard or paradigm for categorizing people as disabled for a particular purpose, such as to determine eligibility for social insurance scheme benefits or statutory protection against disability discrimination, or to determine ineligibility for social roles such as employment or responsibilities such as parenting.

[489] *Ibid* at 23.

[490] *Health Care Consent Act, 1996,* SO 1996, c. 2, Sched. A.

[491] *Eldridge v British Columbia (Attorney General)*, [1997] 3 SCR 624, 151 DLR (4th) 577.

[492] *Charter*, *supra* note 121, s15(1).

[493] *Human Rights Code,* RSO 1990, c H.19.

[494] *Convention on the Rights of Persons with Disabilities,* December 13, 2006, 46 ILM 433, UN Doc A/RES/61/106.

Scholars are interested in the causes or origins of complexity, its consequences and how to reduce it. At one end of the spectrum, scholars integrate the notion of complexity into a very specific existing legal debate, for example, rules vs. standards.[495] At the other end, scholars address complexity at a more abstract level, for example, analysis of the legal system using "complexity theory".[496]

In this dissertation, I use Peter Schuck's definition of legal complexity. He correctly points out that legal complexity can only be located on a continuum that ranges from extreme simplicity at one end to extreme complexity at the other. Thus, a legal rule, process, or institution is only more or less simple or complex compared to some other actual or ideal one. It is neither possible nor desirable to attempt to classify something precisely as simple or complex.[497] The definition is a composite of four variables: "a legal system is complex to the extent that its rules, processes, institutions, and supporting culture possess four features: density, technicality, differentiation, and indeterminacy or uncertainty."[498]

Although Schuck's main argument centres on the claim that legal complexity is increasing and this is problematic for a system of justice, his work also provides an important caveat about simplicity and simplification. Simpler law is not always better law; complexity can be both a weakness and a strength.[499] Indeed, legal complexity sometimes creates fairer, more refined, more efficient, even more certain forms of social control.[500] The critical question that one must ask is: All things considered, are the benefits of a given level of complexity worth the costs?[501] A kind of structural imbalance is created when the lawmaking process presses the law towards greater complexity with little regard as to whether any particular complexity is worth its costs.[502] Generally speaking, complexity-induced costs can be both inefficient and unfair,[503] and

---

[495] Louis Kaplow, "Rules and Standards: An Economic Analysis" (1990) 42:3 Duke LJ 557.
[496] Neville S Harris, *Law in a Complex State: Complexity in the Law and Structure of Welfare* (Oxford: Hart Publishing, 2013) at 30.
[497] Peter Schuck, "Legal Complexity: Some Causes, Consequences, and Cures" (1992) 42:1 Duke LJ 1 at 5.
[498] *Ibid* at 3.
[499] *Ibid* at 8.
[500] *Ibid*.
[501] *Ibid*.
[502] *Ibid*.
[503] *Ibid* at 19.

more importantly, can stultify a society that often depends on vigorous action in problem-solving because complexity promotes passivity and entrenches the status quo.[504]

The proliferation of rules in the LTC sector can also be explained by the more general trend of greater complexity of law governing the welfare state. Neville Harris explores complexity as a dominant characteristic of the modern welfare system in the United Kingdom and elsewhere, including Australia, New Zealand, Germany and Sweden.[505] According to Harris, "The law is perhaps the greatest source of complexity in the welfare system."[506] He concludes that law and structure of the modern welfare state must continue to reflect the welfare system's role in identifying and responding to diverse social circumstances and individual needs while also advancing various social and economic policy agendas. As a result, the complexities are inevitable and they can only be reduced, not eliminated.[507] But simplification is a worthy goal, particularly if it helps ensure that individuals have access to their proper entitlement, and if it supports the accepted value of the benefit system and its rules.[508]

The strength of Harris' book is that it expands the range of theoretical and practical considerations that one may take into account when assessing complexity. He considers the question of whether complexity is also defensible. One of the main supporting arguments for complexity rests on the desirability of ensuring that entitlement closely matches the diverse requirements of each individual or family unit that the welfare system seeks to support.[509] By contrast, rules that apply relatively simple criteria to entitlement may offer a somewhat crude response to social needs. For example, simpler rules (age thresholds for certain entitlements) may be predicated on broad and simplistic assumptions about how people do or should live their lives; unfairness may result from such rules.[510]

Another way of defending complexity is to attend to the need for continual adjustments in the face of social and economic trends, policy shifts, and the impact of judicial decisions.[511]

---

[504] *Ibid*.
[505] Harris, *supra* note 496 at 3.
[506] *Ibid* at 245.
[507] *Ibid* at 236.
[508] *Ibid* at 245.
[509] *Ibid* at 236.
[510] *Ibid* at 238–239.
[511] *Ibid* at 244.

Within the British welfare system, there are a range of programs designed to respond to the transitions in people's lives. It is assumed that citizens want the welfare system to help insulate individuals from the financial effects of various circumstances, such as reaching the end of working life due to old age or infirmity. At the same time, citizens expect benefits to be targeted only to those considered to have real needs, and they want consistent treatment. Equally important, citizens want decisions to be accurate, with an effective process for correcting erroneous decisions. A system designed to meet all these objectives is not going to be simple.[512] Law is used to establish control and certainty, but it is also expected to be adaptive as new or unpredicted situations arise. As a result, frequent limited amendments are made to the law to reflect minor policy shifts and to respond to loopholes or unpredicted outcomes that arise during application.[513]

4.2.4 **Summary**

It can fairly be said that despite its late arrival, LTC now occupies an important place in the study of social policies. I argue here that generally speaking, law governing the modern welfare state is increasingly complex and the regulation and governance of LTC is likely to be a part of this trend. Indeed, increasing legal complexity can be problematic for a system of justice. However, simpler law is not always better law. Situating the issue of regulation of care within the context of legal developments within the welfare state allows us to have a more precise language to describe the LTC sector as “heavily or highly regulated”.

4.3 A Primer on Ontario’s LTC sector

The purpose of this section is to provide the background and context of regulatory changes in the LTC sector in Ontario. Feminist political economy scholars have commented that

---

[512] *Ibid*.
[513] *Ibid* at 32.

LTC is a heavily regulated sector in Canada[514] and elsewhere.[515]The account that follows is not intended to match the depth and breadth of existing work on the history of the sector.[516] It will start by presenting a brief history of the key legal and regulatory milestones between the 1940s and 2003. Then I will turn to the contemporary LTC sector in Ontario: detailing who lives in LTC homes, how the homes are governed, regulated and funded, and the broader changes in the health sector that affect the LTC sector.

4.3.1 Brief regulatory history of the LTC sector in Ontario (key legal / regulatory milestones from post-war to 2003)

All LTC homes in Ontario now operate under the same statute but this has not always been the case. Prior to July 1, 2010, there were three types of LTC facilities in Ontario operating under separate statutory authority: nursing homes, municipal homes for the aged and charitable homes for the aged. Nursing homes (profit and non-profit) were licensed by the province and operated under the *Nursing Homes Act*. Municipal homes (non-profit) were operated by municipalities under the *Homes for the Aged and Rest Homes Act*. Charitable homes are operated by non-profit organizations under the *Charitable Institutions Act*. I will outline the regulatory history by focusing on the following milestones from the 1940s to 2003: the post-war period (beginning of regulation), 1993 (Bill 101) and early 2000s (bankruptcy of the Royal Crest).

4.3.1.1 Post-war period: Beginning of regulation

The *Homes for the Aged Act, 1949* had its roots in the previous *Homes for the Aged Act, 1947* and the *Houses of Refuge Act;* the latter could be found as early as in the 1914 Revised

---

[514] Banerjee, *supra* note 301; Albert Banerjee & Pat Armstrong, "Centring Care: Explaining Regulatory Tensions in Residential Care for Older Persons" (2015) 95 Studies in Political Economy 7; Donna Baines & Tamara Daly, "Resisting Regulatory Rigidities: Lessons from Front-Line Care Work" (2015) 95 Studies in Political Economy; Tamara Daly, "Dancing the Two-Step in Ontario's Long-Term Care Sector: Deterrence Regulation = Consolidation" (2015) 95 Studies in Political Economy 29; Armstrong & Daly, *supra* note 163; Donna Baines & Pat Armstrong, "Promising Practices in Long Term Care: Can Work Organisation Treat Both Residents and Providers with Dignity and Respect?" (2018) 1:001 Social Work and Policy Studies: Social Justice, Practice and Theory 1.

[515] John Braithwaite & Valerie Braithwaite, "The Politics of Legalism : Rules Versus Standards in Nursing-Home Regulation" (1995) 4:3 Social & Legal Studies 307; Jacqueline A Choiniere et al, "Mapping Nursing Home Inspections & Audits in Six Countries" (2016) 41:1 Ageing Int 40; Charlene Harrington et al, "Comparison of Nursing Home Financial Transparency and Accountability in Four Locations" (2016) 41:1 Ageing Int 17.

[516] Daly, *supra* note 514; James Struthers, "Reluctant Partners: State Regulation of Private Nursing Homes in Ontario, 1941-72" in Raymond Blake et al, eds, *The Welfare State in Canada: Past, Present, and Future* (Concord, Ont: Irwin Pub., 1997) 171; James Struthers, "Home, Hotel, Hospital, Hospice Conflicting Images of Long-Term Residential Care in Ontario, Canada" in Sally Chivers & Ulla Kriebernegg, eds, *Care Home Stories: Aging, Disability, and Long-Term Residential Care* (Transcript-Verlag, 2018) 283.

Statutes of Ontario. It is evident that the scope of the 1949 Act was intended to include not just older adults but also the younger disabled. Unlike the 1947 Act, the 1949 Act specifically referred to the older adults when it described who was eligible:

> (a) anyone over the age of sixty years who is incapable of supporting himself, or unable to care properly for himself;
>
> (b) anyone who is mentally incompetent and ineligible for committal to an institution under The Mental Hospitals Act, who requires care, supervision and control for his protection;
>
> (c) anyone over the age of sixty years who is confined to bed but does not require care in a public hospital or hospital for incurables; or
>
> (d) anyone under the age of sixty years who because of special circumstances cannot be cared for adequately elsewhere when his admission has been approved by the Minister.[517]

The 1949 Act addressed matters such as the scope of powers of the board of management for the rest home,[518] water, sewage and electricity,[519] handicrafts and work of residents,[520] authority for committal to home,[521] requirements for admission,[522] and provincial subsidies.[523] Little attention had been paid to address delivery of care other than appointment of staff[524] and regulation-making authority with respect to rules governing the homes, the residents and the staff,[525] as well as medical care to be provided.[526] The *Homes for the Aged Amendment Act, 1966*[527] changed the title of the Act to *The Homes for the Aged and Rest Homes Act* and made other amendments.

---

[517] *The Homes for the Aged Act, 1949,* SO 1949, c 41, s 11.
[518] *Ibid*, s 3.
[519] *Ibid*, ss 7(1), (2) and (3).
[520] *Ibid*, ss 9(1) and (2).
[521] *Ibid*, s 9(3).
[522] *Ibid*, 9(4).
[523] *Ibid*, ss 13–16.
[524] *Ibid*, s 6.
[525] *Ibid*, s 17(c).
[526] *Ibid*, s 17(e).
[527] *Act to Amend the Homes for the Aged Act,* SO 1966, c 259.

Although the *Charitable Institutions Act* can be traced back to the 1930s,[528] the *Charitable Institutions Act, 1956*[529] most resembled the final version (repealed in 2010). Section 1(a) stated that "charitable institution means a building maintained and operated by a charitable organization for persons requiring sheltered care".[530] The 1956 Act specified matters such as approval of by-laws,[531] approval of plans for new sites,[532] provincial subsidies[533] and annual inspections.[534] Similar to the *Homes for the Aged Act, 1949*, the *Charitable Institutions Act, 1956* said little about how care was to be delivered although Cabinet could make regulations about charges, medical services to be provided, qualifications and the powers and duties of staff and rules governing all or specified charitable institutions and the conduct and discipline of persons who are cared for and the staffs.[535]

In 1966, *An Act to Provide for the Licensing and Regulation of Nursing Homes* (The *Nursing Homes Act*) came into effective. Section 1 of the Act stated that " 'nursing home' means any premises maintained and operated for persons requiring nursing care".[536] In other words, there was no specific reference to older adults or the disabled. The 1966 Act, as the long title implied, provided for the licensing of nursing homes: specifically for the issuance, transfer and revocation of licences.[537] The Act specified that the Minister of Health was responsible for the administration and enforcement of the Act and that the Minister's powers and duties may be delegated.[538] Not surprisingly, the 1966 Act said little about delivery of care, other than inspections,[539] conditions for revocation of licence[540] and regulation-making authority about matters such as "respecting the admission, treatment, care, conduct, discipline and discharge of

---

[528] *An Act respecting Charitable Institutions,* SO 1931, c 79.
[529] *The Charitable Institutions Act, 1956,* SO 1956, c 6.
[530] *Ibid*, s 1(a).
[531] *Ibid*, s 6.
[532] *Ibid*, s 7.
[533] *Ibid*, ss 7–10.
[534] *Ibid*, s 11.
[535] *Ibid*, s 13.
[536] *An Act to Provide for the Licensing and Regulation of Nursing Homes, 1966,* SO 495, c 99, s 1(f).
[537] *Ibid*, ss 3–10.
[538] *Ibid*, s 2.
[539] *Ibid*, s 11.
[540] *Ibid*, ss 10(a) and (b).

residents of nursing homes".[541] It should be noted that there was no reference to provincial subsidies.

In sum, the provincial government began to regulate different parts of the LTC sector (as we know it today) at different points in time. The three statutes are closer to the simplicity end of the legal complexity continuum. The first versions of the *Homes for the Aged Act* and *Charitable Institutions Act* looked similar in the sense that they both provided the bare minimum legal authority and administrative requirements to establish those facilities. The *Nursing Homes Act* was denser and more technical because it provided a licensing scheme. Their respective legislative intents were fairly simple and straight-forward. What is common among these three statutes is that they did not really prescribe how care should be delivered in those facilities (although there was the necessary regulation-making authority) and that they envisioned a very limited role for the provincial government. Not surprisingly, the subjects addressed in the original acts would continue to be covered in subsequent versions. However, as I will demonstrate in the next section and then subsequent chapters, how care was to be delivered and paid for would be prescribed in a much more detailed manner in subsequent versions of the three statutes, and later, in the *Long-Term Care Homes Act, 2007*. Additional social and economic objectives were supposed to be accomplished by these statutes. In other words, as time progresses, they all moved closer to the complexity end of the continuum.

4.3.1.2 Long-Term Care Statute Law Amendment Act in 1993 (Bill 101)

Much of the content of these three Acts was updated and standardized with the passage of the *Long-Term Care Statute Law Amendment Act* in 1993 (Bill 101).[542] The then Minister of Health, Hon. Frances Lankin, explained the need for government action at that time and stressed that Bill 101 was the beginning of a major transformation in LTC:

> Bill 101 is an amending statute and it is the beginning of a reform process that will result in major restructuring of long-term care and support services for elderly persons, adults with physical disabilities and people who need health services at home. The amendments

---

[541] *Ibid*, s 12(1)(k).

[542] Bill 101, *Long-Term Care Statute Law Amendment Act, 1993,* (assented to 1 June 1993) SO 1993, c.2; Ministry of Health and Long-Term Care, *Estimates Briefing Book 2004-05* (Toronto: Ministry of Health and Long-Term Care, 2004) at 122. Ontario, Legislative Assembly, *Official Report of Debates (Hansard)*, 35th Parl, 2nd Sess (26 November 1992). http://www.ontla.on.ca/web/house-proceedings/house_detail.do?Date=1992-11-26&Parl=35&Sess=2&locale=en Bill 101 was introduced on November 26, 1992 and received Royal Assent on June 1, 1993.

> will . . . correct several long-standing deficiencies in services for elderly persons requiring residential care and the range of independent living options for adults with physical disabilities . . . this is only part of the overall policy response to the redirection of long-term care that the government will be bringing forward.[543]

Further, the then Minister highlighted the importance of consistent treatment of all homes and their residents. The Bill would:

> change substantially the accountability relationship that the home has with the residents and their families or representatives, and with government. The amendments will introduce for the first time in Ontario a consistent framework for accountability in all three types of homes and enable us to achieve our objective of enhanced accountability to facility residents and the taxpayers of Ontario.[544]

The 1993 bill introduced a consistent funding mechanism (funding based on the nursing and personal care needs of residents) and a new accountability structure. Under the accountability structure at the time, all LTC facilities were required to sign an annual service agreement and to comply with legislation, regulations and Ministry policies and standards. Other changes included: a new resident payment policy, a province-wide system for managing access to LTC and a consistent Resident Bill of Rights for all three types of facilities.[545] The Program Manual was also released in 1993 to present the expectations of the government for facility services.[546]

The significance of Bill 101 was how the funding parity issue was dealt with. Municipal and nonprofit homes that provided custodial and nursing home care were entitled to access more public funds.[547] This was due to the fact that in contrast to the nursing homes, which operated under the Ministry of Health, for other institutions the funding model followed a “deficit funding” budget-based system—70 percent of the funding came from the provincial Ministry of Community and Social Services, and 30 percent came from the municipalities. Any deficits were covered by governments according to their allotted 70/30 budget share.[548]

---

[543] Ontario, Legislative Assembly, *Official Report of Debates (Hansard),* 35th Parl, 2nd Sess *(*1 February 1993).
[544] *Ibid*.
[545] Ministry of Health and Long-Term Care, *Long-Term Care Homes Program Manual* (Toronto: Ministry of Health and Long-Term Care, 2007) at Tab 0401-01 and 0701-01; Ministry of Health and Long-Term Care, *supra* note 542 at 122.
[546] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 0402-01, page 3.
[547] Daly, *supra* note 514 at 42.
[548] *Ibid*.

4.3.1.3 Early 2000s: Bankruptcy of the Royal Crest Lifecare Group

In the 1990s, the LTC sector continued to struggle with proper oversight and accountability and with scandals that compromised the public's confidence in the government's ability to govern and regulate the sector. The bankruptcy of the Royal Crest Lifecare Group Inc. (Royal Crest) represented another point of crisis in the regulatory history of LTC in Ontario. The company operated five nursing homes, six retirement homes and six mixed care (nursing and retirement) homes in southern Ontario, employing some 2500 employees and providing accommodation for some 2250 residents.[549] Royal Crest had a long history of financial difficulties, such as failure to remit to the proper authorities more than $11 million in contributions for pension plan, vacation pay and benefits plans, licensing problems with the Ministry of Health apparently arising from corner-cutting; and inability to arrange a refinancing with its bankers.[550] By late 2002, Royal Crest was in serious financial difficulty: it owed its creditors, mostly banks, in excess of $128 million and was in default under its loan agreements.[551] After its short-lived protection under the *Companies Creditors Arrangement Act*[552] was terminated, Royal Crest was petitioned into bankruptcy in January 2003.[553]

The bankruptcy of Royal Crest prompted questions about the proper role of the government in overseeing the operation of LTC homes, in particular, the financial aspects of facility management. The courts assigned responsibility for the failure of the Royal Crest to its owners: "I agree with the Trustee that each brother had a significant hand, as owner, and also as manager, in the failure of Royal Crest. It was not all the fault of the greedy bank; it took years for the financial problems to develop to the point that the company could not be saved."[554] However, there were demands from unions and others to have an inquiry about how the Ontario

---

[549] *Re Martino (*2004), 2004 CanLII 17978 (ON SC) at para 1 [Martino]. *Canadian Union of Public Employees v Royal Crest Lifecare Group Inc,* 2004 CanLII 19809 (ON CA) at para 7. Aldo Anthony Martino and Giovanni (John) Martino operated Royal Crest and other companies in the nursing, residential and retirement home industry.

[550] *Martino*, *supra* note 549, at para 2.

[551] *Canadian Union of Public Employees v. Royal Crest Lifecare Group Inc.*, *supra* note 549, at para 8.

[552] *Companies' Creditors Arrangement Act,* RSC 1985, c C-36.

[553] *Canadian Union of Public Employees v. Royal Crest Lifecare Group Inc. 2004*, *supra* note 549, at paras 9-10. Ernst & Young was appointed as trustee and receiver.

[554] *Martino*, *supra* note 549, at para 12.

government dealt with the Royal Crest matter.[555] In the years that followed, the government creditors including the MOHLTC and others tried to collect money owed.[556] Coincidentally, the Auditor General's 2002 and 2004 reports concluded that the Ministry did not have all of the necessary procedures in place to ensure that LTC resources were managed with due regard for economy and efficiency.[557] Accordingly, it makes sense that in drafting the LTCHA, the government would put more emphasis on financial accountability, corporate governance and regular monitoring of homes.

This has been a relatively brief exploration of the regulatory history of the intersections between command and control regulation on the one hand and market forces on the other. It is sufficient, however, to make some broad observations. First, there is an uneasy relationship between the expansion of government oversight and the autonomous day-to-day operations of homes which are not owned or directly operated by the government. Second, there is a tension between having a consistent regulatory framework so that all residents are subject to the same protections on the one hand while at the same time having the flexibility to be responsive to the specific challenges of different types of homes on the other. Third, the regulatory framework is intended to serve multiple social and economic objectives, with the emphasis on financial accountability becoming more prominent overtime. Before I turn to an account of the contemporary LTC sector, it is important to understand who lives in LTC homes in Ontario.

4.3.2 A Profile of LTC residents in Ontario

A cursory review of newspaper articles will create the impression that LTC residents comprise a very homogeneous group. Despite the sensational images of older, frail and passive residents in the media, the picture of LTC residents is actually a lot more complex. In Chapter 2, I make the case for applying an interactional model of disability, as articulated by Tom Shakespeare, in the study of LTC sector. It follows that the intrinsic factors of residents matter in the discussion about their experiences with care and caring relationships. Another way of

---

[555] David Mckie, "Advocates demand inquiry into Ontario's costly handling of Royal Crest nursing-home failure", *CBC News* (23 March 2009), online: <http://www.cbc.ca/news/canada/advocates-demand-inquiry-into-ontario-s-costly-handling-of-royal-crest-nursing-home-failure-1.791359>.

[556] *Ibid*. see also *Royal Crest Lifecare Group Inc v Ontario (Health and Long Term Care)*, 2009 ONCA 397, 53 CBR (5th) 44.

[557] Auditor General of Ontario, *2004 Annual Report of the Office of the Auditor General of Ontario* (Toronto: Auditor General of Ontario, 2004) at 381.

understanding LTC residents is to consider how they (along with their families – if any) arrive at LTC.

4.3.2.1 Impairments in old(er) age

Most residents are older females; female residents also tend to be older than male residents (the averages are 85 and 80, respectively).[558] However, the proportion of female residents is also slowly decreasing. Even in terms of chronological age of residents, there is great variation: although 43.9% of residents are between the ages of 85 and 94, 6.6% of residents are 64 or younger and 10.8% are 95 or older[559] i.e., there is at least a 30-year age difference between the youngest and oldest groups of residents. The table below presents a simplified profile of LTC residents in terms of age and gender in from 2012-13 to 2017–18:[560]

Table 5: Profile of LTC residents in Ontario

	2012-13	**2013-14**	**2014-15**	**2015-16**	**2016-17**	**2017-18**
Number of residents	112,621	113,424	115,715	114,082	115,120	115,224
Average age	83	83	83	83	83	83
Younger than 65 (%)	6.6	6.6	6.8	6.9	6.7	6.6
85 and older (%)	53.0	53.3	53.9	54.2	54.6	54.7
Female (%)	68.0	67.7	67.5	67.4	67.1	66.9

Although disability cannot be reduced to or equated with impairment or health condition, we cannot understand care in LTC without referring to the health conditions and impairments as experienced by residents. To put it differently, I adopt Shakespeare's position that failure to meet health needs constitutes an important aspect of the discrimination faced by people with disabilities.[561] From a medical or clinical perspective, residents are entering homes older and

---

[558] Canadian Institute for Health Information, *CCRS Quick Stats, 2017–2018* (Canadian Institute for Health Information, 2018). As of September 27, 2019, the 2017-18 data is not available.

[559] *Ibid*.

[560] Canadian Institute for Health Information. I extracted the information from each year's quick stats.

[561] Shakespeare, *supra* note 106 at 88–105.

with increasingly complex needs.[562] The needs of residents—if narrowly defined by their clinical profiles—also help explain the care they need to receive. In general, residents tend to face several challenges, including diagnoses of dementia (63.9%), severe cognitive impairments (32.5%), depression (32.5%), some aggressive behaviour (45%) and bladder incontinence (48.3%), and they require assistance with activities of daily living (ADL) (11.8% = total dependence).[563] These biomedical characteristics by no means should explain disability, gender, and aging in totality, but they are more than just neutral human variations (or differences). As we will see in subsequent chapters, these not-so-neutral bio-medical characteristics shape the content of care regulation, which in turn may advance or undermine the quality of life of residents.

4.3.2.2 Impairments in young(er) age

It should be noted that increasingly, LTC is also being used to address the needs of younger people with various types of disabilities.[564] In Chapter 2, the significance of de-institutionalization was briefly outlined. One way, albeit arbitrary, to estimate the extent of the problem is to use chronological age and diseases diagnosis. In 2016-17, about 6.7% of residents (7,735) were under the age of 65 and within this age group there were slightly more females than males (3,985 females compared to 3,710 males). The illnesses reported and their corresponding numbers in the whole LTC population may also give us some indication of the circumstances that bring younger people into LTC: Cerebral palsy (677), Multiple sclerosis (1407), Paraplegia (491), and Quadriplegia (390).[565] These health conditions are not generally associated with the process of aging. It is possible that older residents also live with these conditions and that as they age, new illnesses and disabilities develop. Media reports also illustrate the circumstances of these younger residents.[566]

---

[562] Ministry of Health and Long-Term Care, *Living Longer, Living Well: Report Submitted to the Minister of Health and Long-Term Care and the Minister Responsible for Seniors on Recommendations to Inform a Seniors Strategy for Ontario by Dr. Samir K. Sinha* (Toronto: Ministry of Health and Long Term Care, 2012) at 178; Long Term Care Task Force on Resident Care and Safety, *An Action Plan to Address Abuse and Neglect in Long-Term Care Homes* (Toronto: Ministry of Health and Long Term Care, 2012).

[563] Canadian Institute for Health Information, *supra* note 558.

[564] However, this is not a new issue. See Lisa Priest, "Nursing Homes No Answer for the Young", *The Globe and Mail* (18 December 2004), online: <https://beta.theglobeandmail.com/news/national/nursing-homes-no-answer-for-the-young/article1008752/?ref=http://www.theglobeandmail.com&>.

[565] Canadian Institute for Health Information, *supra* note 558.

[566] Peter Goffin, "Thousands of Under-65 Adults with Physical Disabilities Are Being Forced into Ontario Nursing Homes: Ministry Data", *Toronto Star* (9 July 2017), online: <https://www.thestar.com/news/gta/2017/07/09/thousands-of-under-65-adults-with-physical-disabilities-are-being-

The reasons for their admission may be simple enough: they have nowhere else to go. In 2016, the Ombudsman of Ontario put a spotlight on people with developmental disabilities in crisis. In *Nowhere to Turn*, the Ombudsman reports on his office's investigation of more than 1,400 complaints from families of adults with developmental disabilities who are in crisis situations.[567] The report notes that "the lack of appropriate residential resources in the community has, by default, resulted in many adults with developmental disabilities being inappropriately housed in hospitals, long-term care homes and even in jails, for prolonged periods."[568] The lack of meaningful housing and care options is echoed in the key informant interviews. Several interviewees commented on the fact that LTC homes also house individuals with intellectual disability.[569] The significance of the presence of this group of residents is that the LTC home environment is not designed to meet the medical, social and other needs associated with certain types of disability. A closer look at the regulatory regime will reveal how LTC reflects assumptions about disability. I will return to this issue in Chapter 9.

4.3.2.3 Admission wait times: becoming LTC residents

LTC is available to those who are deemed eligible according to criteria established by the province. The eligibility criteria are prescribed and the application process has been standardized across Ontario. Chapter 8 will address the issue of admission in greater detail. For now, I will note that the process of entering LTC is not straightforward at all. Consider the story of AM. AM[570] was a 68-year-old widow who lived in her family home in Toronto. She suffered from late early stages of Alzheimer's disease. AM's preference was to live in one of the two Italian LTC facilities. The difficulty facing AM was the extensive wait time for a bed to become available in those facilities. A non-Italian oriented home had a bed that became available,

---

forced-into-ontario-nursing-homes-ministry-data.html>. This is also happening in other provinces. For example see Jennifer Quesnel, "Active man with Down syndrome being diapered and spoon-fed in long-term care but needs group home, sister says", *CBC* (11 January 2018), online: <http://www.cbc.ca/news/canada/saskatoon/he-needs-a-home-sister-of-man-with-down-syndrome-says-long-term-care-is-wrong-place-for-him-1.4482193>.

[567] Ontario Ombudsman, "Ontario Ombudsman - Adults with developmental disabilities in crisis", online: <https://www.ombudsman.on.ca/Investigations/SORT-Investigations/Completed/Adults-with-developmental-disabilities-in-crisis.aspx>. Andrea Gordon & Laurie Monsebraaten, "A Promise to Fix Disability Crisis: Ombudsman's Scathing Report on Disabled Adults Sparks Minister's Apology and Vow to Make It Right", *Toronto Star* (25 August 2016) A.1.

[568] Ontario Ombudsman, *supra* note 7.

[569] Interviewees #10 (2017), #13 (2017) and #15 (2017).

[570] *AM (Re),* 2010 CanLII 48694 (ON CCB).

however AM and her family decided not to take that placement.[571] AM's son applied to the Consent and Capacity Board to have himself appointed as the representative of AM who was found incapable with respect to admission to a care facility, to give or refuse consent on behalf of AM.[572]

A few questions arise from AM's story. Why did AM prefer an Italian home? Why are those beds in short supply? How did AM and her family decide? Does the government have the right – or even obligation - to force someone who cannot stay in his/her own private dwelling to accept any LTC bed? Is it reasonable to expect (or demand) a publicly-funded system to respond to needs unrelated to the physical survival of residents? Did AM and her family have meaningful choices? Chapters 5 and 8 will explain how the law contributes to these problems and to the experience of AM. In the meantime, the statistics about LTC admission help us to understand the situation of AM (and many like AM).

Despite the expansion in capacity (see the next section) of LTC in Ontario in the 2000s, there are indications that the needs of older Ontarians who require LTC are not adequately met by the sector for a variety of reasons. One indication is the gap between the supply of and the demand for LTC.[573] The wait time for a bed has been subject to intense media scrutiny and has prompted calls for more beds.[574] This is not a new problem. The 2012 Auditor General report remarks: "The median wait times have almost tripled from 36 days in the 2004/05 fiscal year to 98 days in the 2011/12 fiscal year. An increase in the number of LTC home beds of 3% during that period has not kept pace with the rising demand from an aging population".[575]

The table below illustrates the median number of days people waited to move into a LTC home in Ontario by fiscal year between 2012 and 2018. Health Quality Ontario presents wait times by prior location (i.e., hospital or community) or by region (i.e., LHINs).

---

[571] *Ibid* at 4.

[572] *Ibid* at 5.

[573] Ministry of Health and Long-Term Care, *supra* note 562 at 131.

[574] *Ibid* at 133.

[575] Auditor General of Ontario, *2012 Annual Report of the Office of the Auditor General of Ontario (Section 3.8 Long-term-care Home Placement Process)* (Toronto: Auditor General of Ontario, 2012) at 200.

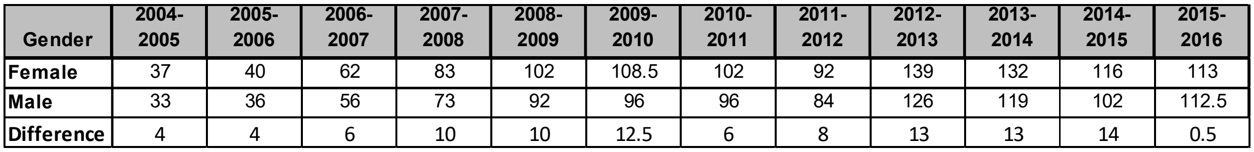
Table 6: Median number of days people waited to move in a LTC home, in Ontario, by prior location[576]

Fiscal Year	All (Days)	Community (Days)	Hospital (Days)
2012-13	133	165	77
2013-14	126	154	72
2014-15	111	135	60
2015-16	113	132	70
2016-17	133	149	92
2017-18	146	163	94

It is obvious that despite modest improvements in 2013-14 and 2014-15, wait times for LTC homes are getting longer, and vary by prior location. The median wait time for people who were living in the community was even longer, reaching 163 days in 2017-18. It should be emphasized that wait times also depend on a variety of factors, such as bed availability, choice, and priority.[577]

However, the picture is even more complex than Table 6 conveys, as median wait times can be presented in different ways, which may illustrate other factors contributing to longer wait times. The tables below present median wait times by gender, bed type, and by priority category:[578]

Table 7: Median wait time (number of days) by gender



Gender	2004-2005	2005-2006	2006-2007	2007-2008	2008-2009	2009-2010	2010-2011	2011-2012	2012-2013	2013-2014	2014-2015	2015-2016
Female	37	40	62	83	102	108.5	102	92	139	132	116	113
Male	33	36	56	73	92	96	96	84	126	119	102	112.5
Difference	4	4	6	10	10	12.5	6	8	13	13	14	0.5

---

[576] The Health Quality Ontario website allows the general public to search for LTC wait times. Wait times for admission to long-term care homes is one of the indicators of the performance of the LTC system tracked by Health Quality Ontario. The data in the table is pulled from the HQO website. Health Quality Ontario, “Wait Times for Long-Term Care Homes”, (2019), online: <https://www.hqontario.ca/System-Performance/Long-Term-Care-Home-Performance/Wait-Times>.

[577] Health Quality Ontario, *Measuring up 2016: A Yearly Report on How Ontario’s Health System Is Performing* (Toronto: Health Quality Ontario, 2016) at 84.

[578] The author requested the information from the MOHLTC (Request # IMSC – 000006303). The data was received on March 6, 2017.

Table 8: Median wait time (number of days) by bed type

Bed Type	2004-2005	2005-2006	2006-2007	2007-2008	2008-2009	2009-2010	2010-2011	2011-2012
Basic	35	35	56	75	102	103	108	90
Private	38	46	70	91	110	120	108	100
Semi-Private	32	35	46	60	67	70	66	63

(Note: data by bed type is not available after 2011–12)

Table 9: Median wait time (number of days) by priority category under the previous regimes

Priority Category	2004-2005	2005-2006	2006-2007	2007-2008	2008-2009	2009-2010
Crisis (1)	17	21	40	58	75	78
Non-Crisis (1B)	121	83	160	190	247.5	262
Non-Crisis (2)	34	38	60	81	101	108
Non-Crisis (3)	64	72	100	123	182	180.5
Spousal Reunification	41	58	82	94	105	105

Table 10: Median wait time (number of days) by priority category under the current regime

Priority Category	2010-2011	2011-2012	2012-2013	2013-2014	2014-2015	2015-2016
Crisis (1)	77	64	98	97	90	92
Non-Crisis (3A)	219	238	318	311	300	258
Non-Crisis (3B)	294.5	484	210	179	173	133
Non-Crisis (4A)	110	95	139	136	116	122
Non-Crisis (4B)	134.5	88	120	88.5	103	89.5
Spousal Reunification (2)	93	75	119	105	90.5	90

In sum, while wait times for LTC beds increased until 2012–13 and then gradually decreased for a few years (but are still higher than the 2005–06 level), there are a few interesting trends at the provincial level that are of note:

- The median wait time for women was higher than men every year until 2015–16.
- The median wait time for non-crisis applicants for religious, cultural, or ethic homes (3A and 3B) has consistently increased since 2010.
- The longest median wait time was for private accommodation (up to 2011-12).

This brief discussion of wait times raises a number of questions. First, as applicants wait longer (on average) in the community, how much support do they and their informal carers (if any) receive? Second, as wait times are longest for non-crisis cultural and religious placements, what can we say about availability of choices of LTC in Ontario? Third, as wait times vary considerably across categories, what is the role of the government in managing the capacity of the system? These issues also emerge from the feminist political economy literature. Addressing these questions requires an understanding of the regulation, governance and funding of the sector.

4.3.3 How the LTC sector in Ontario is regulated, governed and funded

Recall that co-regulation occurs when government and regulated entities co-operate in the development and implementation of a regulatory regime.[579] The concept of co-regulation is useful here to describe how the sector is regulated. In Canada, the regulation and governance of LTC homes is predominantly a provincial and territorial responsibility. The *Canada Health Act*[580] makes reference to "extended health care services", which includes "nursing home intermediary care service".[581] Many scholars have pointed out the lack of federal role in LTC provision in Canada,[582] however the federal government does influence homes through the role it plays at the international level and through the ways it shapes ideas about responsibility, ownership, and care.[583] An example of such influence is the making of immigration policy, which shapes the LTC workforce.[584] Other limited federal responsibilities are related to veterans who need LTC[585], the regulation of drug and health products including medical devices,[586] and

---

[579] Windholz, *supra* note 50 at 162–164.

[580] *Canada Health Act*, RSC 1985, c C-46. The CHA requires only first-dollar public coverage of all hospital and physician services defined as "medically necessary."

[581] *Ibid,* s.2.

[582] Saskia N Sivananthan, Malcolm Doupe & Margaret J McGregor, "Exploring the Ecology of Canada's Publicly Funded Residential Long-Term Care Bed Supply" (2015) 34:1 Can J Aging 60 at 62.

[583] Armstrong, Armstrong & Daly, *supra* note 163 at 51.

[584] For example, see Sharon Roseman, Pauline Gardiner Barber & Barbara Neis, "Towards a Feminist Political Economy Framework for Analyzing Employment-Related Geographical Mobility" (2015) 95 Studies in Political Economy 175.

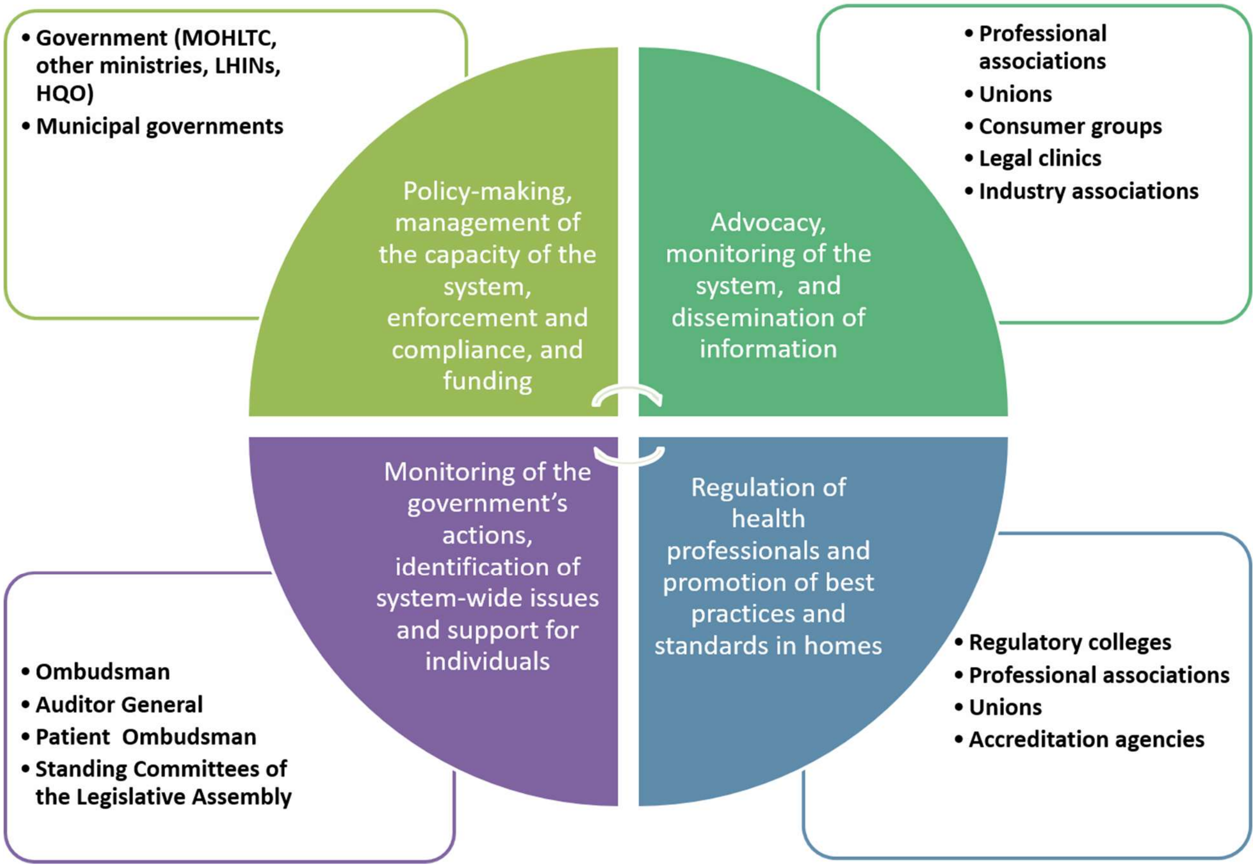
[585] Veterans Affairs Canada, "Long Term Care - Health and well being - Services - Veterans Affairs Canada", (15 December 2014), online: <http://www.veterans.gc.ca/eng/services/health/long-term-care>.

[586] *Food and Drugs Act,* RSC 1985, c F-27.

the use of quasi-criminal and criminal sanction power.[587] The discussion here focuses on the provincial role.

4.3.3.1 Ontario's authority over the LTC sector

Illustration 1: Selected key organizations in Ontario LTC System and their functions



A number of provincial bodies are involved in the regulation and governance of the sector (see illustration 1). MOHLTC is a key governmental actor and its powers in the sector are defined by a number of statutes and agreements. Powers are usually allocated to the Minister, the director of the long-term care program and Ministry inspectors. A good place to start is a review of the *Ministry of Health and Long-Term Care Act*. Section 6(2) of the *Ministry of Health and Long Term Care Act* states:

> It is the function of the Minister and he or she has power to carry out the following duties:

---

[587] *Criminal Code,* RSC 1985, c C-46.

> …
>
> To be responsible for the development, co-ordination and maintenance of comprehensive health services and a balanced and integrated system of hospitals, long-term care homes, laboratories, ambulances and other health facilities in Ontario."
>
> ….
>
> To authorize and provide financial support, alone or in co-operation with one or more persons or organizations, on a periodic basis or otherwise, for the establishment and operation of … long-term care homes and enter into agreements necessary therefor, … with … long-term care homes and … on such terms and conditions and for such periods as the Minister considers advisable to assist in financing all or any part of the cost of such centralized services and commodities or for any other purpose incidental to the foregoing.[588]

The MOHLTC is responsible for regulating the sector, which it does in two key ways: 1) through its enforcement and compliance program, MOHLTC ensures LTC homes are compliant with the applicable law, and 2) through its agency in charge of the quality of the health care system (called Health Quality Ontario), MOHLTC influences the delivery of care (see *Excellent Care for All Act*). As well, other provincial bodies including Office of the Fire Marshal, Office of the Chief Coroner and Public Health Ontario are involved in regulating the sector by enforcing their applicable acts, issuing guidelines and imposing reporting requirements. The regulatory colleges established under the *Regulated Health Professions Act*[589] and the individual health profession acts regulate professionals who work in the sector, such as physicians, registered nurses, registered practical nurses, dietitians, physiotherapists, occupational therapists, social workers, and pharmacists. It should also be noted that the professional associations of these regulated professionals may also influence the behavior of their members by issuing practice guidelines and distributing best practices more generally. Last but not least, LTC homes may be accredited by Accreditation Canada or by CARF Canada, and therefore must comply with their respective service standards if they wish to attain or maintain accreditation status.[590] See Illustration 2 for

---

[588] *Ministry of Health and Long-Term Care Act,* RSO 1990, c M.26, ss 6(1)2, 6(2)9.

[589] *Regulated Health Professions Act, 1991*, *supra* note 61. The list of self-governing health professions is included in Schedule 1 of the RHPA. Although the colleges are self-regulatory organizations, the government (Cabinet) can appoint a college supervisor pursuant to s.5.0.1 of the RHPA.

[590] I thank Professor Arie Freiberg for pointing out the variety of bodies involved in the health sector.

an overview of the bodies that are involved in the regulation (as understood using Julia Black's definition) of the sector.

4.3.3.2 Funding the LTC sector in Ontario

The MOHLTC is both the regulator and primary funder of the LTC sector and regulation and funding are intertwined. MOHLTC transfers funding to regional health authorities (called Local Health Integration Networks), which in turn establish accountability agreements with the LTC homes in their regions and provide funding in accordance with such agreements (called the Long-Term Care Home Service Accountability Agreement). "Where a local health integration network proposes to provide funding to a health service provider or amend a service accountability agreement with a health service provider, the network and the provider shall enter into a service accountability agreement or amend such an agreement in accordance with this section."[591] These agreements are also regulatory tools because they establish performance indicators and sometimes targets and standards[592] and they impose reporting requirements that supplement statutory requirements, such as compliance declaration.[593] In other words, the LHINS are also involved in enforcing compliance of homes with provincial requirements. I will elaborate on this point in Chapter 8.

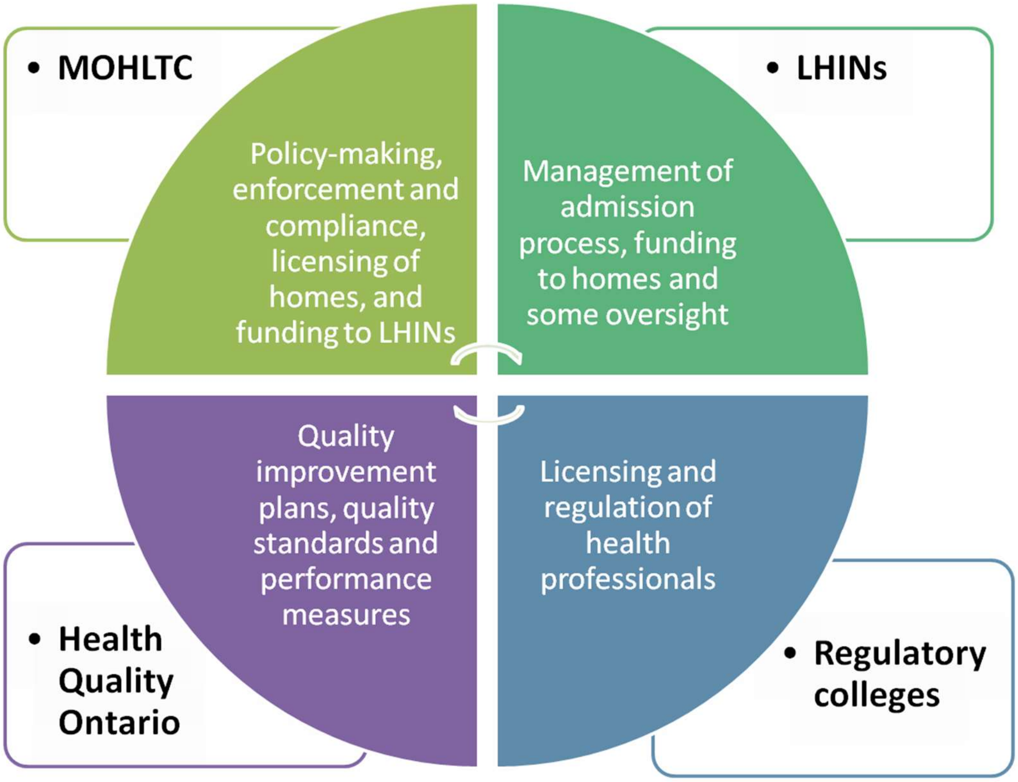
---

[591] *Local Health System Integration Act, 2006,* SO 2006, c. 4.

[592] For example, in "Schedule D – Performance" of the agreement, there are three types of indicators: 1) Organizational Health and Financial, 2) Coordination and Access and 3) Quality and Resident Safety.

[593] See *Long-Term Care Service Accountability Agreements (L-SAA)(2016-2019)* at Schedule C-Reporting Requirements.

Illustration 2: Public bodies that are involved in the funding and regulation of LTC homes



Similar to other provinces, the LTC sector in Ontario includes private, non-profit and municipal homes. The difference is that Ontario has a higher proportion of private homes.[594] In an earlier study based on results from a Statistics Canada survey,[595] commercialization was most widespread in Ontario with respect to the percentage share of the sector owned by proprietary

---

[594] Canadian Institute for Health Information, *Health Spending - Nursing Homes* (Ottawa: Canadian Institute for Health Information, 2014) at 2. According to CIHI, the 2012 Statistic Canada data (except Quebec) showed that in Canada the public sector operated 27% of homes. Private for-profit and non-profit facilities operated 44% and 29% of homes, respectively.

[595] The Residential Care Facilities Survey collected data from residential care facilities across Canada. The survey has been cancelled. According to Statistics Canada, the term "residential care facilities" refers to facilities which have four beds or more and which are approved, funded or licensed by provincial/territorial departments of health and/or social services. Among the facilities included are homes for the aged, persons with physical or developmental disabilities, persons with psychiatric disabilities, persons with alcohol and drug problems, emotionally disturbed children, transients, young offenders and others. Provincial and territorial ministries of health and/or social services are annually requested to update the inventory of residential care facilities. See *infra* note 597.

operators.[596] The table below summarizes the breakdown of homes for the aged as of 2009-10, categorized by size and ownership.

Table 11: Number of homes for the aged by size and ownership 2009-10 (Ontario) [597]

Size of facility	Proprietary	Religious	Lay	Municipal	Provincial
1 to 19 beds	11	1	2	1	0
20 to 49 beds	58	5	12	1	3
50 to 99 beds	189	12	34	14	1
100 beds or more	224	21	60	88	1
Total	482	39	108	104	5

Currently, of the 625 LTC homes, 58% of homes are privately owned, 23% are non-profit/charitable, and 16% are municipal. About 40% of long-term care homes are small, with 96 or fewer beds. Of these small homes, about 47% are located in rural communities that often have limited home care or retirement home options.[598] The top four private LTC providers in Ontario are Revera, Extendicare, Leisureworld and Chartwell. These companies also operate – to various degrees - in other jurisdictions (other Canadian provinces and in the U.S.). With the exception of Revera, all are publicly traded companies. As well, these corporations are not just LTC beds providers, they are also involved in the delivery of other health-related services, such as home care and retirement homes. In other words, the scope of the long-term care sector is actually broader than the operation of long-term care beds.

The Ontario LTC sector went through a phase of rapid expansion between the late 1990s and 2014.[599] One way of describing the expansion is to assess the capacity of the sector in terms

---

[596] Daly, *supra* note 514 at 34.

[597] The data is pulled from Statistics Canada, *Residential Care Facilities 2009/2010* (Ottawa: Statistics Canada, 2011) at 26–27.

[598] Ontario Long-Term Care Association, "About Long-Term Care in Ontario: Facts and Figures", (2018), online: <https://www.oltca.com/oltca/OLTCA/Public/LongTermCare/FactsFigures.aspx#Ontario's%20long-term%20care%20homes%20(June%202017)>.

[599] In 1998, the Conservative government announced an eight-year plan to provide 20,000 new long-term care beds and to renovate non-compliant homes containing 13,583 beds. In March 1999, it announced that the new beds would be completed by 2004. The number of beds to be renovated by 2006 was later revised to 15,835. See Legislative Assembly Standing Committee on Public Accounts, *Long-Term Care Facilities Activity (Section 4.04, 2004 Annual Report of the Provincial Auditor)* (Toronto: Legislative Assembly. Standing Committee on Public Accounts, 2005) at 2.

of quantity of care. The number of beds increased from 57,000 in 1998 to 74,000 in 2005,[600] and to 78,000 (including short-stay beds) in 2014. This increase in the number of beds inevitably required corresponding year-over-year increases to the MOHLTC budget.[601] The increase in funding paid not only for the operating costs of those beds, but also for other initiatives intended to improve the experiences of residents, such as increased funding for Resident and Family Councils.[602] The table below illustrates government spending on the sector in Ontario between 2004-05 and 2016-17.[603]

Table 12: Government funding

Year	2004–05	2005–06	2006–07	2007–08	2008–09	2009–10	2010–11	2011–12	2012–13	2013–14	2014–15	2015–16	2016-17
Expenditure ($ – in billions)	2.5	2.68	2.8	2.8	3.1	3.22	3.5	3.61	3.71	3.83	3.9	3.97	4.05
Increase from previous year (%)		7.2	4.5	0	10.6	4.0	8.6	3.1	2.9	4.3	1.8	1.7	2.0
Consumer Price Index – Ontario (%)	1.9	2.2	1.8	1.8	2.3	0.4	2.5	3.1	1.4	1.0	2.4	1.2	2.4

Regardless of ownership type or geographic location, homes receive government funding for raw food, nursing care, social programs, and so forth. The provincial funding (provincial subsidy) for each home is divided into four “envelopes”: (a) the “Nursing and Personal Care” envelope which may be adjusted for acuity; (b) the “Program and Support Services” envelope; (c) the “Raw

---

[600] Ontario, Legislative Assembly (Standing Committee on Public Accounts), *Official Report Journal of Debates (Hansard)*, 38th Parl, 1st Sess, (May 5, 2005) at 379.

[601] *Ibid* at P-389.

[602] *Ibid* at P-380.

[603] The figures are from the government’s annual planning document (Results-Based Planning Briefing Book). The government does not always state the expenditure figures explicitly and the author calculates some of the figures. For example, in the 2010-11 planning document, it is noted that “During fiscal 2009-10, LTC funding was increased $124 million, compared to the previous year.” The author calculates the 2009-10 figure by adding $124 million to the 2008-09 figure, which was $3.1 billion (from the 2009-10 planning document). Statistics Canada calculates Consumer Price Index (CPI) based on calendar year. However, government expenditure is based on fiscal year (April 1 to March 31). In terms of time period, the change in CPI does not correspond perfectly to the change in expenditure. Statistics Canada, Table 18-10-0005-01 Consumer Price Index, annual average, not seasonally adjusted.

Food" envelope; and (d) the "Other Accommodation" envelope.[604] The LHINs fund homes for every bed in the home (i.e., on a per diem basis).[605] There are rules about how a home is supposed to spend the funding[606] and corresponding reporting requirements, including completion of the Long-term Care Home Annual Report and, the In-Year Revenue/Occupancy Report.[607] Provincial funding for long-term care in 2019 is as follows:

- Approximately $100.26 per day for nursing and personal care (such as assistance with personal hygiene, bathing, eating, and toileting)
- $12.06 per day for specialized therapies, recreational programs, and support services
- $9.54 per day for raw food
- $56.16 for other accommodations (such as laundry and linen, general and administrative services, and facility costs)
- $1.77 global per diem increase
- Top-up funding for various types of bed (e.g. Behavioral Specialized Unit Beds). [608]

Since LTC is publicly funded on a cost-shared basis with residents, residents have to pay a portion of their "room and board" to their homes.[609] LTC home residents must make a co-payment of $1,892 to $2,702 per month (set by the MOHLTC by regulation), depending on the type of accommodations (single room vs. shared room). Homes retain the co-payments; these payments are what long-term care homes use to make a return on their investment.[610] Residents may also elect to pay for extra services, such as hairdressing, cable TV, and telephone services. Those who do not have adequate income to pay the basic rates may apply for a rate reduction

---

[604] Accountability Agreement, *supra* note 593 at Schedule B, s. 2.0.
[605] Ministry of Health and Long-Term Care, *LTCH Level-of-Care Per Diem Funding Policy* (Toronto: Ministry of Health and Long-Term Care, 2017) at 1. Funding is subject to the conditions set out in various funding and financial management policies, applicable law, and the service accountability agreement between the LHIN and the homes
[606] Accountability Agreement, *supra* note 593 at Schedule B, 4.0. For example, section 4.2 states that the home "shall not transfer any portion of the Estimated Provincial Subsidy in the "Raw Food" Envelope to any other Envelope". See also Ministry of Health and Long-Term Care, *supra* note 605.
[607] Accountability Agreement, *supra* note 593 at Schedule B, s. 2.0.
[608] The total of the four amounts is called current base Level of Care (LOC) per diem funding. See Ministry of Health and Long-Term Care, *Policy: LTCH Level-of-Care Per Diem Funding Summary* (Toronto: Ministry of Health and Long-Term Care, 2019). See also Ministry of Health and Long-Term Care, *supra* note 605. These rates are effective August 1, 2019.
[609] Ontario Long-Term Care Association, *supra* note 598.
[610] *Ibid*.

(government subsidy). However, they are not eligible for semi-private or private rooms.[611] Residents also pay out-of-pocket for any medications or other services not covered by their private insurance plans or by the provincial drug benefit program.[612]

In addition to operating funding, capital funding may be available to homes. Under the Enhanced Long-Term Care Home Renewal Strategy, the Ministry is supporting the redevelopment of more than 30,000 LTC beds in over 300 LTC homes to meet current design standards by 2025.[613] The government also provides a LTC Construction Funding Subsidy (CFS) on a per bed per day basis (per diem), to support the costs of developing or redeveloping an eligible LTC home.[614] The per diem is paid to the home on a monthly basis for a period of 25 consecutive years, provided that the home meets the requirements and conditions set by the Ministry.[615] The CFS Per Diem ranges from $16.65 to $23.03, depending on various adjustments, such as home size and Ratio of Basic Accommodation.[616] In addition, for eligible non-profit homes only, a one-time grant of $250,000 is provided to assist in planning and organizing for redevelopment.[617] Homes may receive funding of $300 per bed, per move to cover incidental, non-construction related costs associated with relocating residents and equipment.[618] It should be noted that the CFS Per Diem must be used to repay any loans or other financing arrangements for the construction, and only after the home has paid any current amounts owing in respect of such repayments, may the home use the remaining amounts for other purposes.[619]

Finally, the not-for-profit homes, through municipal contributions and charitable donations, typically contribute additional resources to their operation to further enhance the level of care and service provided.[620]

---

[611] Ministry of Health and Long-Term Care, “Long-term care accommodation costs and subsidy”, (2018), online: <https://www.ontario.ca/page/get-help-paying-long-term-care>. These rates are effective July 1, 2019.
[612] Ontario Long-Term Care Association, *supra* note 598.
[613] Ministry of Health and Long Term Care, *2017- 2018 Published Plan and 2016-2017 Annual Report* (Toronto: Ministry of Health and Long Term Care, 2017).
[614] Ministry of Health and Long-Term Care, *Construction Funding Subsidy Policy for LongTerm Care Homes, 2015* (Toronto: Ministry of Health an Long-Term Care, 2015) at 1.
[615] *Ibid* at 5.
[616] *Ibid* at 4 and 7. Each eligible home must demonstrate to the satisfaction of the Ministry that the construction cost of $120,000 per Bed has been expended by the Eligible Operator in order to receive the maximum applicable Construction Funding Subsidy Per Diem. The Policy specifies eligible and ineligible costs.
[617] *Ibid* at 9. Homes are eligible upon entering into a Development Agreement with the Ministry.
[618] *Ibid*.
[619] *Ibid* at 12.
[620] Interviewee # 16, (2018); Interviewee # 17, (2018).

4.3.4 **Summary**

It is almost trite to note that the LTC sector in Ontario is under-funded and over-regulated, as frequently portrayed in newspaper headlines. The complexity of the regulatory, oversight and funding arrangements applicable to the sector should be apparent. Some of the nuances about the sector and the residents presented above are important because as Nedelsky (and other feminist scholars) has argued, law affects people differently under different circumstances. The context influences how procedural and substantive rights and entitlements are experienced by residents. The next section will explain why numerous regulatory and non-regulatory changes, including the implementation of a new legal framework, occurred between 2004 and 2018.

4.4 Impetus for a new regulatory framework for LTC in Ontario

The LTCHA and its regulation became effective in July 2010. A change in government in October 2003 (from Conservative to Liberal) created a window of opportunity for reform. To initiate legal reforms in the sector, the newly elected Liberal government (centre-to-left) conducted a review of the sector, releasing a report in Spring 2004,[621] followed by a discussion paper in November 2004.[622] While preparing a new statute (*Long-Term Care Homes Act, 2007*), which was tabled in 2006, the government continued to implement non-legislative measures, such as additional funding to improve delivery of care.[623] The new Act and its regulation – with certain provisions unproclaimed and then repealed in 2017 – became effective on July 1, 2010. Once a new legal framework was in place, funding responsibilities were transferred to the newly created LHINs. In 2016, the mandate of LHINs was expanded to take on more responsibilities, including the management of processes of admission to LTC homes (see Bill 41, *Patients First*

---

[621] Ministry of Health and Long-Term Care, *Commitment to Care: A Plan for Long- Term Care in Ontario by Monique Smith, Parliamentary Assistant, Ministry of Health and Long-Term Care* (Toronto: Ministry of Health and Long-Term Care, 2004).

[622] Ministry of Health and Long Term Care, *Future Directions for Legislation Governing Long-Term Care Homes* (Toronto: Ministry of Health and Long-Term Care, 2004).

[623] Ministry of Health and Long-Term Care, *Mcguinty Government Launches Comprehensive Strategy to Protect Seniors in Long-Term Care (May 11 News Release)* (Toronto: Ministry of Health and Long-Term Care, 2004); Ministry of Health and Long-Term Care, *McGuinty Government Gives Long- Term Care Residents and Their Families Greater Say in Decisions" (August 26 News release)* (Toronto: Ministry of Health and Long-Term Care, 2004).

Act, 2016).[624] In 2017, the LTCHA was amended by Bill 160, *Strengthening Quality and Accountability for Patients Act, 2017*.[625] The latest amendments are intended to strengthen Ontario's quality and safety inspection program for LTC homes with new enforcement tools, including financial penalties and new provincial offences for non-compliance.[626] Further regulation amendments are expected in order to fully implement the legislative amendments, which are to be proclaimed at a later date.[627]

4.4.1 Policy problems in search of (legal) solutions

Before I discuss the regulatory changes (by way of law), it is instructive to understand the public policy problems that the LTCHA was intended to address in this period. This discussion will help to contextualize the regulatory changes and situate these changes within a spectrum of tools that the provincial government used to try to "fix" the sector.

First, the notion of quality of care has been driving policy debates about health care, including LTC, for some time.[628] Quality of care is a highly controversial subject and as we will see later in this dissertation, there are opposing views about what quality means. The legal changes related to regulating quality of care in the LTC sector should be understood within this broader discourse of quality of care in the health care system. According to the OECD, three aspects are generally accepted as critical to quality of care: effectiveness and safety, patient-centredness and responsiveness, and care coordination.[629] In OECD and EU countries, three main approaches have been adopted to drive LTC quality improvement: regulatory standards, standards to normalise care practice, and market incentives for providers and users.[630] As we will see in subsequent chapters, these approaches have also been adopted into Ontario's regulatory

---

[624] *Bill 41: An Act to amend various Acts in the interests of patient-centred care* [*Bill 41: An Act to amend various Acts in the interests of patient-centred care*].

[625] *An Act to amend, repeal and enact various Acts in the interest of strengthening quality and accountability for patients, SO 2017, c.25* [*Strengthening Quality and Accountability for Patients Act, 2017*]. The Bill has 10 schedules and covers other issues as well, such as public health.

[626] Ministry of Health and Long-Term Care, "News release: Ontario Passes Legislation to Strengthen Transparency in Health Care", (12 December 2017), online: *news.ontario.ca* <https://news.ontario.ca/mohltc/en/2017/12/ontario-passes-legislation-to-strengthen-transparency-in-health-care.html>.

[627] As of September 27, 2019, provisions about confining and restraining residents have not been proclaimed yet.

[628] Generally see Österle & Rothgang, *supra* note 477.

[629] Yuki Murakami & Francesca Colombo, "Why the Quality of Long-Term Care Matters" in *A Good Life in Old Age? - Monitoring and Improving Quality in Long-term Care* (Paris: OECD / EU, 2013) 37 at 37.

[630] Yuki Murakami & Francesca Colombo, "Regulation to Improve Quality in Long-Term Care" in *A Good Life in Old Age? - Monitoring and Improving Quality in Long-term Care* (Paris: OECD / EU, 2013) 143 at 144.

framework.

Secondly, one of the key policy problems that dominated public debates in this period was the financial sustainability of the LTC system given Ontario's aging population. The problem was three-fold: First, the percentage of Ontarians over 65 would increase significantly[631] and therefore, the government was pressured to add more capacity to the sector (in terms of number of beds) by building new homes or re-developing existing ones.[632] Second, the prevalence of dementia and other cognitive impairments would increase with the aging of the population and existing resources — in LTC and in community settings — were inadequate to address the complex needs of those with challenging behaviours.[633] And third, the health care system was not designed to meet the needs of older Ontarians, and the result was that other parts of the health care system (e.g., hospitals) were under immense pressure.[634]

Thirdly, deficiencies in care attracted intense media and public scrutiny[635] and prompted the provincial government to adopt non-regulatory measures to correct them. The deficiencies were routinely attributed to lack of front-line staff time and resources for the delivery of proper basic care — from infectious disease control to planning of social activities — as well as more complex clinical or medical care.[636] There were also more demands for recognition of individual preferences, cultural/religious sensitivity, and choices in delivery of care.[637] Further, it appeared

---

[631] Ministry of Health and Long-Term Care, *supra* note 562; Institute of Public Administration of Canada, *Healthcare Governance Models in Canada A Provincial Perspective* (Toronto: Institute of Public Administration of Canada, 2013).

[632] Legislative Assembly. Standing Committee on Public Accounts, *supra* note 599 at 11.

[633] Ministry of Health and Long-Term Care, *supra* note 621; Office of the Chief Coroner for Ontario, *Ezz-El-Dine El-Roubi and Pedro Lopez Inquest Jury Recommendations* (Toronto: Office of the Chief Coroner for Ontario, 2005); David Walker, *Caring for Our Aging Population and Addressing Alternate Level of Care (ALC)* (Toronto: Ministry of Health and Long-Term Care, 2011); Ministry of Health and Long-Term Care, *supra* note 562.

[634] Ministry of Health and Long-Term Care, *Alternative Levels Of Care Strategy Will See Patients Discharged From Hospitals Sooner (News release February 10)* (Toronto: Ministry of Health and Long-Term Care, 2005); Walker, *supra* note 633; Ministry of Health and Long-Term Care, *supra* note 562.

[635] Daly, *supra* note 514.

[636] Ministry of Health and Long Term Care, *What We Heard: Long-Term Care Quality Consultation 2008 -A Common Vision of Quality in Ontario Long-Term Care Homes* (Toronto: Ministry of Health and Long-Term Care, 2008); Auditor General of Ontario, *2011 Annual Report of the Office of the Auditor General of Ontario* (Toronto: Auditor General of Ontario, 2011) at 347–354; Auditor General of Ontario, *2009 Annual Report of the Office of the Auditor General of Ontario* (Toronto: Auditor General of Ontario, 2009) at 159–185; Office of the Chief ch for Ontario, *supra* note 633.

[637] Ministry of Health and Long-Term Care, *supra* note 636 at 4–6; Ministry of Health and Long-Term Care, *supra* note 562 at 11; Poland Lai, "Regulation of 'Care' in Long-term Care Homes in Ontario, Canada" in *Aging / Disability Nexus* (Vancouver, BC: UBC Press, 2020).

that the government did not have a good understanding of the needs of LTC residents (and how much it would cost to improve care that would meet their needs) because of poor tracking and monitoring of activities in homes.[638] In response, the government made financial investments — both permanent and one-off — for specific, quantifiable initiatives (in other words, "announceables") that could be linked to "front-line" care, such as increasing the number of registered nurses,[639] and purchasing specific equipment (e.g., specialized mattresses).[640] It is also notable that the government did not incorporate minimum staffing standards in the form of minimum hours of care per resident, mix of staff, or staffing and resident ratios into the law.[641]

Finally, the old regulatory framework (three similar statutes and a program manual) was perceived to be inadequate to protect vulnerable residents, and at the same time, too burdensome for homes. Further, it failed to drive public accountability.[642] Equally important, the old inspection system was not properly resourced in terms of staffing, information technology, and expertise in monitoring compliance.[643] As a result, the government indicated that "developing clear enforceable standards with tougher inspection and enforcement,"[644] was one of the objectives of a new legal framework. Before the new standards were in place, the government also used administrative measures to improve how the sector was regulated, including enhanced risk management,[645] better disclosure of performance of the sector (e.g., posting of inspection results and orders on government website), and establishment of a toll-free number for the reporting of problems in homes.[646]

---

[638] Auditor General of Ontario, *supra* note 557; Legislative Assembly. Standing Committee on Public Accounts, *supra* note 599.

[639] Ministry of Health and Long Term Care, *supra* note 622.

[640] Ministry of Health and Long-Term Care, *Mcguinty Government Investing in Better Patient Care (News Release February 9)* (Toronto: Ministry of Health and Long-Term Care, 2005).

[641] Ministry of Health and Long-Term Care, *supra* note 621.

[642] *Ibid*; Ministry of Health and Long-Term Care, *supra* note 622; Ontario Ombudsman, *Findings Re Ministry of Health and Long-Term Care's Monitoring of Long-Term Care Homes* (Toronto: Ontario Ombudsman, 2010).

[643] Ontario Ombudsman, *supra* note 642.

[644] Ministry of Health and Long-Term Care, *supra* note 621; Ministry of Health and Long-Term Care, *supra* note 622.

[645] Ontario, Legislative Assembly, *supra* note 600.

[646] Auditor General of Ontario, *supra* note 557; Ontario Ombudsman, *supra* note 642.

4.4.2 **Broader Changes in the Health Care System in Ontario**

The new legal framework should be considered in conjunction with broader changes in the Ontario health care system. First, "bending the cost curve"[647] became a priority for the government and was consistent with Canada's pattern of health expenditures.[648] Historically, the MOHLTC's budget grew at an average annual rate of six per cent. The LTCHA was drafted and became effective during a period when the health budget was increasing at a relatively higher rate than the post-2008 period. In recent years, the ministry reduced its budget growth from almost six per cent in 2009–10 to two per cent in 2016–17.[649] Second, the government promised to "create a system that delivers care in a better, smarter way — one that improves quality for patients as it delivers increased value for taxpayers"[650] and improving home and community care was part of that commitment. The emphasis was on "ensuring patients are receiving care in the most appropriate setting, wherever possible at home instead of in hospital or long-term care".[651] Several initiatives were connected to this objective, such as the Aging at Home initiative[652] and the Seniors Strategy.[653] Finally, the government also intensified its efforts to offer more choices, more information, and more support so that users (patients) could make informed decisions about their health. For example: "[a]s a government, we're increasingly putting our efforts into promoting healthy habits and behaviours, supporting lifestyle changes and better management of chronic conditions. But to succeed, we need everyone to play an active role in their health care by participating in healthy living and wellness".[654]

---

[647] Ministry of Health and Long-Term Care, *Ministry of Health and Long-Term Care Results-based Plan Briefing Book 2014-2015* (Toronto: Ministry of Health and Long-Term Care, 2014); Ministry of Health and Long-Term Care, *Ministry of Health and Long-Term Care 2015-16 Published Plans and 2014-2015 Annual Reports* (Toronto: Ministry of Health and Long-Term Care, 2015); Ministry of Health and Long-Term Care, *Ministry of Health and Long-Term Care 2016-17 Published Plans and 2015-2016 Annual Reports* (Toronto: Ministry of Health and Long-Term Care, 2016).

[648] OECD, *OECD Health Policy Overview: Health Policies in Canada* (Paris: OECD Publishing, 2016).

[649] Ministry of Health and Long-Term Care, *supra* note 647.

[650] Ministry of Health and Long-Term Care, *Ontario's Action Plan for Health Care* (Toronto: Ministry of Health and Long-Term Care, 2012) at 6.

[651] *Ibid* at 11.

[652] Ministry of Health and Long-Term Care, *Results-based Plan Briefing Book 2008-2009* (Toronto: Ministry of Health and Long-Term Care, 2008) at 27–28.

[653] Ministry of Health and Long-Term Care, *supra* note 562.

[654] Ministry of Health and Long-Term Care, *supra* note 650 at 7.

4.4.3 Summary

The development of the LTCHA can be viewed as the culmination of government responses to a number of problems and challenges emerging in the sector: quality of care agenda, the needs of an aging population, deficiencies in care and an inadequate enforcement framework. The LTCHA should be considered alongside broader changes in the health care system: bending the cost curve, timely access to the most appropriate care in the most appropriate place and more choices for users. However, the LTCHA is not the "full and complete answer" to problems in the sector. The subsequent implementation of the LTCHA did not negate the sense of urgency that further changes to the LTC sector are required. I now turn to the feminist political economy literature to further my understanding of the problems and more importantly, promising practices[655] in LTC.

4.5 Themes in LTC research in the feminist political economy literature

I rely on secondary literature to draw out critical themes and insights about the LTC home sector. Clearly, there is a rich and growing body of literature on LTC homes, including important contributions in the feminist political economy literature. The last section of this chapter will briefly explain the basic premises and assumptions of political economy and then feminist political economy. Recall that care matters to the state.[656] Continuing on with the debates about care outlined in Chapter 2, the following themes in LTC research will be elaborated: the gendered nature of care work, the concept of care as a relationship, conditions of work as conditions of care and vice versa, and regulation including rigidity of the workplace. A number of policy prescriptions in the form of promising practices have now emerged in the feminist political economy literature as a result of an international project which seeks to identify promising practices for conceptualizing and organizing LTC.[657]

---

[655] Baines & Armstrong, *supra* note 514; Pat Armstrong, "Balancing the Tension in Long-Term Residential Care" (2018) 43:1 Ageing Int 74 at 76–77.

[656] Herring, *supra* note 112 at 93.

[657] The Re-imagining Long-term Residential Care project is led by Dr. Pat Armstrong at York University, and includes academics from five Canadian provinces, three American states, the U.K., Sweden, Germany and Norway. The project includes scholars trained in sociology, medicine, social work, history, media studies, philosophy, architecture, health policy and more. http://reltc.apps01.yorku.ca

4.5.1 **Basic Premises and Assumptions**

According to Armstrong *et al*, the term "political economy" originates from the central assumption that the political and the economic are integrally related. This unity of the political and the economic is understood in the more abstract sense of a fundamental link between power and economic control.[658] As a method of analysis, political economy takes in multiple forms and remains a work-in-progress.[659] The shared assumptions of various strands of political economy are as follows. First and foremost, states, markets, ideas, discourses, and civil society are analyzed as interrelated parts of the same whole, rather than as separate variables.[660] They are shaped by how people provide for their needs, by the means of producing and reproducing, as well as by collective and individual efforts to resist.[661] Contradictions are also critical to understanding both historical developments and daily life. Contradictions are about opposing forces and internal tensions, some are possible to eliminate and others are integral to social relations. And it is not only economics, but also ideas, discourses, and practices developed over time that matter.[662]

Feminist political economy is also concerned with the material practices of power and the distribution of social resources. Gender and class are interrelated systems of power that work through and are continuously (re)constituted by social relations of production and reproduction. Feminist political economy also examines the differential political and economic effects that flow from social and political relationships and structures.[663] This field has now expanded to explore the multiple intersections of gender, race, and class (as well as other social locations including immigration status, geography, sexuality, and age) and the complex power relationships enacted through them.[664] Three key concerns are addressed by feminist political economy: the sexual division of labour, the role of the state, and the construction of and

---

[658] Pat Armstrong, Hugh Armstrong & Krista Scott-Dixon, *Critical To Care: The Invisible Women in Health Services* (Toronto: University of Toronto Press, 2008) at 63.
[659] *Ibid*.
[660] *Ibid*.
[661] *Ibid* at 7.
[662] *Ibid* at 7.
[663] Beth Jackson, "Chapter 1: Theory and Methods for Thinking Women" in Pat Armstrong, Barbara Clow & Karen Grant, eds, *Thinking Women and Health Care Reform in Canada* (Toronto: Canadian Scholars' Press and Women's Press, 2012) 15 at 18-19.
[664] *Ibid* at 20-21. See also Armstrong, Armstrong & Scott-Dixon, *supra* note 178 at 65-66.

relationships between the public and private spheres.[665] Of particular interest to this dissertation are feminist political economy's insights into the public / private divide. Generally speaking, the public sphere is associated with politics, government, markets, and workplaces whereas the private sphere is associated with the so-called domestic elements of social life (e.g., family, sexuality, child/elder care). Accordingly, feminist political economy examines the construction of these spheres and how they reinforce and recreate one another.[666]

4.5.2 **Gendered nature of LTC**

There is a consensus among feminist political economists about the gendered nature of LTC. According to Morgan Seely, until recently, LTC was not always well-identified as a women's issue. Historically, biomedically-oriented approaches to health and aging have ignored issues of gender, sex, and diversity.[667] In the section entitled "a profile of LTC residents", I explained that the majority of residents are older women with serious illnesses and impairments but there is also a group of younger disabled adults. It should be noted that in North America, the resident population has also become more racially and culturally mixed.[668] LTC is gendered also because care work is done by women, and in Ontario and elsewhere, many of them are racialized or immigrant women.[669] It is important to unpack assumptions about women's "natural" propensity to do care work. Care work, as Donna Baines and Diane van den Broek state, is often seen as an extension of what women do 'naturally' in the home and community, making it difficult to improve pay or conditions.[670] Most importantly, as Seely explains, issues central to discussions of residential LTC, such as access to beds, contracting out services, adoption of for-profit managerial practices, and heavier workload of paid staff, have differing impacts on women and are experienced differently by particular groups of men and women.[671] In a nutshell, as Tamara Daly and colleagues state: "LTC is thus a highly gendered home space and workplace

---

[665] Leah Vosko, "The Pasts (and Futures) of Feminist Political Economy in Canada: Reviving the Debate" (2002) 68(Summer) Studies in Political Economy 5 cited in Jackson, *supra* note 663.
[666] Jackson, *supra* note 663 at 19-20.
[667] Morgan Seely, "Women, Aging, and Residential Long-Term Care" in Pat Armstrong et al, eds, *Thinking Women and Health Care Reform in Canada* (Toronto: Canadian Scholars' Press and Women's Press, 2012) 107 at 113.
[668] Armstrong & Daly, *supra* note 163 at 15.
[669] Banerjee & Armstrong, *supra* note 514 at 10.
[670] Donna Baines & Diane van den Broek, "Coercive Care: Control and Coercion in the Restructured Care Workplace" (2017) 47:1 British Journal of Social Work 125 at 129.
[671] Seely, *supra* note 667.

regulated by overarching gendered norms and expectations of women that are shared across places but with obligations to provide familial care that are place specific."[672] As explained above, scholars generally explore the intersections of sexism with other social locations. For this reason, their empirical studies of LTC (many of which are based on rapid ethnography) are particularly useful in revealing how different contexts matter to those who work in LTC.

The following findings emerge from the empirical studies conducted in Ontario and elsewhere and inform my own analysis. Firstly, LTC has been almost exclusively strongly influenced by biomedicalization i.e., aging tends to be viewed as a series of medical problems requiring medical solutions.[673] In a biomedical model, frontline care workers are positioned at the bottom of a gendered and racialized hierarchy that put 'scientific' practices and physicians at the top and other professionals, such as managers, nurses, technicians and others in descending order.[674] Gender is central to expectations managers, workers and service users have of female workers.[675] Baines reported that workers and managers alike normalized unpaid overtime as an expectation of their job and they attributed it to their 'professionalism and commitment' to the residents. It also overlapped with altruism and the naturalized and gendered notion that women have an endless willingness to sacrifice on behalf of others, regardless of cost to self.[676]

Secondly, assumptions about race and gender matter in the organization of care in homes. For example, often immigrant women are considered to be better caregivers due to what are perceived as cultural values of respect for old age.[677] In Ontario's LTC system, inequities of gender, race, class, and immigration status are built into the care arrangements, shaping exploitation of workers.[678] In many urban facilities, newer immigrant workers, many of whom have nursing qualifications from their countries of origin, work in the most demanding, lower-

---

[672] Tamara Daly et al, "Prescriptive or Interpretive Regulation at the Frontlines of Care Work in the 'Three Worlds' of Canada, Germany and Norway" (2016) 77:0 Labour 37 at 40.

[673] Donna Baines, "Neoliberalism and the convergence of nonprofit care work in Canada" (2015) 19:3 Competition & Change 194 at 196.

[674] *Ibid* at 196–197.

[675] *Ibid* at 198.

[676] *Ibid* at 202.

[677] Palle Storm, Susan Braedley & Sally Chivers, "Gender Regimes in Ontario Nursing Homes: Organization, Daily Work, and Bodies" (2017) 36:2 Canadian Journal on Aging 196 at 198.

[678] Susan Braedley & Gillian Martel, "Dreaming of Home: Long-Term Residential Care and (in)equities by Design" (2015) 95 Studies in Political Economy 59 at 71.

paid RPN jobs, while white, Canadian-born workers dominate management positions.[679] Even more concerning is their encounter with racisms or at the very least, cultural insensitivity, along with harassment and violence.[680] Tensions around gender, culture, race and class are complex in LTC as resident choices have to be balanced with equity considerations.[681]

Thirdly, and related to the previous finding, the very high illness and injury rates in health care among workers are often understood in terms of the attributes of the individual worker or the person requiring care. This includes gender, which is often viewed as an individual characteristic.[682] For Armstrong *et al*, illness and injury rates should not be understood as the inevitable result of care work; rather they can be understood as indicators of structural violence.[683] In an article based on four qualitative research studies of different kinds of care workers in Canada and Australia, workplace violence is gendered with the majority female victims being blamed or self-blaming for the violence, in conjunction with muted or unhelpful institutional responses and requirements to interact again with the abuser soon after the abuse.[684]

The examination of gender and other social locations in care is always tied to critical analysis of larger market and political forces. Scholars have examined issues such as inadequate resources allocation,[685] neoliberalism and the New Public Management (NPM),[686] neoliberal globalization[687] and austerity.[688] By way of example, Baines asserts that NPM has gendered impacts and outcomes as agencies that implement the cutbacks that accompany government contracts, end up relying on the unpaid work of the self-sacrificing, largely female workforce to sustain service levels and care.[689] The point is not that care workers are passive and powerless. Rather, resistance to uncaring management, government and larger society among care workers

---

[679] *Ibid*. See also Roseman, Barber & Neis, *supra* note 584.
[680] Armstrong & Daly, *supra* note 163 at 26–27.
[681] Armstrong, *supra* note 655 at 87.
[682] Armstrong et al, *supra* note 171 at 119; Armstrong, *supra* note 655 at 83.
[683] Armstrong et al, *supra* note 171 at 113.
[684] Baines & van den Broek, *supra* note 670 at 129.
[685] Armstrong et al, *supra* note 171.
[686] Baines, *supra* note 673.
[687] Roseman, Barber & Neis, *supra* note 584.
[688] Baines & van den Broek, *supra* note 670.
[689] Baines, *supra* note 673 at 206.

is uneven due to factors such as educational background and space for resistance in the workplace and in the social values embedded in each subsector.[690]

Feminist political economy is not only concerned with examining the living and working conditions of women. The presence of male workers in LTC homes may present dilemmas in terms of respecting choices and preferences of residents and families. Simply put, researchers heard from staff and residents about resistance to male care providers, which may be further complicated by racism, given that most of the male staff are from racialized communities.[691] An emerging area of research is the experience of racialized men in LTC. According to Palle Storm *et al*, there is limited knowledge about men's experiences in care work, and the dilemmas and opportunities they face in relation to their gender.[692] Their claim is that organizational conditions such as degree of discretion exercised by workers shape how masculine gender positions are produced, understood, and accepted or rejected by other workers.[693] In a study that draws on observations from two Ontario nursing homes and on interviews with direct care workers and managers, the men who work in nursing homes tend to be from working class, racialized, immigrant, and other subordinated groups. They have to find a balance between acceptable expressions of masculinity and required expressions of feminine caring.[694] The authors conclude that male care workers were reported to be accepted more readily and viewed more positively by their women co-workers and residents if the workers are provided with a higher degree of discretion to decide how to complete care work.[695] I will return to the discussion about working conditions later in this section.

4.5.3 **Care as a relationship**

A central concept in the literature is that care is conceptualized as a relationship involving residents, their families and workers.[696] This stands in contrast to the dominant trend in LTC,

---

[690] *Ibid*.
[691] Pat Armstrong, "Families and Choices" in Pat Armstrong & Tamara Daly, eds, *Exercising Choice in Long-Term Residential Care* (Toronto: Centre for Policy Alternatives, 2017) 105 at 109; Armstrong, *supra* note 655 at 86.
[692] Storm, Braedley & Chivers, *supra* note 677 at 196.
[693] *Ibid* at 197.
[694] *Ibid* at 207.
[695] *Ibid* at 206.
[696] Pat Armstrong & Tamara Daly, "Exercising Choices: Ideas Worth Sharing" in Pat Armstrong & Tamara Daly, eds, *Exercising Choice in Long-Term Residential Care* (Ottawa: Canadian Centre for Policy Alternatives, 2017) 121 at 121.

which is “to treat care as a commodity, workers as objects of control, and quality as something that flows naturally from market competition.”[697] In other words, there are similarities between the critique of LTC in the feminist political economy literature and the work of Herring on caring and the law as explained in Chapter 2.

Albert Banerjee and Pat Armstrong expand on the idea of care as a relationship using Annemarie Mol’s logic of care in *The Logic of Care: Health and the Problem of Patient Choice*. Mol rejects the logic of choice, where pre-given individuals are added together to form collectives.[698] According to Mol, the logic of choice assumes that we are autonomous individuals. In contrast, the logic of care is attuned to people who are first and foremost related. While some of these relations cannot be changed, others can.[699] Banerjee and Armstrong advance four inter-related ideas that represent a useful summary of what relational care means. First, relationships are central to the determination of good care for any particular person.[700] Secondly, relationships are understood as a means of delivering good care and doing so safely for both residents and workers.[701] Thirdly, relational care involves the use of individual skills and capacities by workers, for example communication, that can be supported by organizational processes, such as allowing sufficient autonomy for workers to apply their skills. In other words, care is much more than the completion of tasks such as toileting and dressing.[702] Thirdly, the relationality of care includes a nexus of relationships among residents, their family members, other residents, inspectors, other care workers, volunteers, and administrators and these relationships sometimes entail competing values. It follows that care requires empowering strategies that permit needs to be communicated and be heard on the one hand, and the flexibility to balance tensions as much as possible on the other.[703]

Research on the involvement of families of residents is an interesting way to explore relational care. For Armstrong and Daly, the key point is that families should have more choices

---

[697] Banerjee & Armstrong, *supra* note 514 at 9.
[698] Annemarie Mol, *The Logic of Care: Health and the Problem of Patient Choice* (London: Routledge, 2008) at 59.
[699] *Ibid* at 62.
[700] Banerjee & Armstrong, *supra* note 514 at 11.
[701] *Ibid* at 11–12.
[702] *Ibid* at 12.
[703] *Ibid*.

about how, when and in what ways they participate in care.[704] To understand this point, it is important to understand how families may be involved in different aspects of care now. Rachel Barken and Ruth Lowndes explain that family members and friends provide significant support for older relatives in LTC. Many of these unpaid carers are women and they provide and manage body care, offer emotional support, promote social engagement, advocate for residents, oversee the care that staff provide, and contribute resources and ideas.[705] An important nuance is that as Armstrong points out, sometimes families of residents often have little choice about doing the work (such as laundry and bathing) due to low staffing levels and the lack of continuity in staff.[706] Barken and Lowndes use data gathered from rapid ethnography and key informant interviews to identify promising care practices associated with three phases of the LTC trajectory: (1) moving in of a resident, (2) throughout the time a resident was living in a LTC home, and (3) during the final stages of life and after the passing of a resident.[707] They conclude that working conditions needed to support the well-being of family and friend carers as well as residents and staff include: a greater appreciation of relational care work, time for effective communication, teamwork, and finally, appropriate, inclusive physical spaces that make it possible for individuals to spend meaningful time together.[708] Barken and Lowndes' conclusions are similar to those reached by Armstrong, who proposes promising practices such as the establishment of Family Councils that can provide meaningful input into decision- making regarding the operation of homes.[709]

Importantly, scholars attend to contributions made by non-regulated staff, including those staff members who provide so called "ancillary services" such as cleaning and housekeeping, to relational care. Obviously scholars are interested in forms of work organization that foster respectful care relationships between staff and residents, and inspire quality care.[710] For example, Banerjee *et al* study the relational dimensions of nursing home medicine.[711] In a study about

---

[704] Armstrong & Daly, *supra* note 696 at 125–126.
[705] Rachel Barken & Ruth Lowndes, "Supporting Family Involvement in Long-Term Residential Care: Promising Practices for Relational Care" (2018) 28:1 Qualitative Health Research 60 at 60.
[706] Armstrong, *supra* note 691 at 106–107.
[707] Barken & Lowndes, *supra* note 705 at 63.
[708] *Ibid* at 69.
[709] Armstrong, *supra* note 691 at 109.
[710] Baines & Armstrong, *supra* note 514.
[711] Albert Banerjee et al, "Nursing Home Physicians Discuss Caring for Elderly Residents: An Exploratory Study" (2018) 37:2 Canadian Journal on Aging 133.

cleaning staff conducted by Müller *et al*, it is argued that the contributions of cleaning work are related to infection control, the maintenance of a home-like appearance and providing relational care.[712] The researchers found that the important factors that allow cleaning staff to contribute to health and relational care are as follows: a flexible division of labour, team work, training, equipment, staffing and to some extent, autonomy.[713] These factors are reiterated in the research that examines conditions of care.

4.5.4 **Conditions of work are the conditions of care and vice-versa**

It follows that appropriate conditions of work are central to care as a relationship.[714] Accordingly, scholars are particularly interested in exploring how structural issues determine working conditions, such as health care providers' exposure to violence,[715] professional autonomy and teamwork in the workplace,[716] geographic mobility,[717] and social injustices including but not limited to racism and sexism.[718] Again, these issues are examined within a broader context with respect to structural issues in the sector, in particular privatization. A consistent claim in the literature is that the structural aspects of care that set the conditions for care are funding, ownership, and staffing levels.[719]

It is argued that ownership matters for working and living conditions in LTC. Scholars build on earlier systematic reviews of studies investigating quality of care in for-profit versus not-for-profit nursing homes[720] and draw attention to new challenges, such as austerity measures. For-profit, and especially corporate, nursing homes are associated with inferior care when

---

[712] Beatrice Müller, Pat Armstrong & Ruth Lowndes, "Cleaning and Caring: Contributions in Long-term Residential Care" (2018) 43: 1 Ageing International 53.

[713] *Ibid* at 8.

[714] Armstrong & Daly, *supra* note 696 at 121.

[715] Armstrong et al, *supra* note 171.

[716] Katherine Laxer et al, "Comparing Nursing Home Assistive Personnel in Five Countries" (2016) 41:1 Ageing Int 62.

[717] Roseman, Barber & Neis, *supra* note 584.

[718] Susan Braedley et al, "We're told, 'Suck it up': Long-Term Care Workers' Psychological Health and Safety" (2017) Ageing Int 1.

[719] Banerjee & Armstrong, *supra* note 514 at 7; Margaret McGregor & Pat Armstrong, "Chapter 8 Ownership Tensions" in Pat Armstrong & Ruth Lowndes, eds, *Negotiating Tensions in Long-Term Residential Care: Ideas Worth Sharing* (Montreal: Centre for Policy Alternatives, 2018) 83.

[720] For example, see Vikram R Comondore et al, "Quality of Care in for-Profit and Not-for-Profit Nursing Homes: Systematic Review and Meta-Analysis" (2009) 339 BMJ b2732; Michael P Hillmer et al, "Nursing Home Profit Status and Quality of Care: Is There Any Evidence of an Association?" (2005) 62:2 Med Care Res Rev 139; Karen Spilsbury et al, "The Relationship Between Nurse Staffing and Quality of Care in Nursing Homes: A Systematic Review" (2011) 48:6 International Journal of Nursing Studies 732.

compared with their non-profit counterparts.[721] According to Armstrong *et al* in a study about long-term residential care (both LTC homes and retirement homes), privatization—particularly in the form of for-profit care delivery—undermines four aspects of security in old age.[722] Indeed, Armstrong *et al* express strong reservations with respect to market and health care reform: "Faith in markets and the position that health care in particular should be viewed as a commodity have long been driving the push for privatization as the principal route to 'reform'."[723] This push was reinforced by fear of population aging and, mounting public debts and deficits, especially since the 2008 financial crisis.[724]

In Canada, security in access to care is declining along with expansion of for-profit services.[725] For those in need of care in old age, there is no guarantee the needed services will be available, other than those available in the niche market of affluent older adults with limited care needs. As well, eviction is mainly up to the owner in private-pay facilities, as are transfers to hospital.[726] Security in locational access can be undermined by the business going bankrupt, closing or moving to a different location for financial reasons, or by evicting residents or leaving them at emergency rooms.[727] Security of employment for those providing care is vital to quality of care. Indicators of good working conditions are low staff turnover and low staff injury and illness rates. They are more likely to be issues in for-profit chain facilities, where cutting expenses is a focus of efficiency.[728] Most importantly, security in quality of care is also undermined in the process of privatization. Although governments have responded to scandals and complaints with investigations, new legislation and standards, they fail to legislate staffing minimums and mixes, to require appropriate training, to enforce legislation through appropriate inspections and to regulate the sectors that are not directly subsidized.[729] That said, Margaret McGregor and Pat Armstrong are also careful to point out that while summary statistics of facilities indicate more verified complaints, more hospitalizations and lower staffing levels in

---

[721] Armstrong & Daly, *supra* note 163 at 18.
[722] Pat Armstrong, Hugh Armstrong & Krystal Kehoe MacLeod, "The Threats of Privatization to Security in Long-Term Residential Care" (2016) 41:1 Ageing Int 99 at 99.
[723] *Ibid* at 100.
[724] *Ibid*.
[725] Armstrong, Armstrong & MacLeod, *supra* note 722.
[726] *Ibid* at 107–108.
[727] *Ibid* at 104.
[728] *Ibid* at 110–111.
[729] *Ibid* at 110.

for-profit homes compared to non-profit or government ones, individual homes may deviate from this overall pattern.[730]

Some factors internal to a home are important for creating good working conditions. Here are a few examples of promising practices that have been identified by scholars such as Armstrong and Daly that have not yet been addressed elsewhere in this chapter. A well-trained and well-supported staff are seen as necessary prerequisites for quality care.[731] As well, providing enough staff to allow variation from rigid routines and time to take individual differences into account is critical for supporting choices.[732] Further, staff continuity, together with shared decision-making among staff is conducive to responding to resident choices appropriately.[733] Last but not least, where and when they exist, taboo topics and ageist, sexist, racist, homophobic or ableist attitudes should be acknowledged and addressed. Supporting staff in making decisions that allow them to navigate these complex issues in a communal setting also supports residents' choices.[734]

4.5.5 **Regulation including rigidity of workplace**

The last and related to the previous theme is the regulation – not just formal law but also internal rules and technology required for monitoring of activities in homes – of LTC homes. Earlier work on explaining the proliferation of regulation in Ontario and elsewhere and its consequences serves as a useful starting point to illuminate the current regulatory regime in Ontario. Their viewpoints on regulation flow directly from their positions on privatization, ownership, and other structural issues in the sector. To be certain, scholars do not necessarily advocate for de-regulation (in the sense of emphasizing both private property and freedom of contract[735]) but they do have strong criticisms of regulation that aims at facilities and/or care providers.[736] Scholars have explored different aspects of front-line care, such as design

---

[730] McGregor & Armstrong, *supra* note 719 at 87.
[731] Baines & Armstrong, *supra* note 514 at 13.
[732] Armstrong & Daly, *supra* note 696 at 123–124.
[733] *Ibid* at 124.
[734] *Ibid* at 125.
[735] Sunstein, *supra* note 62 at 11.
[736] Baines & Daly, *supra* note 514; Daly, *supra* note 514; Banerjee & Armstrong, *supra* note 514; McGregor & Armstrong, *supra* note 719 at 84.

standards,[737] skill utilization,[738] and organization and division of care work[739] in order to illustrate why, how and under what conditions regulation might actually be detrimental to care.

In an earlier publication, Albert Banerjee is critical of the current state of regulation of LTC homes in Canada (focusing on Ontario), and traces its origin to the place of for-profit corporations in the provision of welfare services. Banerjee rejects reliance on the regulation and documentation of care work as a means of ensuring quality, because regulations tend to change the organization of caring work, constituting it as the completion of predetermined, standardized and documented tasks.[740] Regulation of LTC in Ontario has become ideological, in the sense of a seemingly natural and accepted way of thinking about and responding to problems around quality of care — one that leaves resources, structures and political issues unaddressed.[741] These political issues concern for-profit ownership, resources and the role of the state.[742] The result is that the regulation of care work can detract from quality, paradoxically resulting in calls for further regulation.[743] Banerjee's conclusions are similar to those reached by Pat Armstrong, Susan Bradley and Rosemary Warskett and others.[744]

More recent scholarly work builds on the findings about the linkage between regulation and structural issues and helpfully captures the tensions in balancing competing objectives in and through regulation as well as the nuances in various approaches to regulations. Recent studies include less-studied topics such as dining[745] and music activities[746] in order to interrogate the implications of regulation on care work. The notion of resistance continues to be a common way

---

[737] Braedley & Martel, *supra* note 678.
[738] Pat Armstrong, "Puzzling Skills: Feminist Political Economy Approaches" (2013) 50:3 Canadian Review of Sociology/Revue canadienne de sociologie 256; Armstrong, Armstrong & Daly, *supra* note 163; Barken & Armstrong, *supra* note 464.
[739] Tamara Daly & Marta Szebehely, "Unheard voices, unmapped terrain: Care work in long-term residential care for older people in Canada and Sweden" (2012) 21:2 International Journal of Social Welfare 139.
[740] Banerjee, *supra* note 301 at 205–206.
[741] *Ibid* at 206–207.
[742] *Ibid* at 213.
[743] *Ibid*.
[744] Pat Armstrong, "Chapter 7 Regulating Care: Lessons from Canada" in Gabrielle Meagher & Marta Szebehely, eds, *Marketisation in Nordic Eldercare: a Research Report on Legislation, Oversight, Extent and Consequences* (Stockholm: Department of Social Work, Stockholm University, 2013) 217; Susan Braedley & Rosemary Warskett, "Regulating Care: An Introduction" (2015) 95 Studies in Political Economy 3; Braedley & Martel, *supra* note 678.
[745] Ruth Lowndes, Tamara Daly & Pat Armstrong, "'Leisurely Dining': Exploring How Work Organization, Informal Care, and Dining Spaces Shape Residents' Experiences of Eating in Long-Term Residential Care" (2018) 28:1 Qual Health Res 126.
[746] Daly et al, *supra* note 672.

to articulate responses from workers and homes when facing regulatory rigidities.[747] It should also be noted that more comparative studies are now available to highlight the diversity of promising and not-so-promising practices across the globe. In advancing eight practices that promote care as a relationship, Baines and Armstrong summarize a general argument in the literature well: there is a "need for adequate funding and for rules that set goalposts and guidelines but do not micromanage through standardization and the removal of staff initiative and discretion."[748]

Some scholars adopt a comparative focus in their analysis in order to illustrate alternatives to highly prescriptive regulation and rigid organization of care work.[749] Scholars attempt to demonstrate the link between extent of privatization in the sector and the need for more regulation, auditing and reporting. Generally speaking, jurisdictions with higher rates of privatization (mostly the liberal welfare regimes such as those in the U.S) have more standardized, complex and deterrence-based regulatory approaches.[750] In a study of frontline care work in Canada, Germany and Norway, Daly *et al* investigate how regulatory frameworks affect workers' responses.[751] They advance two concepts at opposite ends of the interpretation continuum: prescriptive regulation and interpretive regulation.[752] Prescriptive regulation is defined as "a tendency to identify which staff should do what work and when and how they should do it" while interpretive regulation "reflects a tendency to broadly define care but not which staff should do it, nor when and how they should do it."[753] One key finding is that the prescriptive regulations (Ontario sites) did not promote a high standard of relational care, nor did they promote good working conditions. Rather, prescriptive regulations promoted reactive work organization.[754] On the other hand, the flow of the day was calmer in the German and Norwegian sites (representing examples of interpretative regulation) where there was less paperwork and more time to provide health and social care.[755] They caution that de-professionalizing the LTC

---

[747] *Ibid*; Baines & Daly, *supra* note 514; Baines & van den Broek, *supra* note 670.
[748] Baines & Armstrong, *supra* note 514 at 23.
[749] Daly et al, *supra* note 672; Choiniere et al, *supra* note 515.
[750] Choiniere et al, *supra* note 515; Daly et al, *supra* note 672.
[751] Daly et al, *supra* note 672.
[752] *Ibid* at 38.
[753] *Ibid*.
[754] *Ibid* at 71.
[755] *Ibid* at 68.

sector may increase the need for prescriptive regulation, which in turn, hinders the provision of good quality, flexible care.[756]

Recall that a long-standing theme in the literature is that working conditions are care conditions. Regulation is considered to be part of "conditions of work and care".[757] It is argued that one way that regulation could potentially be beneficial is a mandated minimum number of staffing hours per resident. However, such a mandated standard has not yet been adopted in Canadian provinces.[758] Drawing on practices from around the world, three main observations can be made about how regulation should and should not look like in LTC in order to promote quality of life for residents and safe working conditions. First, there is a growing tension between basic trust and detailed regulations.[759] The increasingly detailed regulations at the level of the home have not been shown to result in significantly better quality and often result in more time for documentation, resulting in less time for care.[760] Again, it is argued that ownership has an impact on the type of regulation and its enforcement.[761] As for-profit ownership becomes more prevalent, profit-making rather than care may become a driving interest and accordingly, more regulation is required. The result is less trust in staff, and greater need for reporting, inspection and regulation.[762] Second, Armstrong and Baines propose that "standards (principles) that are effectively enforced and funded"[763] is one of the promising practices. Standards are distinguished from standardisation and regulation. In particular, standards establish principles and allow individual care providers to make decisions in an equitable and evidence-informed manner.[764] In contrast, "standardisation, which tends to underlay regulation, means one right way exists."[765] The claim is that in the context of principles, there is more room for individualised care for residents (and therefore meeting individual needs and preferences) and worker discretion and autonomy.[766] Third, regulatory systems should strike a balance between risk and safety,

---

[756] *Ibid* at 71.
[757] Baines & Armstrong, *supra* note 514 at 6.
[758] McGregor & Armstrong, *supra* note 719 at 84.
[759] Armstrong, *supra* note 655 at 79.
[760] *Ibid* at 81.
[761] Armstrong & Daly, *supra* note 163 at 19.
[762] McGregor & Armstrong, *supra* note 719 at 84.
[763] Baines & Armstrong, *supra* note 514 at 8.
[764] *Ibid* at 12.
[765] *Ibid*.
[766] *Ibid* at 12–13.

accountability and autonomy, and finally, medical and social care. In particular, too great emphasis on safety and accountability frequently results in standardization reflected in rigid schedules, limited activities and few options for either residents or staff.[767]

4.5.6 **Summary**

My research is informed by and builds on the themes in the feminist political economy literature in three main ways. First, since working conditions are caring conditions, I will expand on this theme by providing updates on recent (albeit limited) efforts to address violence experienced by health care workers in Ontario. This will be linked to the work of Herring and Nedelsky in order to explain why an exclusive focus on the rights of residents to a safe and secure home is not effective in the protection of residents. The problem is, as I will show in Chapters 6 and 9, the safety of workers has not been adequately addressed as integral to the safety of residents. My contribution will be centred around the legal protections currently available to workers (e.g. whistleblower protections) under the LTCHA and can be used to compare with similar protections in other jurisdictions in order to extend the debate about working conditions.

Secondly, feminist political economy scholars are correct to point out that LTC is a gendered space and have also attended to other social locations such as race, citizenship and immigration status in order to expose inequity and inequality. However, disability has not received as much attention as other social locations, but there are exceptions.[768] In a recent article about balancing tensions that are central to reimagining LTC, Armstrong refers to a tension between ability and disability when she discusses autonomy of residents: "How can we balance the need to allow people to live to the full extent of their capacities and maintain or even improve those capacities while recognizing that they have significant incapacities?"[769] My research also recognizes this tension and engages disability in a more substantive way, for example, by integrating the criticisms of care outlined in Chapter 2. Care ethics scholarship has been influential in the debates in the feminist political economy literature.[770] And feminist

---

[767] Armstrong & Daly, *supra* note 696 at 122.

[768] Chivers, *supra* note 239.

[769] Armstrong, *supra* note 655 at 83.

[770] For example see Baines & Daly, *supra* note 514; Daly & Szebehely, *supra* note 739; Müller, Armstrong & Lowndes, *supra* note 712; Banerjee & Armstrong, *supra* note 514.

political economists have already written extensively on the concepts of choice and autonomy,[771] which are of great significance to disability scholars and activists. A more balanced view of care is possible if the views of disability scholars are also incorporated in the analysis.

Thirdly, I will expand on the theme of tensions embedded in the more and more detailed regulations, reporting requirements and enforcement techniques. The existing studies have already thoroughly examined how front-line care (including practices that matter to care such as security and scheduling) is regulated and the impact of this type of regulation on quality of care while structural issues such as minimum standard of care remain outside of the reach of formal law to a large extent. But other topics of the LTC regulatory framework remain under-examined, such as legally mandated participation mechanisms for residents and families and consumer protection measures. As well, for some of the extensively written topics, such as regulation of safety of residents, the analysis would benefit from adding the constitutional and quasi-constitutional context, such as the *Canadian Charter of Rights and Freedoms*. In doing so, I will be able to provide a more comprehensive review of how different aspects of care (not just front-line or hands-on care) is regulated in Ontario. This Ontario case serves as exploratory study of other topics in the regulation of LTC and generates potential research questions for case studies in other provinces and territories.

4.6 Conclusion

LTC is a type of social policy and likewise is not immune from the increasing legal complexity of the modern welfare state. The preceding pages show a LTC sector that has been responding to a number of changes in the LTC sector and the broader health care system in Ontario between 2004 and 2018. A key change obviously is the implementation of the LTCHA, which should be seen as a milestone in the relatively short history of formally regulating LTC (as we understand it today). At the centre of the recent regulatory changes is the diverse group of residents living in very different homes across Ontario: older, more frail and more likely to be women. The fact that the residents are now older and more frail than their predecessors has significant implications for the funding and regulation of the sector. But it will be a mistake to

---

[771] Pat Armstrong & Tamara Daly, *Exercising Choice in Long-Term Residential Care* (Ottawa: Canadian Centre for Policy Alternatives, 2017).

ignore those around the residents - formal and informal caregivers, family and friends – if we accept Herring’s idea that caring is about relationships and individual acts of care can only be understood in the context of the relationship between parties involved in care. Many themes in the feminist political economy literature exemplify this point.

The challenge is to decipher how the law respond to the needs of the residents and those around them. In the next four chapters, I turn to a more detailed exploration of the regulatory changes that affect the LTC sector in Ontario between 2004 and 2018. The scholarly debates explored above and previously in Chapter 2 are instrumental in the identification of the themes of the regulatory changes to be discussed in the next four chapters. I propose that to understand the implications of regulatory changes for residents and those around them, four themes of changes can be identified: rights and entitlements to quality “care”, respect for safety and security of the person, inclusion and participation in decision-making and tensions in the state / citizen (consumer) relationship.

5 Rights and Entitlement to Quality "Care"

5.1 Introduction

Recall the conceptualization of care that I offered in chapter 2: First, care is grounded in caring relationships and is fundamentally important for human survival; that care embodies intermingled needs and interests of all involved in caring relationships but must also recognize the actual and potentials for harm in caring. Second, caring relationships are constructed by law in many different ways and the promotion of caring relationships is simultaneously limited by current legal tools such as "rights". Third, caring relationships are shaped by the administrative processes and legal structures of public benefit schemes and regulatory regimes, many of which are indicative of the role of the state in supporting or neglecting care regardless of the setting in which care occurs.

This chapter queries how care in LTC has changed in Ontario as a result of the implementation of the LTCHA and other statutory changes from a "law on the books" perspective. This chapter seeks to reveal the ways in which the government attempted to use social regulation to control quality of care as a policy objective between 2004 and 2018. Quality of care is a controversial matter in the feminist political economy literature.[772] By way of example, scholars question how quality is being measured as well as policy rhetoric such as "person-centred care". These criticisms will be referenced below.

This chapter is divided into three sections: the first section will explore what care means in the context of LTC; the second section will examine how care is delivered; and third section will examine how disability is accommodated in care delivery. The description below demonstrates that at the core of the changes to improve care is the notion that residents' medical and clinical needs must be met by highly prescriptive requirements (i.e., what must be done and how). These requirements are tied to the more proactive dissemination of norms in the form of residents' rights, and to the idea that these rights should be enforceable. Quality of care, if understood more narrowly in relation to residents' physical and clinical needs, is also supported

---

[772] For example see Baines, *supra* note 673 at 198.

by ad hoc accommodation of certain types of disabilities. The discussion about care here will set the context for other regulatory changes in subsequent chapters.

In this chapter, I argue that the caring relationship between residents and their formal care providers has not changed substantively with the implementation of the LTCHA and other statutory amendments. It is true that some progress has been made in terms of accessibility and accommodation of disabilities more generally. In the context of LTC, the caring relationship continues to be defined on the one hand by rights and entitlements for individual residents and on the other, standardized program requirements and health sector initiatives such as "person-centred care". My reading of the changes is that they were few in substance and more in legal form, however, to some extent, they respond to the disability scholars' criticisms of care. These changes can be interpreted as a way to communicate the idea that disabled people have the right to support and that they should have some control and choice over how their care is provided – an objective that disability scholars have reiterated.[773] The problem is that care – very much defined and described in relation to tasks or activities in the provisions described here but there are some exceptions– continues to be based on a medical model of disability and focuses on the needs associated with the physical survival of residents, rather than the promotion of caring relationships.

5.2 What is care in LTC?

In essence, care is expressed legally in the language of individual rights and entitlements to services.[774] At the core of care requirements in the LTCHA is the Residents' Bill of Rights,[775] supported by the Home Principle[776] and the Preamble.[777] It is evident that the expansion of resident rights is limited and arguably sets the context of other rights and entitlements related to receipt of care. Care must be individualized and therefore resident choices and preferences must be respected.[778] Care is intended to address medical and clinical needs as well as dietary, social

---

[773] Morris, *supra* note 197.

[774] Lai, *supra* note 637.

[775] *Long-Term Care Homes Act, supra* note 425, s 3.

[776] *Ibid*, s 1.

[777] "A preamble to a new Act is part of that Act and may be used to help explain its purpose." *Legislation Act, 2006,* SO 2006, c 21, Sched F, s 69.

[778] Lai, *supra* note 637.

care and housing (shelter) needs. The remaining section is a close study of the rights and entitlements that constitute care.

5.2.1 Care as individual rights and entitlements

Recall that the rights discourse is a matter of contention in the disability scholarship.[779] Being left without necessary care, as Kröger explains, is an expression of a limited social citizenship and a serious breach of a person's human right to a life with dignity.[780] It follows that the question is whether the formal expansion of rights will give demands for adequate and appropriate care a more solid basis. Here I will consider how the language of individual rights and entitlements for services is engaged in the LTCHA, compared to the previous *Nursing Homes Act*.

5.2.1.1 Changes to the Residents' Bill of Rights

The rights ehshrined in the Bill of Rights relate to the care, treatment, living circumstances, and participation of residents in homes and can be enforced like a contract.[781] As we will see below, the requirements about care should be interpreted with the Residents' Bill of Rights[782] and it is useful to begin with the sources of rights in the Bill. These rights are not new in the sense that they existed in other legal instruments not specific to LTC. In fact, many rights in the Bill build on the fundamental rights, protections and freedoms that residents enjoy as citizens and the Bill articulates them in the LTC context. For example, "Every resident has the right to pursue social, cultural, religious, spiritual and other interests, to develop his or her potential and to be given reasonable assistance by the licensee to pursue these interests and to develop his or her potential."[783] This right reflects the expectations articulated in the *International Convention on the Rights of Persons with Disabilities*, *Canadian Charter of Rights and Freedoms*, the *Human Rights Code of Ontario*, *Personal Health Information Protection Act* and the *Accessibility for Ontarians with Disabilities Act, 2005*. Other rights may be characterized as

---

[779] For a summary see Kröger, *supra* note 156 at 412–414.
[780] *Ibid* at 414.
[781] *Long-Term Care Homes Act*, *supra* note 425, s 3(3).
[782] "The LTCHA, the Regulation, and any agreements between the Home and the Crown or between the Home and the resident must be interpreted in a way that advances the respect of the resident's rights." Ministry of Health and Long-Term Care, *A Guide to the Long-Term Care Homes Act, 2007 and Regulation 79/10* (Toronto: Ministry of Health and Long-Term Care, 2010) at 2–1.
[783] *Long-Term Care Homes Act*, 2007, *supra* note 425, s 3(1)23.

"service rights"[784] i.e., rights that residents enjoy when they receive care. An example is "Every resident who is dying or who is very ill has the right to have family and friends present 24 hours per day."[785] A good starting point for understanding how these rights evolved is to compare the content of the Residents' Bill of rights under the *Nursing Homes Act* and the LTCHA.

The *Nursing Homes Act* contained a Residents' Bill of Rights that included 19 rights (clauses) which were substantially the same as the LTCHA. They ranged from very tangible entitlement (such as the right to live in a safe and clean environment[786]) to more intangible (but no less important) rights (such as the right to form friendships and enjoy relationships[787]). Some rights were procedural (such as the right to be informed of any law, rule or policy affecting the operation of the home[788]), while others were substantial in nature (such as the right to be properly sheltered, fed, clothed, groomed and cared for[789]). The *Nursing Homes Act* also enshrined the ability of residents to enforce their rights as if a contract had been entered into between the resident and the home.[790] In the Program Manual, the Bill of Rights was incorporated into one of the "Resident Safeguards" standards: "There shall be mechanisms in place to promote and support residents' rights, autonomy and decision-making."[791]

In the LTCHA, the Residents' Bill of Rights contains 27 rights (clauses). However, this should not be interpreted as an additional eight rights for residents: "The Residents' Bill of Rights expands on and strengthens the rights which existed in the legislation that governed Homes before the LTCHA."[792] In general, the majority of these additional rights are wording clarifications and expansions of the scope of existing rights or guidance in the Program Manual. It is commendable that some of the rights do address relations in the home (such as a resident's

---

[784] Kerri Joffe, *Enforcing the Rights of People with Disabilities in Ontario's Developmental Services System* (Toronto: Law Commission of Ontario, 2010) at 4. Joffe uses the term "service rights" to denote those rights that relate to the day-to-day lives of people with intellectual disabilities and the specific developmental services and supports they receive. They are distinguished from the fundamental rights, freedoms and protections provided for in the *Canadian Charter of Rights and Freedoms*, federal, provincial and territorial human rights codes, and other legislation.

[785] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 3(1)15.

[786] *Nursing Homes Act,* RSO 1990, c N.7, s 2(2)18 [*Nursing Homes Act*].

[787] *Ibid*, s 2(2)13.

[788] *Ibid*, s 2(2)16.

[789] *Ibid*, s 2(2)2.

[790] *Ibid*, s 2(5).

[791] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 0902-01, page 1.

[792] Ministry of Health and Long-Term Care, *supra* note 782 at 2–1.

right to have any friend or family member or other person attend any meeting with the home or staff of the home) and in theory, should help residents to maintain and establish relations. One could argue that the Bill recognizes that relationships, not just medical care or other care activities, are an important part of a resident's life in LTC. Rights which are new or amended are summarized in the table below:[793]

Table 13: Comparison of the Resident's Bill of Rights under the *Nursing Homes Act* and the LTCHA

Changes	***Nursing Homes Act***	***LTCHA***
Right to participate in plan of care	Opportunity to participate fully in the development and revision of the resident's plan of care[794]	Right to participate fully in the development, implementation, review and revision of his or her plan of care[795]
Right to receive care and assistance towards independence	Consistent with individual's requirements[796]	Based on a restorative care philosophy[797]
Right to meet privately in a room that assures privacy	With spouse[798]	With spouse or anybody[799]
Right to have family members present	When death is imminent[800]	When dying or very ill[801]
Personal health information	Kept confidential in	Kept confidential

---

[793] See also Jane Meadus, *ACE Newsletter Special Insert "A Brand New World: Ontario's New Long-Term Care Homes Act"* (Toronto: Advocacy Centre for the Elderly, 2010).
[794] *Nursing Homes Act*, *supra* note 786, s 20.1(d).
[795] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 3(1)11.
[796] *Nursing Homes Act*, *supra* note 786, s 2(2)7.
[797] *Long-Term Care Homes Act*, *supra* note 425, s 3(1)12.
[798] *Nursing Homes Act*, *supra* note 786, s 2(2)14.
[799] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 3(1)21.
[800] *Nursing Homes Act*, *supra* note 786, s 2(2)10.
[801] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 3(1)15.

Changes	***Nursing Homes Act***	***LTCHA***
	accordance with law[802]	Have access to their records in accordance with law[803]
Right to have any friend or family member or other person to attend any meeting with the home or staff of the home	None	Yes[804]
Right of individuals to have their lifestyles and choices respected	None	Yes[805]
Use of restraints	Right to be fully informed about the procedure and the consequences of receiving or refusing them.[806]	Rights not to be restrained (except as allowed by law)[807]

5.2.1.2 Right to respect for individual preferences and choices in care

A related idea is that care must involve choices and respect for individual preferences, including cultural and religious preferences. The LTCHA has not changed substantively but a few changes are notable. As noted in the chart above, a new right in the Bill of Rights is the right of individuals to have their lifestyles and choices respected.[808] In particular, the LTCHA formalizes some of the requirements about respecting choices and preferences previously expressed only in the Program Manual. Although the *Nursing Homes Act* and its regulation did not have explanation about individual preference (other than in the plan of care), the Program

---

[802] *Nursing Homes Act*, *supra* note 786, s 2(2)(6)iv.
[803] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 3(1)11.
[804] *Ibid*, s 3(1)27.
[805] *Ibid*, s 3(1)29.
[806] *Nursing Homes Act, supra* note 786, s 2(2)8.
[807] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 3(1)13.
[808] *Ibid*, s 3(1)19.

Manual provided considerable guidance on how to respect individual preferences, most of the guidance was located in the part about resident care and services standards and criteria. For example: "Each resident is provided with choices about his/her daily routine (e.g., bath or shower, time of activity, food preferences, amount of food, clothing, and involvement in programs).[809] For many programs, it was emphasized that resident preferences must be respected. "Each resident shall have opportunities and assistance to participate in programs which are appropriate to his/her cognitive status, interests and preferences, both within the LTC home and in the community."[810] The LTCHA clarifies that the resident can choose the methods of bathing, and alternative meal and beverage choices.[811] The preferences of a resident must be respected in a number of ways such as dressing and bedtime and rest routine.[812] But since certain details about programs have been dropped, there are simply fewer requirements about respecting preferences under the LTCHA.

It should be noted that the notions of choice (and the related concept of autonomy) as well as rights are also embedded in soft law as important values that should guide the behaviours of providers. Most often choice is implied in guidance about autonomy in treatment decision-making, for example, the College of Physicians and Surgeons of Ontario (CPSO), which regulates the practice of medicine in Ontario, states that physicians embody the values of compassion, service, altruism and trustworthiness and uphold the reputation of the profession by respecting patient autonomy with respect to health-care goals, and treatment decisions.[813] The College of Nurses of Ontario (CNO) identifies that client well-being and client choice as primary values[814] and reiterates these values in different guidelines. Similarly, Accreditation Canada states that one of four values that are fundamental to a resident- and family-centred care is dignity and respect: "Listening to and honouring resident and family perspectives and choices. Resident and family knowledge, values, beliefs, and cultural backgrounds are incorporated into

---

[809] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 0902-02, page 3.
[810] *Ibid* at Tab 0903-01, page 16.
[811] General, O Reg 79/10, ss 33, 71 [O Reg 79/1*0*].
[812] *Ibid*, ss 40, 41.
[813] College of Physicians and Surgeons of Ontario, *Policy Number: #3-15: Consent to Treatment* (Toronto: College of Physicians and Surgeons of Ontario, 2015).
[814] CNO has identified the following values as being most important in providing nursing care in Ontario: client well-being; client choice; privacy and confidentiality; respect for life; maintaining commitments; truthfulness; and fairness. College of Nurses of Ontario, *Practice Standard: Ethics (Pub. No. 41034)* (Toronto: College of Nurses of Ontario, 2009) at 4.

the planning and delivery of care."[815] Also, Accreditation Canada reiterates the LTCHA's expectations about offering choices to residents in their daily routine such as dinning and respecting their choices in care.[816] The notions of choice and rights may be discussed as guidance for professionals to balance competing demands. The CNO explains the meaning of and limits on client choice: "Client choice means self-determination and includes the right to the information necessary to make choices and to consent to or refuse care. Clients know the context in which they live and their own beliefs and values. As a result, when they have the necessary information, they can decide what is best for themselves." Further, the CNO stresses that there are limits to client choices, with emphasis on the boundaries of law and professional obligations to prevent harm to client and others.[817]

Another point about care is that it should be individualized. At the core of individualized care is the idea that care must be based on assessed needs of individual residents, in relation to their illnesses, capabilities and functionalities. The entitlement to individualized care is not a new concept but simply formalized in law. While the *Nursing Homes Act* and its regulation did not mention individualized care other than stipulating that a resident's individuality must be recognized,[818] the Program Manual contained specific guidance on individualized care in the areas of continence care,[819] skin care,[820] recreation and leisure service,[821] therapy services,[822] medical care,[823] and nutritional care.[824] Some of the guidance was elevated from Program Manual to regulation under the LTCHA such as guidance pertaining to: personal care,[825]

---

[815] Accreditation Canada, *Standards: Long-Term Care Services (Ver. 11)* (Ottawa: Accreditation Canada, 2016) at 1.
[816] *Ibid* at 63.
[817] "There are limits to client choice. For instance, clients do not have the right to choose to endanger the safety of others. Client choice may be restricted by policies that promote health . . . Client choice is also influenced by the resources available in a particular situation. There may be situations in which clients request nurses to perform an act that is illegal or may cause serious harm. In these situations, nurses need to inform clients, in a nonjudgmental manner, about the potential risks and harm associated with the practice, or that the practice is illegal in Canada or Ontario. By exploring the implications of the request and providing education and support to clients, nurses have a better chance of preventing a practice that has a risk of harm." College of Nurses of Ontario, *supra* note 814 at 6.
[818] *Nursing Homes Act*, *supra* note 786, s 2(2)1.
[819] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 0903-01, page 4, 5 and 12.
[820] *Ibid* at Tab 0903-01, page 19.
[821] *Ibid* at Tab 1003-01, page 1.
[822] *Ibid* at Tab 1006-01, page 1.
[823] *Ibid* at Tab 1002-01, page 1.
[824] *Ibid* at Tab 1014-01, page 5.
[825] *O Reg 79/10*, *supra* note 811, s 32. See also Ministry of Health and Long-Term Care, *supra* note 782 at 2–22 to 2–23.

continence care products,[826] bedtime and rest routines,[827] menu planning[828] and on-site physiotherapy.[829] It should be noted that even if the new regulatory framework does not mention individualized care as much as the Program Manual, that does not necessary mean care in those areas such as skin care is not supposed to be individualized anymore. Professional guidelines also refer to individualized care[830] or individualized care plan.

It is also important to highlight what has not been changed either substantively or in legal form. In addition to the more abstract and subjective rights, there are also entitlements in the form of specific discreet services or activities. In some care categories, a few concrete and quantifiable care standards could be identified, such as a minimum of three meals and snacks between meals,[831] a minimum of two baths or showers per week[832] and an annual physical examination.[833] These quantifiable standards continue in the new regime, sometimes with slight modifications.

5.2.2 **Meeting Bodily Needs**

In the feminist political economy literature, one topic is how care needs are being met (or not) including body work[834] and the tensions that may be involved, such as autonomy of workers in meeting the needs of residents vs management and community control.[835] One way for the government to influence body work, medical care and other tasks involved in care is to create more formal care categories or programs in order to name and define what a home has to deliver and by extension, what the government is willing to pay for.

The *Nursing Homes Act* and its regulation attempted to capture key aspects of care by addressing the delivery of nursing and medical services, activities of daily living, and to a lesser extent, social care. The premise appeared to be that quality of care could be achieved by

---

[826] *Ibid*, s 51(2)(b). See also *Ibid* at 2–31.
[827] *Ibid*, s 41.
[828] *Ibid*, s 71(5).
[829] *Ibid*, s 59(a).
[830] Registered Nurses' Association of Ontario, *Promoting Safety: Alternative Approaches to the Use of Restraints* (Toronto: Registered Nurses' Association of Ontario, 2012) at 22. "The philosophy of individualized care is foundational to the therapeutic nurse patient relationship."
[831] RRO 1990, Reg 832: General, ss 75(1)(a), 75(1)(e) [Reg 832].
[832] *Ibid*, ss 56(9), 56(9.1).
[833] *Ibid*, s 51.(4)(b).
[834] Daly & Szebehely, *supra* note 739.
[835] Baines & Armstrong, *supra* note 514 at 12–13; Armstrong, *supra* note 655 at 83–86.

specifying broad categories of care (some are in the form of programs) to which residents were entitled, such as nursing care,[836] laundry,[837] recreation and social programs,[838] and nutrition care[839] in law. The detailed descriptions of these and other categories were mostly contained in the Program Manual, rather than the *Nursing Homes Act* and regulation.

The LTCHA and its regulation respond to the perceived deficiencies in quality of care (see Chapter 4) in a number of ways. The LTCHA definition of care is as follows: "“care” includes treatment and interventions”.[840] To begin with, care is further differentiated and more categories of care have been introduced. For example, the category of “personal support services” is now separate from “nursing care” and is defined.[841] Residents are also entitled to more types of care. For example, “foot care and nail care”,[842] “End-of-life care / palliative care”, [843] “hydration program”,[844] “pain management”[845] and “organized program for religious and spiritual practices”[846] are some of the new prescribed categories of care that homes must deliver. But these new categories were simply elevated from the Program Manual to regulation or statute with further guidance to provide greater legal certainty to residents. For example, the Program Manual included requirements about cutting nails and O Reg 79/10 reflects such a requirement and the LTCHA Guideline further explains that residents cannot be charged for basic foot and nail care, including the cutting of toenails and fingernails.[847] It should be noted that many of the details about how care should be provided are in soft law. For example, the RNAO has guidelines that can be used to implement care described in the LTCHA such as assessment and management of pain, end of life care, continence and pressure ulcer.[848] Similarly, the Canadian Patient Safety Institute (CPSI) has guidelines about fall prevention and medication

---

[836] Reg 832*, supra* note 831, ss 1, 56(8).
[837] *Ibid*, s 22.
[838] *Ibid*, s 72.
[839] *Ibid*, ss 74 -77.
[840] *Long-Term Care Homes Act, 2007, supra* note 425, s 2(1).
[841] *Ibid*, s 8(2).
[842] O Reg 79/10, ss 35(1)-(2).
[843] *Ibid*, s 42.
[844] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 11(b); *O Reg 79/10*, *supra* note 811, s 68(1).
[845] O Reg 79/10, *supra* note 811, s 52.
[846] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 14.
[847] Ministry of Health and Long-Term Care, *supra* note 782 at 2–24.
[848] Registered Nurses’ Association of Ontario, “Clinical Best Practice Guidelines | Long-Term Care Best Practices Toolkit, 2nd edition”, online: <http://ltctoolkit.rnao.ca/clinical-topics>.

management.[849] It is possible that law simply gives deference to the regulated professionals to follow their respective guidelines.

However, it should be noted that some requirements have been eliminated under the new regime (regulatory contraction). Certain details about the following programs have been dropped:

- social and recreation program (e.g. purposes of the program);[850]
- accommodation (e.g. homes have to provide dry cleaning)[851]
- nutrition and hydration (e.g. number of servings of vegetables).[852]

Another point about meeting medical and clinical needs is that residents are being measured, monitored and reported on a regular basis. This is not simply a regulatory change but is also the government's use of other non-regulatory tools in an attempt to influence quality of care. There are statutory requirements to measure, monitor, and report on residents by way of care plans and various documentation requirements, for example, in relation to responsive behavior (to be discussed in Chapter 6). But there has to be the necessary infrastructure to enable the implementation of these statutory requirements. The implementation of Resident Assessment Instrument - Minimum Data Set (RAI-MDS)[853] is a good example how regulatory and non-regulatory tools are intertwined to influence delivery of care. The RAI-MDS is now the "standardized assessment tool for admission, quarterly assessment, significant change in health status and annual assessments for each resident."[854] Specifically, this tool captures information about a resident's functioning, mental and physical health, social support and service use.[855] All LTC homes in Ontario have submitted data to the Canadian Institute for Health Information (CIHI) on a quarterly basis since 2009.[856]At the time of implementation, MOHLTC characterized

---

[849] Canadian Patient Safety Institute, *Medication Reconciliation in Long-Term Care Getting Started Kit (version 3)* (Ottawa: Canadian Patient Safety Institute, 2015); Canadian Patient Safety Institute, *Reducing Falls and Injuries from Falls – Getting Started Kit* (Ottawa: Canadian Patient Safety Institute, 2015).
[850] Ministry of Health and Long-Term Care, *supra* note 545 at 1003–02, page 1.
[851] *Ibid* at Tab 1013-01, page 8.
[852] Reg 832, *supra* note 831, s 76(1)2.
[853] For a critical view, see Daly, *supra* note 514 at 48.
[854] Ministry of Health and Long-Term Care, *RAI-MDS 2.0 LTC Homes – Practice Requirements* (Ministry of Health and Long-Term Care, 2007).
[855] Health Quality Ontario, "Measuring Long-Term Care Homes", (2017), online: <http://www.hqontario.ca/System-Performance/Measuring-System-Performance/Measuring-Long-Term-Care-Homes>.
[856] *Ibid*.

the assessment tool as follows: "It's a really significant assessment tool that not only helps with benchmarks, but just helps them manage people's care better so that they don't deteriorate while waiting for care. They're actually assessed quickly and they can get occupational therapy, physiotherapy, what-ever the individual requires, at the home and right from the hospital as well."[857] Further, the quality indicators derived from the RAI-MDS "have the advantage of having been captured right at the bedside by the care teams and then aggregated up through the system."[858] As we will see in subsequent chapters, the use of quality indicators is highly controversial and reveals assumptions about our understanding of risks in LTC.

The last point about meeting medical and clinical needs is that there is an increasing emphasis on care should be "inter-disciplinary" and "multi-disciplinary". While the previous regime also required inter-disciplinary review of care plans and care conferences[859] and inter-disciplinary approach to specific types of care (e.g. skin care), the new regime formalizes these approaches in law. All the required programs must be interdisciplinary,[860] weight assessment has to be interdisciplinary[861] and restorative care also has to be interdisciplinary.[862] This formalization may simply reflect a longer term shift towards an inter-disciplinary approach to care (as an ideal or objective) in professional standards.[863] Some of the guidelines reviewed also refer to "inter-disciplinary" teams.[864] This apparent emphasis on inter-disciplinary care stands in contrast to the rigid division of labour depicted in the feminist political economy literature.

5.2.3 **Housing (or Shelter) Needs**

Although LTC is a basket of medical, personal assistance, dietary and social services, it is also intended to address the housing (or shelter) needs of residents. In particular, regulation is intended to address the challenges of congregate (or communal) living while respecting individual preferences and providing choices. Both old and new frameworks emphasize facilities

---

[857] Ontario, Legislative Assembly (Standing Committee on Public Accounts), *Official Report of Debates (Hansard)*, 39th Parl, 2nd session, (12 May 2010) at 109.

[858] *Ibid.*

[859] Reg 832, ss 127(1)-(2).

[860] O Reg 79/10, *supra* note 811, s 78(1).

[861] *Ibid*, s 69.

[862] *Ibid*, s 56. *Long-Term Care Homes Act, 2007*, *supra* note 425, s 9(1).

[863] One of the objects of a health profession regulatory college is "To promote inter-professional collaboration with other health profession colleges." *Regulated Health Professions Act, 1991*, *supra* note 61, s 3(1)9.

[864] Canadian Patient Safety Institute, *supra* note 849 at 27, 40 and 61. Accreditation Canada, *supra* note 815 at 25.

are primary the homes of residents and some considerations must be made to balance the safety and security rights of different people living / working in the home. The Program Manual states: “Risks to each resident's health and safety shall be identified and addressed in ways that consider his/her choice, freedom of movement, dignity and respect, in keeping with other residents' rights.”[865] Similarly, the rights to decorate his / her room and to keep a rest routine are also subject to respecting other residents’ rights.[866]

The legislative intent of balancing of competing interests in terms of individual vs. collective is more obvious in the new act. In the LTCHA’s preamble:

> The people of Ontario and their Government:
>
> . . . Strongly support collaboration and mutual respect amongst residents, their families and friends, long-term care home providers, service providers, caregivers, volunteers, the community and governments to ensure that the care and services provided meet the needs of the resident and the safety needs of all residents.

During clause-by-clause consideration of Bill 140, the Parliamentary Assistant explained the rationale behind this clause when responding to requests to amend the Bill of Rights to reflect collective rights: “… that mutual respect in the preamble allows for the homes to have something to turn to, should they need to address a concern around a collective right versus bill of rights situation in a home . . . We address the issue by addressing not only the residents but their family and friends, which I think goes some way to addressing the concern that has been raised about individual versus collective rights.”[867] One way this debate unfolds is around safety and security of residents as well as those who work and volunteer in the home. The underlying tensions will be explored in subsequent chapters.

5.2.4 **Summary**

The table below summarizes the changes:

---

[865] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 1011-01, page 7.

[866] *Ibid* at Tab 0902-01 page 3, Table 0903-01 14 and 19.

[867] Ontario, Legislative Assembly (Standing Committee on Social Policy), *Official Report of Debates (Hansard)*, 38th Parl, 2nd session, (30 January 30 2007).

Table 14: Key changes about care under the *Nursing Homes Act* and the LTCHA

	Nursing Homes Act	**LTCHA**
Rights and entitlements	Bill of Rights Guidance on how to respect individual preferences provided in the Program Manual	Bill of Rights - Wording clarifications and expansions of the scope of existing rights or guidance in the Program Manual Respect for individual preferences and choices in care more formalized
Meeting bodily needs	Much guidance in the Program Manual	Care is further differentiated and new categories of care elevated from the Program Manual to regulation or statute New IT system to monitor, track and measure residents Emphasis on care should be “inter-disciplinary” and “multi-disciplinary” formalized
Housing Needs	Emphasis on balancing rights in a communal setting in the Program Manual	New - Home to be safe, secure environment principle Legislative intent of balancing of competing interests is more obvious

In this section, I have explored the role of law in defining and constructing care. It is evident that regulatory expansion has occurred in the sense that more activities seem to be brought under the reach of formal law but substantively may not be very different. One could argue that under the LTCHA, the care relationship is defined mainly by what the care provider (the home and its employees) must provide to the care recipients (residents). Care recipients are armed with rights and entitlements to ensure that they receive what they need for physical survival and that they are legally able to assert their choices and preferences for certain types of activities. I will now turn to the question of the delivery of care.

5.3 How is care delivered?

In Chapter 4, I explain that one of the themes in the feminist political economy literature is the regulation of care including rigidity of workplace. In this section, I will explain how the delivery of care is subject to various instruments of control. Obviously funding level is critical to the delivery of care and works together with regulatory instruments, but I will put aside the issue of funding here. This section will being by describing how delivery of care is standardized and highly prescriptive so that each home will have the same programs. Then I will then explore how the government attempts to control homes' discretion over staffing. This section will conclude by explaining the concept of "patient-centred" care, which is not necessarily new but has become more prominent in this period.

5.3.1 Standardized and Highly prescriptive

Under both the previous *Nursing Homes Act* and the current LTCHA, there are programs of various degrees of legal formality offered in homes. See Table 15 for a comparison. On first glance, it may appear that under the LTCHA, residents are now entitled to more programs. However, these programs are not new in the sense that they were not offered under the previous regime. Rather, some of them were elevated from Program Manual to statute or regulation and given a set of standardized processes and structures. One could argue that the programs are supposed to look and feel the same (at least consistent) across all homes under the LTCHA so that residents are assured of receiving similar support and services regardless of where they live in the province.

Table 15: Comparison of programs under the *Nursing Homes Act* and the LTCHA

	Nursing Homes Act	**LTCHA**
Programs	Nursing Services, Staff Education, Recreation and Leisure Service, Social Work Service, Spiritual and Religious Program, Therapy Services, Volunteer Services, Dental Services, Foot Care Services, Facility Organization and Administration, Medical Services, Environmental Services, Dietary Services, Diagnostic Services and Pharmacy Services.[868]	Four inter-disciplinary programs: falls prevention and management, skin and wound care, continence care and bowel management, and pain management.[869] The organized programs are as follows: nursing and personal support services, restorative care, recreational and social activities, dietary services and hydration, medical services, information and referral assistance, religious and spiritual practices, accommodation services and volunteer programs.[870]
Requirements	Within each program, there were standards, criteria and guidelines in the Program Manual.[871]	The LTCHA mandates the establishment of and prescribe detailed requirements for all programs in each home.[872]
Standardization	Certain components were	All programs must comply

---

[868] Ministry of Health and Long-Term Care, *supra* note 545. See Tab 10 "Standards: Programs and Services".
[869] Ministry of Health and Long-Term Care, *supra* note 782 at 2–20.
[870] *Ibid*.
[871] Ministry of Health and Long-Term Care, *supra* note 545. See Tab 9901-01 for the definitions for criteria, guidelines and standards.
[872] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 8–18.

	Nursing Homes Act	**LTCHA**
	very common across the programs, such as written program description, evaluation, and policies and procedures.	with certain process or procedural type of requirements regardless of the substance of the program: • There must be a written program description. • All equipment and aids used by staff must be appropriate for the resident. • The program must be evaluated and updated at least annually in accordance with evidence-based practices and, if there are none, in accordance with prevailing practices. • A written record of each evaluation must be maintained. • All actions taken with respect to every resident under a program must be

	Nursing Homes Act	LTCHA
		documented.[873]

A few observations can be made about the differences in programs offered under the *Nursing Homes Act* and the LTCHA. First, with respect to how care was supposed to be delivered, the level of detail varied significantly in both old and new regimes. Second, the LTCHA and its regulations continue to be highly prescriptive mainly because some of the Program Manual requirements were incorporated. For example, the following programs have been formalized into law: volunteer program, recreation and social program, religious and spiritual practices program.[874] Further, the requirements have become more complex in the sense that they anticipate different situations in which care may be provided. By way of example, more rules are required in order to permit exceptions to the availability of 24/7 RN requirement.[875] Some requirements are incorporated to reflect a more risk-based approach, which in turn necessitates more rules. For example, while monitoring residents' weight has always been a requirement, the LTCHA provides more elaborate guidance on weight monitoring and assessment based on the changes in weight and duration.[876] However, some requirements have been removed also such as certain details about the volunteer program[877] (although the existence of the program is now mandated by law).

5.3.2 Homes' discretion over staffing

Feminist political economists have made claims about the importance of structural aspects of care that set the conditions for care including funding, ownership, and staffing levels.[878] LTC is a labour-intensive sector, and it is instructive to understand how the government uses various instruments to control homes' discretion over staffing (full-time vs part-time, mix of staff, how many staff and when). The changes in staffing requirements under the LTCHA are more about legal forms than substance. The basic approach has not changed: there are

---

[873] Ministry of Health and Long-Term Care, *supra* note 782 at 2–20 to 2–21.

[874] *Long-Term Care Homes Act, 2007*, *supra* note 425, ss 16, 10, 14.

[875] *Morriston Park Nursing Home v Ontario (Health and Long-term Care),* 2014 CanLII 62311 (ON HSARB) [Morrison Park].

[876] O Reg 79/10, *supra* note 811, ss 68–69.

[877] Ministry of Health and Long-Term Care, *supra* note 545. The Program Manual provided a list of services that volunteers may provide and detailed responsibilities of the volunteer coordinator.

[878] Banerjee & Armstrong, *supra* note 514 at 7.

prescriptive requirements about how many minimum hours certain positions or occupations (administrator,[879] director of nursing and personal care,[880] nutrition manager,[881] food service workers[882]) have to work depending on the size of facility (in terms of bed) supplemented by requirements that certain positions (medical director and designated leads for certain programs) are mandatory but no specific quantity (in terms of staffing hours) is indicated. Further, there is no prescribed minimum number of hours of care to be provided by the nursing staff (other than the stipulation that a home must have at least one RN 24/7 with some narrow exceptions[883]), therapists, and personal support workers (to be discussed further below). There are very few completely new requirements (as in the sense of never been implemented). They are about homes having processes in place and articulating the government's policy intent. They build on and go beyond the Program Manual requirements: continuity of care principle, written staffing plan and the government's authority to prescribe staffing and care standards by regulation. Otherwise, the LTCHA and its regulation do not provide any guidance on staffing related matters (other than outlining the rights and obligations of staff when the home is under the control by an interim manager – to be discussed in Chapter 8).

5.3.2.1 Staffing level

The LTCHA builds on the previous regime's expectation about the use of agency or casual staff. In a 2006 memo about the 24/7 RN requirements, the Ministry explained that limited and temporary utilization of contracted/agency Registered Nurses could be considered as an acceptable short-term plan until such time that permanent Registered Nurse staff is secured.[884] In the LTCHA, there is a new continuity of care provision intended to limit on the use of temporary, casual or agency staff: "In order to provide a stable and consistent workforce and to improve continuity of care to residents, every licensee of a long-term care home shall ensure that

---

[879] O Reg 79/10, *supra* note 811, s 212(1)–(3).
[880] *Ibid*, s 213(1)–(3).
[881] *Ibid*, s 75.
[882] *Ibid*, s 77.
[883] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 8(3). *Morriston Park*, *supra* note 875.
[884] Ministry of Health and Long-Term Care, *supra* note 545. See the memo from Vahe Kehyayan, Director Compliance Inspections and Enforcement of the LTC Homes Programs to Long-Term Care Home Administrators (January 9, 2006) in Tab 1001-01. Two conditions must be met: 1) a formal agreement with an agency that facilitates the same RN assigned and 2) mandatory comprehensive orientation program for temporary agency staff.

the use of temporary, casual or agency staff is limited in accordance with the regulations".[885] There is no regulation in place to provide further guidance on what homes have to do in order to limit causal or agency staff.

It appears that the government relies on procedural solutions to manage the tension between the objective of safety of residents and the need to allow homes to manage the majority of their direct care staff. A written staffing plan is required for the nursing and personal support services program and must:

- Provide for a staffing mix consistent with residents' assessed care and safety needs;
- Set out the organization and scheduling of staff shifts;
- Promote continuity of care by minimizing the number of different staff members to each resident;
- Include a back-up plan that addresses situations when staff cannot come to work, including 24/7 RN coverage; and
- Be evaluated and updated annually. A written record of each evaluation must be maintained.[886]

Although each home must have an organized program of personal support services,[887] there is no minimum staffing level for personal support workers, either in the form of resident-to-staff ratio or number of care hours per resident per day.

The last point about delivery of care is that the LTCHA provides for staffing and care standards to be prescribed by regulation.[888]The legislative intent was to have a provision "broad enough to allow for consultation on what should be included in a staffing and care standard and would allow the government to bring that in under regulation."[889] It should be emphasized that these are not minimum standards that each resident is entitled to.[890] To date, there are no new staffing and care standards prescribed by regulation to date.

---

[885] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 78(1).
[886] Ministry of Health and Long-Term Care, *supra* note 782 at 2–22 to 2–23.
[887] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 8(b).
[888] *Ibid*, s 17.
[889] *Supra* note 867.
[890] *Ibid.*

5.3.2.2 Skills and qualifications of caregivers

As explained above, the LTCHA regulates care directly by specifying the what, how and when of care delivery but the LTCHA also regulates those who provide care indirectly in the following ways. First, there is a new general statutory requirement that a home must ensure that all the staff of the home have the proper skills and qualifications and possess the qualifications provided for in the regulations.[891] As well, each program must have a designated lead. Second, while staff qualifications requirements have always existed in different instruments, the LTCHA imposes more qualification requirements on caregivers (from regulated health professionals to cooks), such as higher formal education level attained[892] and membership in regulatory or professional bodies. By way of example, the qualifications for the position of administrator are higher now and the expectations are clearer. Rather than education in management or education in health services, the LTCHA specifically requires that either a diploma or degree. The LTCHA also specifies the skills required: communication, leadership, and supervisory/managerial experience.[893] Similarly, the qualifications for the position of director of nursing and personal care are now enshrined in legislation.[894] The designed lead for housekeeping, laundry, maintenance services must have a post-secondary degree or diploma, knowledge of evidence-based practices and, if there are none, prevailing practices relating to housekeeping, laundry and maintenance, as applicable; and a minimum of two years' experience in a managerial or supervisory capacity.[895] But the Program Manual did not have these formal education requirements.[896]

However, it should also be pointed that some of the more detailed responsibilities of select professionals have been dropped in the sense that they were in the Program Manual but they are not included in any legal instrument anymore. In a way, the LTCHA is less prescriptive

---

[891] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 73.

[892] Some of the changes are probably unrelated to the LTC sector. The necessary changes to professional regulation happened in other statutes and the LTCHA simply reflects those changes. For example, the baccalaureate requirement for RN became effective January 1, 2005. See http://cou.on.ca/wp-content/uploads/2015/05/COU-Position-Paper-on-Collaborative-Nursing-Programs-in-Ontario.pdf

[893] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 70. O Reg 79/10, *supra* note 811, s 212.

[894] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 71. See also Reg 832, *supra* note 831, s 213.

[895] *O Reg 79/10*, *supra* note 811, s 92(2).

[896] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 1013-02, page 1.

than the previous regime in terms of containing fewer requirements about what certain professions should be doing and how while directing or providing care. These include:

- Detailed description of the responsibilities of the Director of Nursing and qualifications[897]
- Detailed description of the responsibilities of RN managing each unit, functions of nursing services, criteria for evaluation[898]
- Responsibilities of attending physicians and medical directors[899]
- Role of the co-ordinator of the religious and spiritual practices program and qualifications.[900]

This apparent reduction in regulation does not negate the fact that care activities are still subject to many complex standards that front-line care providers including unregulated professionals are responsible for. The increasing importance of monitoring quality backed by formal legal sanctions will be addressed in subsequent chapters. The table below is a simplified illustration of these changes:

Table 16: Changes to staffing requirements under the LTCHA

More substantive	**Form (some effect)**
• Written staffing plan • Formal educational and skill requirements that are above the *Nursing Homes Act* • Medical director has to consult with the director of nursing and other health professionals • Limit on temporary, casual or agency staff	• Move certain positions from regulation to statute • Written agreement between home and medical director (from program manual to regulation) • Orientation for volunteers

---

[897] *Ibid* at Tab 1001-02, page 1 to 3.
[898] *Ibid* at Tab 100102, page 3 to 5.
[899] *Ibid* at Tab 1012-01 and 1012-02.
[900] *Ibid* at Tab 1005-02, page 1 to 2.

• Government's authority to prescribe staffing and care standards	• 24/7 RN (from regulation to statute) • Training and orientation of staff (from regulation to statute)
Less substantive	**Form (No real legal effect)**[901]

One could interpret the changes with respect to staffing as a way to avoid harm that may result from incompetent care: it is believed that legally-mandated professional qualifications, orientation and training will produce quality care. Other than that, regulation is more about making sure the home has a plan in place to control its staffing and scheduling at its discretion. But to understand the interaction between residents and their formal caregivers, the work now turns to the notion of patient-centred care which will help to explain what care means in the LTC sector.

5.3.3 Patient-centred care

As noted in Chapter 4, according to the OECD, one of the three aspects generally accepted as critical to quality of care is patient-centredness.[902] In the feminist political economy literature, it is argued that patient-centred and person-centred care focuses almost exclusively on medical care while failing to recognize the larger social and economic context in which care is delivered and received.[903] As well, there is the tension of whether to prioritize the collective and community, or the individual, person-centred needs of residents.[904]

The increasing prominence of the notion of "patient-centred" care[905] (which has a few variants such as "person-centred", "client-centred", "resident-centred" and "resident-focused" care) marks a significant change as part of the quality of care agenda during this period. To understand the notion of resident-centred care within a broader systemic change in quality of

---

[901] For example, a requirement in regulation has the same legal effect as if it is in statute. Moving a requirement from regulation to statute will not make it more enforceable.
[902] Murakami & Colombo, *supra* note 629 at 159.
[903] Baines & Armstrong, *supra* note 514 at 3–4.
[904] Gudmund Ågotnes & Christine Øye, "Chapter 10 Person-Centred or Community-Centred Care? Why Doing It Wrong Is Sometimes Right" in Pat Armstrong & Ruth Lowndes, eds, *Negotiating Tensions in Long-Term Residential Care: Ideas Worth Sharing* (Montreal: Canadian Centre for Policy Alternatives, 2018) 97.
[905] For example see Cathy Fooks et al, "The Patient Experience in Ontario 2020: What Is Possible?" (2015) 14:4 HealthcarePapers 8.

care, one must refer to the *Excellent Care of All Act, 2010*: "The people of Ontario and their Government: . . . Recognize that a high quality health care system is one that is accessible, appropriate, effective, efficient, equitable, integrated, patient centred, population health focused, and safe".[906] Further, patient-centredness is one of the current indicators that health care organizations have to report on in their quality improvement plans.[907] The Health Quality Ontario has since developed many frameworks and guidelines on quality improvement, which will be addressed in Chapter 8.

As explained in Chapter 4, Bill 41, the *Patients First Act* was introduced in October 2016, and received Royal Assent in December 2016. The long title of the bill is *An Act to amend various Acts in the interests of patient-centred care*.[908] Despite the title, Bill 41 does not further elaborate what patient-centred care means. However, since the Bill purports to streamline the health care system and empower the remaining organizations such as the LHINs to undertake additional functions, it is probably fair to say that the perception is that more bureaucracy means "system-centred" care rather than "patient-centred" care. Accordingly, the notion of "patient-centred care" is used to convey the idea that there is a pressing need to reform the health care system because delivery of care is cumbersome, inefficient and too bureaucratic.

While the *Nursing Home Act*, its regulation and the Program Manual did not reference any variants related to "patient-centred care", the LTCHA refers to resident-centred care in the Preamble: "The people of Ontario and their Government: Believe in resident-centred care"[909] but provides no guidance on what that means. Similarly, the LTCHA Guideline explains: "The LTCHA is designed to help ensure that residents of long-term care homes receive safe, consistent, high-quality, resident-centred care."[910]

Other new legal or quasi-legal instruments also refer to person-centred care as a way to disseminate norms about what the government expects from the health care system. The Ministry-LHIN Accountability Agreement includes the following in the introduction: "The MOHLTC has defined the next phase of health care system transformation through Patients

---

[906] *Excellent Care for All Act 2010,* SO 2010, c14, Preamble.
[907] *Annual Quality Improvement Plan,* O Reg 187/15, ss 2(1)-(2).
[908] *Patients First Act*, *supra* note 624.
[909] *Long-Term Care Homes Act, 2007*, *supra* note 425.
[910] Ministry of Health and Long-Term Care, *supra* note 782 at 1.

First: Action Plan for Health Care" which "is focused on creating a health care system that is person-centred, . ."[911] Throughout the agreement, "person-centred" care is referenced in the provision regarding principles,[912] accountability,[913] and performance improvement.[914] Likewise, the background section of the LHIN-home service accountability agreement states it "supports a collaborative relationship between the LHIN and the HSP [health service provider]… to create a health care system that is person-centered, accountable, transparent, and evidence-based."[915] More recently, the Ministry also imparts the importance of Ministry and LHINs "work[ing] together to put patients at the centre of a high performing health care system."[916] However, the notion of "person-centred" care is never defined or elaborated in these agreements. For this reason, I think it is safe to assume that the term is used to describe an objective of the health care system rather than to guide care delivery at the individual level (i.e., at the point of care).

It is likely that different health professional associations have always had their own definitions of "patient-centred" care as a means to define the provider to client / patient relationship.[917] A common theme in soft law is "patient-centred", "client-centred" or "resident-centred" care in the discharge of professional obligations and expectations. The definitions vary but it is fair to say that they overlap with or integrate concepts I addressed elsewhere in the dissertation, such as "choice" and "autonomy". They all illustrate what a caring relationship should look like i.e., it should not be solely about the care activities or transactions but should entail fostering the autonomy of users, patients and residents. The College of Dietitians of Ontario explains: "The client collaborates and is a partner in the decision-making process ... This means that the client's own experiences and knowledge are central, and carry authority within the client-professional partnership. This assumption forms the basis of a client-centred approach wherein mutual respect, trust, and shared objectives are fundamental."[918] RNAO's definition is

---

[911] *Ministry-LHIN Accountability Agreement (2015-16-2017-18)*.

[912] *Ibid*, s 2.

[913] *Ibid*, s 5.

[914] *Ibid*, s 7.

[915] *Long-Term Care Service Accountability Agreements* (L-SAA)(2016-2019).

[916] Ministry of Health and Long-Term Care, *Mandate Letter from the Minister of Health and Long-Term Care to Toronto Central LHIN* (Toronto: Ministry of Health and Long-Term Care, 2017).

[917] Other delivery organizations also work on their definitions of patient-centred care. For example, see Danielle Bender & Paul Holyoke, "Bringing Person- and Family-Centred Care Alive in Home, Community and Long-Term Care Organizations" (2016) 19:1 Healthcare Quarterly, online: <http://www.longwoods.com/content/24605>.

[918] College of Dietitians of Ontario, *The Jurisprudence Handbook for Dietitians in Ontario* (Toronto: College of Dietitians of Ontario, 2015) at 3–4.

as follows: "An approach in which clients are viewed as whole; it is not merely about delivering services where the client is located. Client-centred care involves advocacy, empowerment, and respecting the client's autonomy, voice, self-determination, and participation in decision-making."[919] Accreditation Canada incorporates more concepts into patient-centred care: "Providing resident- and family-centred care means working collaboratively with residents and their families to provide care that is respectful, compassionate, culturally safe, and competent, while being responsive to their needs, values, cultural backgrounds and beliefs, and preferences." Further, four values are identified as fundamental to patient-centred care: 1) dignity and respect 2) information sharing 3) partnership and participation and 4) collaboration.[920] None of the values that Accreditation Canada identifies are new in soft law or hard law but the concept of resident- or person- or client-centred care connects them together.

Viewed from this lens, other regulatory changes also support the notion of resident-centred care. One such change is related to care plans and care planning, including assessing and reassessing residents and planning, delivering and evaluating their care, beginning when residents are first admitted to the home.[921] Participation of residents in the development, review and implementation of their plan of care is now a right,[922] supplemented by other requirements to have others involved.[923] However, this may not be a significant change since under the *Nursing Homes Act* residents had the opportunity to participate in the plan of care development and review.[924] The Program Manual also reflected the policy intent to direct homes to get to know residents and include them: "Assessment is the systematic collection and review of resident-specific information gathered from all available sources. . . Whenever possible, the primary source of any information is the resident. In discussion with the resident, staff comes to better understand the resident's values, needs, wishes, strengths, social and personal resources, culture, interests, health status, extent of independent functioning, type and amount of supports

---

[919] Registered Nurses' Association of Ontario, *Preventing and Addressing Abuse and Neglect of Older Adults: Person-Centred, Collaborative, System-Wide Approaches* (Toronto: Registered Nurses' Association of Ontario, 2014) at 87.

[920] Accreditation Canada, *supra* note 815 at 1.

[921] Ministry of Health and Long-Term Care, *supra* note 782 at 2–12.

[922] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 3(1)11.

[923] *Ibid*, s 3(1)26.

[924] *Nursing Homes Act*, *supra* note 786, s 20.10(d).

required."[925] The LTCHA requirements about what must be included in the care plan (called care domains) and how to do assessment and re-assessment[926] build on the Program Manual requirements[927] and are formalized in law. In sum, one manifestation of "resident-centred" care may be that residents are being assessed, documented and monitored more closely. However, the emphasis on engaging residents, their substitute decision-makers and family members in operational planning is a consistent theme in the operation of homes, and not just in care.

5.3.4 Summary

The table below summarizes the changes:

Table 17: Comparison of delivery of care under the *Nursing Homes Act* and the LTCHA

	Nursing Homes Act	**LTHCA**
Standardized program requirements (such as written program description, evaluation and documentation of actions taken with respect to every resident)	Common processes and procedures across all programs	Standardized program structure, processes and procedures in law
Home's discretion over staffing	Expectation about utilization of contracted/agency Registered Nurses in the Program Manual Detailed descriptions of certain positions	New - continuity of care principle, written staffing plan and the government's authority to prescribe staffing and care standards by regulation. New – more formal qualification requirements

---

[925] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 0903-01, page 1.
[926] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 6. See also *O Reg 79/10*, *supra* note 811, s 26.
[927] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 0903-01.

	Nursing Homes Act	**LTHCA**
Concept of Patient-centred care	None	In the LTCHA and other legal instruments

In this section, I have described how care is delivered by attending to the standardized and prescriptive programs and homes' discretion over staffing under the LTCHA. The increasing prominence of the concept of "patient-centred care" is also explained. The care relationship is further defined by standardized program structures and process, which set the context in which care providers interact with residents, substitute decision-makers, families and friends. The pro is that residents have greater certainty about what programs or services they are entitled to and how those programs should be managed. The downside is that the changes say very little about the substance of those programs and are unlikely to improve significantly the care received by residents.

So far I have described the care relationship as unidirectional as law focuses on what the providers have to do and how. But there are other requirements that connect providers and residents in different ways. As I will demonstrate in subsequent chapters, the notion of working collaboratively with residents and families is exemplified in other requirements around the operation of the home. This includes formal mechanisms mandated by law to provide feedback to the home and receive information so that residents and their families have more influence (but not necessarily control) over how decisions are made. I will return to this issue in Chapter 8.

5.4 How do the changes mandate accommodation of disability in care delivery?

Recall that for disability studies scholar such as Tom Shakespeare "disability" and "disablism" are conceptualized as relational in nature.[928] In this section, I will explain how the LTCHA has addressed the accommodation of residents' care needs associated with their disabilities within the homes. The focus here is on individual residents with respect to care, rather than on all aspects of living in LTC homes. These requirements should be considered within the context of legal framework of disability rights in Ontario, mainly the *Accessibility for*

---

[928] Shakespeare, *supra* note 4.

Ontarians with Disabilities Act (AODA) and the *Human Rights Code*. I will also briefly note the significance of the *Convention on the Rights of Persons with Disabilities*. While the equality rights guaranteed under the *Canadian Charter of Rights and Freedoms* are relevant to this research, these will be discussed in Chapter 7 when I address how residents exercise control over their lives.

5.4.1 **Personal assistance, social environment and program design**

The *Nursing Homes Act* and its regulation contained few requirements about accommodating impairments or disabilities. The overall principle of accommodation can be inferred from the Bill of Rights: "Every resident has the right to receive reactivation and assistance towards independence consistent with his or her requirements."[929] A resident's plan of care must include, among other things, "the assistance to be given to the resident with activities of daily living, and the safety and security precautions to be taken with respect to the resident".[930] In the Program Manual, there were requirements about accommodating physical disabilities such as self-help aids (such as walkers and canes) being included in the charges for basic accommodation,[931] cleaning and repair of sensory and communication aids, as well as large print for certain documents.[932] Also, one of the standards was "[a]rrangements shall be made to facilitate spiritual and religious care for the hearing and visually impaired, where resources are available."[933] As well, the Program Manual provided additional guidance for dealing with residents with cognitive impairments and/or "disruptive behavior" (which could "result in risk to themselves or others"), such as requirements for in-service education program for staff and orientation for new volunteers.[934] There were also ad hoc requirements, for example, one of the resident care standards was: "Each resident shall have opportunities and assistance to participate in programs which are appropriate to his/her cognitive status, interests and preferences, both within the LTC home and in the community."[935]

The LTCHA has not changed significantly from the *Nursing Homes Act* in terms of what

---

[929] *Nursing Homes Act*, *supra* note 786, s 2(2)7.
[930] Reg 832, *supra* note 831, s 126(c)ii-iii.
[931] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 0608-01, page 2.
[932] *Ibid* at Tab 0902-01, page 2.
[933] *Ibid* at Tab 1005-01, page 1.
[934] *Ibid* at Tab 1002-01, page 3, Tab 1007-02, 4 and Tab 1102-01, 30.
[935] *Ibid* at Tab 0903-01, page 16.

homes have to do to accommodate residents. "Independence" continues to be a goal for residents, however, there is a recognition in the LTCHA that residents (or their health conditions) cannot always be changed (or "cured") and therefore the law performs the function of mandating that the environment – physical and social – to be altered or adapted in order to deliver care. One could argue that this resembles the idea that the environment can be disabling and the focus should be on accommodation of differences. Homes must take steps to respond to and accommodate limitations experienced by residents at the individual level and at the program design level, such as mandating provision of services for residents with cognitive impairments, and residents who are unable to leave their rooms. The goal is to allow all residents to access the same categories of care or services despite their impairments / disabilities in order to be as independent as possible. Some of the LTCHA requirements were elevated from the Program Manual to regulation and therefore are not necessarily new. The table below summarizes how resident impairments are accounted for under the *Nursing Homes Act* and the LTCHA.

Table 18: Accommodation of impairments under the *Nursing Homes Act* and the LTCHA

	Nursing Homes Act	**LTCHA**
Personal care	Homes must provide assistance (e.g. dining)[936] and cannot charge for mobility devices[937]	Homes must provide assistance (e.g. dining and oral care), support or tools (such as assistive devices)[938]
Social environment	in-service education program for staff and orientation for new volunteers to deal with cognitive impairments and/or "disruptive behavior"[939]	Home must develop and implement strategies to meet the needs of residents with compromised communication and verbalization skills, with cognitive impairment and those who cannot communicate in the languages used in the home[940]

---

[936] *Ibid* at Tab 0903-01, page 16–18.

[937] *Ibid* at Tab 0608-01, page 2.

[938] O Reg 79/10, *supra* note 811, ss 34, 73. Ministry of Health and Long-Term Care, *supra* note 782 at 2–43 to 2–51.

[939] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 1002-01, page 3, Tab 1007-02, 4.

[940] *O Reg 79/10*, *supra* note 811, s 43.

	Nursing Homes Act	**LTCHA**
		Include references to communication challenges in pain management, volunteer training and information posting[941] Include responsive behavior provisions(to be discussed in chapter 6)
Program design	Opportunities and assistance to participate in programs which are appropriate to his/her cognitive status, interests and preferences[942] Facilitate spiritual and religious care for the hearing and visually impaired[943]	For social and recreation activities, homes must include services for residents with cognitive impairments, and residents who are unable to leave their rooms[944] Every resident must be assisted and supported to participate in activities that may be of interest if he or she is not able to do so independently[945] Arrangements should be made to facilitate the participation in the religious and spiritual programs of residents who have hearing or visual impairments, based on availability within the community[946]

---

[941] *Ibid*, ss 52(1), 223(2), 225(2).

[942] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 0903-01, page 16.

[943] *Ibid* at Tab 1005-01, page 1.

[944] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 10(2).

[945] O Reg 79/10, *supra* note 811, s 65(1)(f); Ministry of Health and Long-Term Care, *supra* note 782 at 2–41.

[946] *Ibid*, s 85(3).

	Nursing Homes Act	LTCHA
		It should be noted that impairment is not specifically referenced in other programs or categories of care.

The professional guidelines reviewed show some more awareness of the needs of disabled residents (or patients) within a care context when compared to statutes. Very few guidelines mention "disability" or "impairment" directly with the exception of dementia and other cognitive impairments, especially in relation to consent to treatment (to be discussed in Chapter 7). One exception is the RNAO guideline on oral health that focuses on vulnerable adult populations, which include "those with special needs may include older adults, those who are medically compromised, intellectually challenged, physically challenged, and/or have severe and persistent mental illness. Many may be frail or dependent upon caregivers to help with their activities of daily living. These adults may live in the community or may be in institutions."[947] In particular, there is more recognition of how impairment and disability (and other social locations such as age) should be taken into consideration when delivering care (compared to statutes). In the best practices guideline about pain management, it is acknowledged that some people may be unable to talk about or report pain, such as older adults with cognitive impairment and people with intellectual disability. Accordingly, there is guidance on how to perform a comprehensive pain assessment on such persons.[948] While these guidelines appear to reflect a medical model of disability (as they are intended to disseminate clinical best practices), a few of them also attend to issues other than the individual impairments or illnesses. In particular, these guidelines acknowledge the interaction of individual impairment and the environment similar to Shakespeare's interactional approach to disability. For example, in the RNAO best practices guideline "Prevention of Falls and Fall Injuries in the Older Adult", while many interventions focus on individual illness or impairment (such as medications management), one of the

---

[947] Registered Nurses' Association of Ontario, *Oral Health: Nursing Assessment and Intervention* (Toronto: Registered Nurses' Association of Ontario, 2008) at 13.

[948] Registered Nurses' Association of Ontario, *Assessment and Management of Pain (Third Edition)* (Toronto: Registered Nurses' Association of Ontario, 2013) at 25–26.

recommendations is that "[n]urses include environmental modifications as a component of fall prevention strategies."[949] Similarly, the RNAO best practices guideline about continence also acknowledges that the problem of incontinence does not just locate at the individual by making recommendations about removal of physical and social barriers (or extrinsic factors)[950] to enable residents to exercise more autonomy over their own bodily needs.

The discussion above shows that there is more recognition of how certain types of disability should be integrated in care delivery, especially in the professional guidelines. The professional guidelines fill a regulatory gap as the LTCHA says little about how a provider should accommodate disability. However, it is difficult to argue with the observation that despite the increasing acuity of residents, the only area that has changed significantly between the current and previous regulatory regimes is accommodation of cognitive behaviors. Since this issue is understood as closely (although not exclusively) related to resident safety and caregiver and security, I will address the issue of responsive behavior in chapter 6.

5.4.2 ***Accessibility for Ontarians with Disabilities Act, 2005*** **(AODA)**

From a disability law perspective, a key development during this period is the passing and coming into effect of the AODA. The AODA was passed unanimously by the legislature in May 2005 and received Royal Assent and took effect on June 13, 2005.[951] The AODA is part of the legal framework protecting disability rights that includes two other Ontario laws: the *Human Rights Code* and the *Ontarians with Disabilities Act, 2001*.[952] The implementation of the AODA is a change for the LTC sector because the *Ontarians with Disabilities Act*, *2001,* the precursor to the AODA, was not (and is not) applicable to the LTC sector.[953] The AODA authorizes the

---

[949] Registered Nurses' Association of Ontario, *Prevention of Falls and Fall Injuries in the Older Adult* (Registered Nurses' Association of Ontario, 2005).

[950] Registered Nurses' Association of Ontario, *Promoting Continence Using Prompted Voiding* (Toronto: Registered Nurses' Association of Ontario, 2011) at 20. The recommendations are: "Identify attitudinal and environmental barriers to successful toileting. Barriers include: Proximity and availability of the nearest bathroom; Accessibility of commode; Satisfactory lighting; Use of restraints; Staff expectation that incontinence is an inevitable consequence of aging; and Staff belief that few interventions exist to promote continence."

[951] Mayo Moran, *Second Legislative Review of the Accessibility for Ontarians with Disabilities Act, 2005* (Toronto: Ministry of Economic Development, Employment and Infrastructure, 2014) at 8.

[952] *Ibid* at 51 to 52.

[953] *The Ontarians with Disabilities Act, 2001,* SO 2001, c 32 (to be repealed at a later date) is a much narrower Act. It only covers the public sector including the Ontario government and its agencies, hospitals, public transportation organization and educational institutions.

Government to establish accessibility standards by regulation. These standards set out requirements for the identification, removal and prevention of barriers that keep persons with disabilities from participating fully in all aspects of society. The standards also contain time periods for implementing the required measures.[954] It should be noted that if the AODA standards conflict with other accessibility standards, the highest level of accessibility must prevail.[955] Currently, accessibility standards are in place in the following areas: Information and Communications Standards,[956] Employment,[957] Transportation,[958] Design of Public Spaces[959] and Customer Services.[960] It should also be noted that more standards are under development. A Standards Development Committee will develop a new accessible Health Care Standard.[961] The standards most relevant to this project are communication and customer service standards.

- The Customer Service standard requires goods or services providers to: establish policies, practices and procedures for accessible customer service; train staff and volunteers; allow service animals and support persons; and create a feedback process.[962]
- The Information and Communications standard requires the provision of accessible formats and communication supports on request and also covers such areas as emergency and public safety information; websites; feedback processes; educational, training and library materials and resources; and training of educators.[963]

The AODA has been used in legal arguments raised in a variety of formal legal processes: small claims court, Superior Court, Law Society discipline hearings, and Workplace Safety and Insurance Appeal Tribunal, just to name a few. In the sample cases (see Chapter 3 on

---

[954] Moran, *supra* note 951 at 9.

[955] "If a provision of this Act, of an accessibility standard or of any other regulation conflicts with a provision of any other Act or regulation, the provision that provides the highest level of accessibility for persons with disabilities with respect to goods, services, facilities, employment, accommodation, buildings, structures or premises shall prevail." *Accessibility for Ontarians With Disabilities Act, 2005,* SO 2005, c 11, s 38.

[956] *Integrated Accessibility Standards*, O Reg 191/11*,* s 9-19.

[957] *Ibid*, s 20-32.

[958] *Ibid*, s 33-80.

[959] *Ibid*, s 80.1-80.44.

[960] *Ibid*, s 80.45-80.51.

[961] Ontario Government, "Accessibility: legislative reviews, committees and councils", (2 June 2015), online: *Ontario.ca* <https://www.ontario.ca/page/accessibility-legislative-reviews-committees-and-councils>.

[962] Moran, *supra* note 951 at 12.

[963] *Ibid*.

the search method), the issues involved WheelTran[964] (an accessible transportation option offered by the Toronto Transit Commission), "handicapped" parking,[965] professional misconduct,[966] termination of sales contract[967] and limitation period.[968] Although these cases are not related to LTC, they are still useful in terms of understanding the broader context of accommodation of disability because they illustrate how the AODA is being interpreted by the courts. In all of the cases I reviewed, the court (or tribunal) correctly identifies the broad policy objective and legislative intent of the AODA. In two cases (WheelTrans and municipal parking by-law), the courts used the AODA to illustrate the context and background of the legal issues before them and explained that the spirit of the AODA would be supported by the respective judicial decisions. These cases would probably arrive at the same conclusion even if the AODA was not mentioned. In a case about accessible parking by-law, Kastner J. explains:

> [128] The by-law's context is fully set out in the preamble, and it is to recognize the spirit and intent of the Accessibility for Ontarians with Disabilities Act, 2005.
>
> [129] If one were to interpret this by-law as the Appellant submits, the result would be to dishonour that spirit and intent, and unfairly set the strides disabled people have made in achieving accessibility back decades, resulting in an absurd result.[969]

Similarly, in a zoning by-law case, the Ontario Municipal Board allows an appeal about variance to the maximum driveway width of a private residence:

> [14] The Board is of the view that the Appellant undertook this work in utter good faith and for the purpose of facilitating access to his dwelling by persons in wheelchairs.
>
> [15] In keeping with the purpose of the Accessibility for Ontarians with Disabilities Act, 2005, the City has incorporated s. 9.4.3, regarding Accessibility, into its official plan. The policy in that section explicitly says that the owners of existing buildings will be encouraged to retrofit them to be universally accessible.[970]

In a case about sales tax exemption for equipments designed for the use of persons with disabilities, the court was alive to the history of disabled people in Ontario and attended to the

---

[964] *Toronto Transit Commission v Ontario (Finance),* 2008 CanLII 67910 (ON SC).

[965] *City of Mississauga v 1747114 Ontario Inc*, 2013 ONCJ 623.

[966] *Law Society of Upper Canada v Battaglio*, 2014 ONLSTH 222.

[967] *Friman v Toledo Estates Ltd*, 2013 CanLII 41976 (ON SCSM).

[968] *SOT-68407-16 (Re),* 2016 CanLII 88178 (ON LTB).

[969] *City of Mississauga v. 1747114 Ontario Inc.*, *supra* note 965 at paras 128-129.

[970] *Ahmed v Mississauga (City)*, 2017 ON LPAT 19981 at paras 14-15.

barriers faced by people with disabilities and how the elimination of those barriers can benefit them as well as society as a whole. Strathy J. states:

> . . . there has been significantly greater appreciation by our society of the barriers affecting people with disabilities and the extent to which the elimination of those barriers can enrich the lives of people with disabilities and society as a whole. This appreciation, and a resolve to eliminate barriers, are reflected in section 15 of the Canadian Charter of Rights and Freedoms, Schedule B to the Canada Act (U.K.), 1982, c. 11, the Ontario Human Rights Code, R.S.O. 1990, c. H.19 and Accessibility for Ontarians with Disabilities Act, 2005, S.O. 2005, c. 11. It is expressed in section 1 of the latter statute, which has as its purpose to "improve opportunities for persons with disabilities and to provide for their involvement in the identification, removal and prevention of barriers to their full participation in the life of the province." It seems to me that these goals are not advanced by the interpretation put forward by the Minister.[971]

However, besides the "expressive role"[972] of the AODA as evidenced in these decisions, the AODA is not necessarily useful for the purpose of helping individuals to assert their rights when they encounter barriers in their daily lives. First of all, the AODA does not have primacy over other legislation. Unlike the *Human Rights Code*, the AODA does not enable individuals to demand a particular organization remove a barrier or correct an accessibility issue. As the Moran report notes: "As some observers noted, while the Code is about individual cases, the AODA is about proactive change and can't be everything for everybody."[973] Secondly, enforcement of the minimum standards rests with the government[974] and it is not clear if compliance activities are adequate in the eyes of disability stakeholders. It could be described as a self-reporting regime: "The Tribunal accepts the premise that to ensure compliance with this important legislative initiative, self-reporting is a key component."[975] More recently, the government explained that it has adopted a "Progressive Approach" to compliance: "Awareness, Improvement and Enforcement."[976]

A more fundamental problem is whether the existing accessibility standards are suitable for the LTC sector, and the broader health sector. The Moran report suggests that the clearest

---

[971] *Toronto Transit Commission v. Ontario (Finance)*, *supra* note 964, at para 69.

[972] Windholz, *supra* note 50 at 9.

[973] Moran, *supra* note 951 at 52.

[974] O Reg 191/11, *supra* note 956, ss 82-86.1.

[975] *8677 v Director under the Accessibility for Ontarians with Disabilities*, 2014 2014 CanLII 46359 (ON LAT).

[976] Accessibility Directorate, "The Path to 2025: Ontario's Accessibility Action Plan", (1 June 2015), online: <https://www.ontario.ca/page/path-2025-ontarios-accessibility-action-plan>.

areas to consider for new standards development are health care and education. Specifically, during consultations, the hospital sector proposed developing a hospital or health-specific standard that would encompass the requirements of the existing AODA standards and adapt them to a health-care setting. Hospitals are serving patients with temporary or permanent disabilities at all times, which sets them apart from other organizations. Accessibility in a retail environment, for example, may not reflect the needs of health care patients. A health-specific standard would also reflect the complex statutory and regulatory environment in which health care functions, including the *Excellent Care for All Act, 2010* that has areas of overlap with the AODA.[977] The question whether any new standard can reflect the needs of LTC residents remain to be seen.

5.4.3 **Human Rights Code ("The Code")**

The Code was amended significantly in 2006: *Human Rights Code Amendment Act,* 2006, SO 2006, c 30 (Bill 107). Since June 30, 2008, all claims of discrimination under the Human Rights Code are dealt with through applications filed directly with the Human Rights Tribunal of Ontario (HRTO).[978] A new section of the Code enables a court to order monetary compensation or restitution for loss arising out of injury to dignity, feelings and self-respect, where a finding is made that a right under Part I of the Act has been infringed. But a person is not allowed to commence an action based solely on an infringement of a right under Part I.[979] An example of such monetary compensation can be found in *Friman v Toledo Estates Ltd, 2013*, a small claims court decision about provision of disabled parking space in a condominium building. The defendants were found liable for misrepresentation and infringement of the Code.[980] "The Ontario small claims court is now authorized under the OHRC to determine whether a defendant has breached the OHRC if the plaintiff is litigating in the small claims court on a related non OHRC matter."[981] As well, in 2012, Toby's Act (Bill 33), added "gender identity" and "gender expression" as prohibited grounds of discrimination under the Code. The grounds make it clear that trans people and other gender non-conforming individuals are entitled to legal protections in the same way that people are protected from discrimination and

---

[977] Moran, *supra* note 951 at 49.

[978] Tess Sheldon & Ivana Petricone, *Addressing the Capacity of Parties before Ontario's Administrative Tribunals: Promoting Autonomy and Preserving Fairness* (Toronto: Law Commission of Ontario, 2009) at 16 to 17.

[979] *Human Rights Code, supra* note 493, ss 46.1(1)-(2).

[980] *Friman v Toledo Estates Ltd*, *supra* note 967 at para 72.

[981] *Ibid* at para 70.

harassment based on race, age, disability and all other prohibited grounds.[982] The Code was also amended as a result of various omnibus bills, including government-wide initiatives to remove mandatory retirement[983] and update the definition of "spouse".[984]

The Code is relevant for my discussion about care because the Code can be used to deal with individual cases of discrimination since LTC is a service. It should be noted that individual regulatory colleges of health professionals also have guidelines on complying with the Code.[985] There are only three HRTO cases (but multiple decisions including interim decisions) that involve LTC residents. This small number of cases cannot really tell us much about systemic issues with LTC. Indeed, the low number of cases to date may be indicative of the difficulties of initiating a human rights compliant for LTC residents and for older disabled people in general. But each of these cases can shed some light on specific issues: capacity for initiating a legal proceeding;[986] whether medical judgment falls within the purview of the Code;[987] and the need to protect disabled people from their relations.[988] These issues will be addressed in future chapters.

5.4.4 *Convention on the Rights of Persons with Disabilities*

Finally, norms about human rights in international law can also be relevant in the lives of LTC residents. The *Convention on the Rights of Persons with Disabilities* (CRPD) is an international human rights treaty adopted by the United Nations General Assembly in 2006 which came into force on May 3, 2008.[989] The CRPD does not recognize new rights per se, nor is it the only instrument to address issues with disabilities.[990] Unlike many earlier international

---

[982] Ontario Human Rights Commission, "Policy on preventing discrimination because of gender identity and gender expression", online: <http://www.ohrc.on.ca/en/policy-preventing-discrimination-because-gender-identity-and-gender-expression/1-introduction>; *Bill 33, Toby's Act (Right to be Free from Discrimination and Harassment Because of Gender Identity or Gender Expression), 2012*.

[983] *Ending Mandatory Retirement Statute Law Amendment Act,* 2005, SO 2005, c 29.

[984] *Spousal Relationships Statute Law Amendment Act, 2005*, SO 2005, c 5.

[985] The CPSO expects its members to comply with their duty to accommodate and to make accommodations in a manner that is respectful of the dignity, autonomy and privacy of the person. College of Physicians and Surgeons of Ontario, *Policy Statement #2-15: Professional Obligations and Human Rights* (Toronto: College of Physicians and Surgeons of Ontario, 2015).

[986] *Romanchook v Garda Ontario*, 2009 HRTO 1077.

[987] *TenBruggencate v Elgin (County)*, 2010 HRTO 1467.

[988] *Romanchook v. Garda Ontario*, *supra* note 986; *Gan v College of Physicians and Surgeons*, 2015 HRTO 1045.

[989] United Nations Office of the High Commissioner for Human Rights, "Questions and Answers" online: <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/QuestionsAnswers.aspx>

[990] Walker, Julian, *The United Nations Convention on the Rights of Persons with Disabilities: An Overview (Publication No. 2013-09-E)* (Ottawa: Library of Parliament, 2013) at 2.

treaties that simply stated what rights are recognized by the UN, the CRPD outlines key steps and actions for States Parties (states that have given their consent to be bound by the CRPD) to take in order to promote and protect the human rights of people with disabilities.[991] CRPD requires states to report to the UN on their implementation progress and seeks to develop more dynamic participation with civil society and closer monitoring by independent mechanisms.[992] The Committee on the Rights of Persons with Disabilities ("Committee") is a body of 18 independent experts which monitors implementation of the CRPD. The members of the Committee serve in their individual capacity, not as government representatives. They are elected from a list of persons nominated by the States at the Conference of the State Parties.[993]

Canada signed the CRPD on March 20, 2007 and ratified it on March 11, 2010. Three issues are relevant to Canada's implementation of the CRPD. First, Canada has not yet signed the Optional Protocol, which establishes two additional mandates for the Committee: 1) the receipt and examination of individual complaints; 2) the undertaking of inquiries in the case of reliable evidence of grave and systematic violations of the Convention.[994] The Committee cannot receive communication from or on behalf of individuals or groups of individuals who claim to be victims of a violation of the rights recognized and protected by the CRPD if it concerns a State party to the Convention that is not a party to the Optional Protocol.[995] On November 30, 2017, the Government of Canada tabled the Optional Protocol in the House of Commons as a step towards accession of the Optional Protocol.[996] Second, Canada made two reservations when it ratified the CRPD. Canada reserved the right to continue to use substitute decision-making arrangements in appropriate circumstances and subject to appropriate and effective standards. It further reserved the right not to subject all such measures to regular review by an independent authority, "where such measures are already subject to review and

---

[991] *Ibid* at 1.
[992] *Ibid.*
[993] United Nations Office of the High Commissioner for Human Rights, *supra* note 989. See also *Ibid* at 10–11.
[994] *Ibid.*
[995] United Nations Committee on the Rights of Persons with Disabilities. *Fact sheet on the procedure for submitting communications to the Committee on the Rights of Persons with Disabilities under the Optional Protocol to the Convention* (Geneva: United Nations Committee on the Rights of Persons with Disabilities, 2011) online: <http://www.ohchr.org/Documents/HRBodies/CRPD/CRPD.C.5.2.Rev.1_en.doc>
[996] Employment and Social Development Canada, *The Government of Canada tables the Optional Protocol to the United Nations Convention on the Rights of Persons with Disabilities (News Release November 30, 2017)* (Government of Canada, 2017).

appeal." Another reservation pertains to the provision that sets out the obligation on States Parties to create a framework that includes one or more independent mechanisms to promote, protect and monitor the CRPD's implementation. Canada noted that this should be interpreted as accommodating the "situation of federal states where the implementation of the convention will occur at more than one level of government and through a variety of mechanisms, including existing ones." To date, the federal government has not designated a national mechanism.[997]

Although Canadians cannot take their complaints directly to the Committee, the CRPD is still relevant because of its normative values. Advocacy groups and scholars may still use the CRPD to contextualize the rights of long-term care home residents. The following provisions are particularly relevant:

- "States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life." (Article 12.2)
- "States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation." (Article 25)
- "States Parties recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability." (Article 28.1)
- "States Parties recognize the right of persons with disabilities to take part on an equal basis with others in cultural life" (Article 30.1)

5.4.5 **Summary**

The table below summarizes the changes:

---

[997] Library of Parliament, The United Nations Convention on the Rights of Persons with Disabilities: An Overview (Publication No. 2013-09-E) by Julian Walker (Ottawa: Library of Parliament, 2013) at 12. See also Council of Canadians with Disabilities "Monitoring of the CRPD" (http://www.ccdonline.ca/en/international/un/canada/monitoring-of-the-crpd)

Table 19: Accommodation of impairments under the previous and current regimes

	Previous	**Current**
Personal assistance, program design and social environment	Some guidance about accommodating impairments or disabilities in the Program Manual	Some of the guidance formalized in law New language of responsive behaviour
AODA	N/A	New
Human Rights Code	Yes	New - monetary compensation or restitution New – gender identity as a prohibited ground for discrimination
Convention on the Rights of Persons with Disabilities	No	New

In Chapter 2, I explain the definition of disabilism, which highlights "the existence of relationships (at individual and institutional scales) between those designated normal and those designated disabled in any social arena."[998] It follows that an important question is whether the responsibility to adjust rests with society or the disabled individual.[999] It is reasonable to conclude that the changes described in this section acknowledge that there is an obligation on those who provide care to accommodate the impairments of residents individually and collectively, although this obligation appears to be ad hoc and limited. Residents can be described as "right-bearers" if we consider the claims for accommodation that they can make under the LTCHA and the Human Rights Code. This discussion should not be construed as a complete explanation of how disability is addressed in the relevant legislation, but rather a description of the broader legal context in which LTC is delivered in Ontario. So far I have only

---

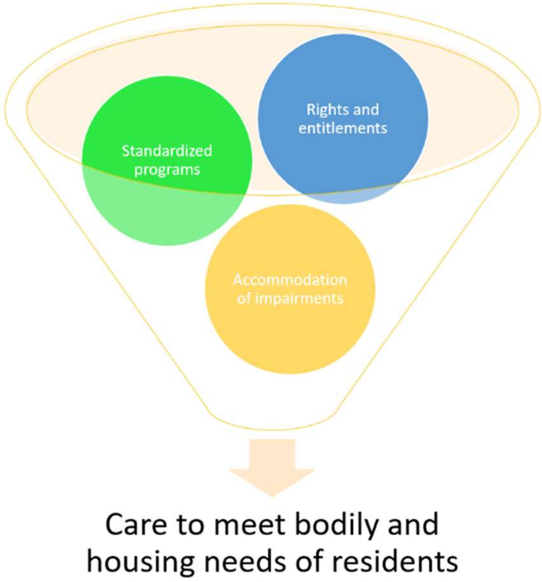
[998] Thomas, *supra* note 104 at 45.

[999] Christine Milligan & Carol Thomas, "Dementia and the Social Model of Disability: Does Responsibility to Adjust Lie with Society Rather Than People with Dementia?" (2015) 21:3 Signpost 5.

explained the most visible (and mostly positive) ways in which regulation responds to the needs of residents with disabilities. This could be depicted as law's promise for progressive changes in relation to disability. As we will see in subsequent chapters, disability is also reflected in regulation in less visible and more ambiguous manners.

5.5 Conclusion

Illustration 3: Care in LTC



In this chapter, I have explored how care - a contested concept in disability scholarship - manifested itself in the regulation of LTC homes. Illustration 3 summarizes what care looks like in law. There are indications that "rights" and choices for residents are built into the legal framework and therefore individual residents have some control over how care is delivered – at least from a "law on the books" perspective. The caring relationship is defined by standardized program structures and process, which set the context in which care providers interact with residents, substitute decision-makers, families and friends. I have also explored how disability is being accommodated in the provision of personal assistance, the social environment and program design. The changes reflected in the LTCHA should be explained and interpreted in conjunction with the AODA, the *Human Rights Code* and the *Convention on the Rights of Persons with Disabilities*.

I have referred to the feminist political economy literature in order to tease out the key themes in care. A closer examination of the changes has revealed that while care is indeed highly prescriptive and standardized, it is not uniformly so across all areas. The complexity of regulating care can also be explained by the fact that other bodies, such as regulatory colleges and professional associations, have influence over the meaning of quality of care. However, despite the plethora of requirements pertaining to delivery of care in hard law and soft law, government intervention is notably absent in mandating minimum staffing level other than the 24/7 RN requirement.

In sum, the LTCHA responded to the criticisms of care to some extent. In particular, the criticisms about disabled people being treated as objects of care or passive recipients of care can be partially addressed by the legally enabled mechanisms described in this chapter. However, some disability scholars reject the concept of care because of potential harm inherent in care. The LTCHA also emphasizes resident safety and security as integral to care, issues that will be addressed in the next chapter.

6 Respect for safety and security of the person

6.1 Introduction

The new legal framework for LTC emphasizes resident safety and security as integral to care. One could argue that legal recognition of the potential for violence in LTC homes acknowledges the painful history of the institutionalization of disabled people in Ontario and elsewhere. However, the notion of protecting safety and security simultaneously justifies institutional risk avoidance measures intended to protect residents from others present in homes and from each other. This is complicated by the fact that LTC is a communal setting and the safety of one person cannot easily be separated from the safety of others. Herring's idea of "intermingled interests"[1000] provides the theoretical basis for analyzing the impact of safety measures in the context of caring relationships. In addition to meeting needs, Herring notes that respect, responsibilities and relationality are also markers of care.[1001] These markers are useful for analyzing whether the safety measures mandated by law promote care. These measures also raise knotty questions about the tensions between acknowledging the extent of various impairments experienced by some residents and resisting the inclination to treat residents as helpless and dependent. As Pat Armstrong and other feminist political economy scholars argue persuasively, negotiating tensions between risk and safety is common in LTC, and many regulatory requirements are designed to avoid risk but at the expense of choice and autonomy of residents and workers.[1002] Hugh Armstrong explains the matter succinctly: "To rigorously protect against every possible risk is to transform a nursing home into some sort of 'total institution,' paradoxically generating the attendant risks of boredom, inactivity and social isolation, risks that are themselves unhealthy."[1003]

This chapter will proceed as follows. The first section provides a short review of sections 7 and 9 of the *Canadian Charter of Rights and Freedoms*. The second section will begin with unpacking the changes to responsibilities of the home and then outline the measures intended to

---

[1000] Herring, *supra* note 112 at 59–60.
[1001] *Ibid* at 14.
[1002] Armstrong, *supra* note 655.
[1003] Hugh Armstrong, "Chapter 1 Tensions Between Risk and Safety" in Pat Armstrong & Ruth Lowndes, eds, *Negotiating Tensions in Long-Term Residential Care: Ideas Worth Sharing* (Montreal: Centre for Policy Alternatives, 2018) 33 at 33.

identify those who can be admitted and remain in the home from a safety and security perspective. The third section will examine how regulatory changes respond to the risk of harm or interference of the body that may occur in caring relationships. The fourth section will explain the regulatory changes that correspond to challenges associated with living in a communal setting. I argue that these measures should be considered as part of a complex regulatory response to the potential harms in caring relationships. The residents' impairments are recognized as something that others in the home have to respond to and accommodate accordingly but at the same time the effects of the impairments are used to justify more intense monitoring, reporting and limitations on the liberty of residents. The main question is whether the interests of all in a caring relationship can be protected while still holding those institutions and persons accountable for harms that occurred in caring relationships. Some of the issues around accountability for protecting LTC residents as vulnerable citizens will be revisited again in Chapter 8.

6.2 Sections 7 and 9 of the *Charter*

Before proceeding to analyzing the LTCHA requirements with respect to safety and security of the person, it is useful to lay out the relevant *Charter* provisions that deal with safety and security of the person, mainly sections 7 and 9.[1004] While it is not the intention of this project to review the sections 7 and 9 jurisprudence in a comprehensive manner, it is useful to be mindful of the interests that are protected by these provisions. Many of the leading cases are in the areas of criminal law (such as policing and solitary confinement in prison) and immigration (such as being detained while awaiting immigration removal), therefore not all of them will be directly applicable to my case study. But the LTCHA requirements have to comply with the requirements of the *Charter* and my objective here is to provide a foundation that will help to account for the interests that the regulatory changes in LTC are supposed to protect.

6.2.1 **Section 7**

Section 7 reads: ''Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental

---

[1004] Hall suggests that sections 10 and 12 may be applicable to care facilities or nursing homes. Margaret Hall, *Developing an Anti-Ageist Approach Within Law* (Toronto: Law Commission of Ontario, 2009) at 20–21.

justice."[1005] While much of the jurisprudence of section 7 and, therefore, fundamental justice, has been in relation to criminal law, the Supreme Court has permitted its application to extend well beyond this area such that the demands of fundamental justice now apply to a range of civil and administrative contexts.[1006]

The rights to life, liberty and security of the person require further elaboration. According to *Carter v. Canada*: ". . . the case law suggests that the right to life is engaged where the law or state action imposes death or an increased risk of death on a person, either directly or indirectly."[1007] Further, the Supreme Court opines on the scope of "liberty and security". Liberty and security of the person are distinct interests but underlying both is a concern for the protection of individual autonomy and dignity.[1008] Liberty protects the right to make fundamental personal choices free from state interference. Security of the person encompasses a notion of personal autonomy involving control over one's bodily integrity free from state interference. This interest is engaged by state interference with an individual's physical or psychological integrity, including any state action that causes physical or serious psychological suffering.[1009] It is important to remember that "[s]ection 7 does not promise that the state will never interfere with a person's life, liberty or security of the person — laws do this all the time — but rather that the state will not do so in a way that violates the principles of fundamental justice."[1010] The courts have recognized a range of rights protected under s.7 within and outside of the criminal context.[1011]

[1005] *Charter*, *supra* note 121, s 7.

[1006] Mark Carter, "Fundamental Justice" (2017) 78 SCLR(2d) 259, para 16.

[1007] *Carter v Canada (Attorney General)*, 2015 SCC 5 at para 62, [2015] 1 SCR 331 [*Carter*].

[1008] *Ibid* at para 64.

[1009] *Ibid*, s 64; Hall, *supra* note 1004 at 16.

[1010] *Ibid* at para 71.

[1011] Examples include right to privacy (*R. v. O'Connor*, [1995] 4 S.C.R. 411), parental decision-making and other attributes of custody (*New Brunswick (Minister of Health and Community Services) v. G. (J.*), [1999] 3 S.C.R. 46), one's choice to purchase private health insurance for services covered by the public health care scheme (*Chaoulli v Quebec (Attorney General), 2005 SCC 35*, [2005] 1 SCR 791 (SCC).) and accessing health services in a safe injection site (*Canada (Attorney General) v PHS Community Services Society 2011 SCC 44*, [2011] 3 SCR 134.). Shaun O'Brien, Nadia Lambek & Amanda Dale, "Accounting for Deprivation: The Intersection of Sections 7 and 15 of the Charter in the Context of Marginalized Groups" (2016) 35 National Journal of Constitutional Law; Scarborough 153 at 178; Young, Margot, ed, *Poverty: Rights, Social Citizenship, and Legal Activism* (Vancouver: UBC Press, 2007); Margot Young, "Social Justice and the Charter: Comparison and Choice" (2013) 50:3 Osgoode Hall Law Journal 669.

In recent cases such as *Bedford v Canada*[1012] and *Carter v. Canada,* the Supreme Court of Canada has articulated a structured two-part test for breach of s.7 rights.[1013] The first part considers infringements to one of the rights to life, liberty, and security of the person by the government. Courts have been relatively strict in determining that what qualifies as an ‘‘infringement” is an action or inaction (but almost exclusively an action) taken by the government that ‘‘deprives” the claimant of their rights to life, liberty or security of the person.[1014] The second part then considers the violations of the principles of fundamental justice.[1015] “Laws that impinge on life, liberty or security of the person must not be arbitrary, overbroad, or have consequences that are grossly disproportionate to their object.”[1016] Hamish Stewart explains that each of these norms is distinct from the other two: “a law that is effective in achieving its purposes but goes too far (overbreadth) is not the same as a law that is ineffective (arbitrary) or effective and suitably tailored but nonetheless excessively damaging to section 7 interests (grossly disproportionate).”[1017] Although it is difficult to justify a s.7 violation, in some situations the state may be able to show that the public good justifies depriving an individual of life, liberty or security of the person under s. 1 of the *Charter*.[1018]

How the court considers an alleged infringement to one of the rights to life, liberty, and security of the person by the government has great significance for the construction of safety risks in LTC and for the measures designed to address those risks in law. As Margaret Hall states, the principles of fundamental justice, have both a procedural and a substantive aspect.[1019] According to Mark Carter, the principles of fundamental justice form the standards that legislation and government activity must meet in order for deprivations of life, liberty and security to be permissible.[1020] I believe that it is not difficult for the government to argue that a protection related law that restricts a resident’s liberty has a “rational connection between the

---

[1012] *Canada (Attorney General) v Bedford*, 2013 SCC 72, [2013] 3 SCR 1101.

[1013] Kiran Kang & Sonia K Kang, “Interpreting Equality Rights under Sections 7 and 15 in New and Old Ways: An Empirical Analysis of the Concurrent Claims Approach” (2016) 35:2 NJCL 235 at 244.

[1014] For example, see O’Brien, Lambek & Dale, *supra* note 1011 at 160.

[1015] Bailey Fox, “You Are Not Alone: Ontario and British Columbia Invalidate Solitary Confinement”, (6 February 2018), online: *TheCourt.ca* <http://www.thecourt.ca/not-alone-ontario-british-columbia-invalidate-solitary-confinement/>; O’Brien, Lambek & Dale, *supra* note 1011 at 161.

[1016] *Carter*, *supra* note 1007, at para 73.

[1017] Hamish Stewart, “Bedford and the Structure of Section 7” (2015) 60:3 McGill Law Journal 575 at 585.

[1018] *Carter*, *supra* note 1007, at para 95.

[1019] Hall, *supra* note 1004 at 18; *Cunningham v Canada*, [1993] 2 SCR 143 at 152.

[1020] Carter, *supra* note 1006, para 1.

object of the law and the limit it imposes on life, liberty or security of the person”.[1021] However, it is more difficult to construct a law that does not violate the other two norms. Although the inquiry is not about whether Parliament has chosen the least restrictive means, the government still has to demonstrate “whether the chosen means infringe life, liberty or security of the person in a way that has no connection with the mischief contemplated by the legislature.” [1022] LTC residents are a very diverse group (see Chapter 4). Any law that restricts liberty has to be construed in such a way that it is only applicable to a particular class of people that requires protection and does not encompass those who do not require protection (as the claimants in *Carter*). Further, the government will also have to argue that the impact of the restriction on the individual’s life, liberty or security of the person is not grossly disproportionate to the object of the measure.[1023] That means the government will have to prescribe very specific criteria about who requires protection, for how long, for what a home can or cannot do in order to ensure safety, and how there are no other alternatives.

6.2.2 **Section 9**

Section 9 guarantees the right to be free from arbitrary detention: “Everyone has the right not to be arbitrarily detained or imprisoned.”[1024] According to Newman, in a broad sense, the prohibition against arbitrary detention or imprisonment protects individual liberty against unjustified state interference. But in a narrower sense, the right guarantees that the state must not detain or imprison individuals on a discretionary basis but only based on law.[1025] Claims under section 9 of the *Charter* that have made their way before the Supreme Court have generally taken one of two forms. First, the guarantee has been used to challenge the constitutionality of a wide array of legislation that authorizes detention or imprisonment. The second category of claims under section 9 of the *Charter* involves challenges directed at the decision to detain or imprison

---

[1021] *Carter*, *supra* note 1007 at para 83.
[1022] *Ibid* at para 85.
[1023] *Ibid* at para 89.
[1024] *Charter*, s 9.
[1025] Halsbury’s Laws of Canada (online), *Constitutional Law: Charter of Rights*, “IX. Legal Rights: Sections 8 to 14” at HCHR-73 "Purpose of s. 9 protection and general approach" (2014 Reissue).

in individual cases.[1026] Issues of contention include: (1) what "detention" means; (2) what "arbitrary" means and; (3) whether "arbitrary" has or should be equated with "unlawful".[1027]

In *R v. Therens*,[1028] three types of detention were explained: (i) physical detention, where a person is actually subject to physical constraint; (ii) detention by lawful compulsion, where there are legal consequences for the failure to comply with a police officer's demand (as in *Therens*); and (iii) psychological detention, where although in fact the police have no authority to detain a person that person reasonably feels compelled to remain. In *R v. Grant*,[1029] the test for a psychological detention was created: whether a reasonable person in the individual's circumstances would conclude that he or she had been deprived by the state of the liberty of choice, taking into account a number of factors.[1030] The factors are as follows: (a) the circumstances giving rise to the encounter as they would reasonably be perceived by the individual; (b) the nature of the police conduct; and (c) the particular characteristics or circumstances of the individual where relevant including age, physical stature, minority status and level of sophistication.[1031]

Arbitrariness is determined by whether there are appropriate express or implied standards that determine whether a power to detain or imprison is exercised. This general principle applies both to the analysis of a particular detention or imprisonment and to the testing of a law that authorizes a particular detention or imprisonment. The existence of detailed and demanding criteria applied prior to a detention or arrest will typically undermine any claim for arbitrariness.[1032] Detention without adequate or prompt review is also arbitrary, such as a failure leading to an inability to apply standards to that detention.[1033] It should be noted that the courts have decided on required legal standards for non-arbitrariness in specific detention contexts. For

---

[1026] James Stribopoulos, “The Forgotten Right: Section 9 of the Charter, Its Purpose and Meaning” (2008) 40 SCLR(2d) 211 at paras 13–15.

[1027] Steve Coughlan, “Arbitrary Detention: Whither -- or Wither? -- Section 9” (2008) 40 SCLR(2d) 147 at para 6.

[1028] *R v Therens*, [1985] 1 SCR 613. This case was about an accused who was stopped for a breathalyser test, and was argued under s.10(b) of the *Charter*. The definition of "detention" was applicable to both section 9 and section 10. See Steve Coughlan & Robert J Currie, “Sections 9, 10 and 11 of the Canadian Charter” (2013) 62 SCLR(2d) 143 at para 9.

[1029] *R v Grant*, 2009 SCC 32, [2009] 2 SCR 353. The case was about the legality of police stopping a pedestrian.

[1030] Coughlan & Currie, *supra* note 1028 at para 73.

[1031] *R. v. Grant*, *supra* note 1029, at para 44; Coughlan & Currie, *supra* note 1028 at para 12.

[1032] Halsbury’s Laws of Canada (online), *Constitutional Law: Charter of Rights*, “IX. Legal Rights: Sections 8 to 14”, at HCHR-75 "Arbitrariness of detention or imprisonment" *(*2014 Reissue).

[1033] *Ibid*.

example, detention in psychiatric facilities cannot be based on blanket categories but must be based on carefully defined criteria furthering such objects as the safety of the public and the safety of individuals.[1034]

Although section 9 is considered most frequently in the criminal law context, it has been considered in the context of mental health.[1035] According to Hall, Section 9 may be applicable where a person is "involuntarily committed" to a care facility or nursing home and where the criteria for "committal" is determined to be vague and overly broad.[1036] Although the regulatory framework for LTC does not use the language of "committal" and there is no change in legal status[1037] for those residents in locked units, it is instructive to consider how the courts decide *Charter* challenges related to criteria for involuntary committal. In *Thwaites v. Health Sciences Centre Psychiatric Facility*, the Manitoba Court of Appeal was asked to rule whether the criteria for involuntary committal contained in the legislation offended sections 7, 9 and 15 of the *Charter*.[1038] The case was decided on section 9 of the *Charter* and the challenge was successful. The comments of Philip J.A. indicate the importance that standards for committal should be non-arbitrary:

> [34] In *Lyons*, La Forest J. said of the appellant's contention that Part XXI of the *Criminal Code* offends s. 9 of the *Charter* [at p. 227 D.L.R., p. 35 C.C.C.]:
>
> > However, even giving the word "arbitrary" its broadest signification, it is readily apparent that not only is the incarceration statutorily authorized, but that the legislation narrowly defines a class of offenders with respect to whom it may properly be invoked, and prescribes quite specifically the conditions under which an offender may be designated as dangerous.
>
> Applying those considerations to the compulsory admission provisions of the Act, detention is statutorily authorized, but the legislation does not narrowly define those persons with respect to whom it may be properly invoked, and does not prescribe

---

[1034] Halsbury's Laws of Canada (online), *Constitutional Law: Charter of Rights*, "IX. Legal Rights: Sections 8 to 14", at HCHR-76 "Required legal standards for non-arbitrariness in specific detention contexts" (2014 Reissue).

[1035] Hall, *supra* note 1004 at 18.

[1036] *Ibid* at 19.

[1037] Pursuant to the *Mental Health Act*, there are different categories of patients: voluntary or informal patients and involuntary patients. A person's status may change (the status of an informal or voluntary patient to that of an involuntary patient and vice versa). *Mental Health Act,* RSO 1990, c M.7, ss 19, 20(6)-(7).

[1038] *Thwaites v Health Sciences Centre Psychiatric Facility,* 1988 CanLII 5697 (Man CA), at para 2. The cases were *Bobbie v Health Science Centre,* [1989] *2* WWR 153 (Man QB); *McCorkell v Director of Riverview Hospital 1993* CanLII 1200 (BC SC).

> specifically the conditions under which a person may be detained. The compulsory admission provisions of the Act fail the test and are clearly arbitrary.
>
> [35] Scollin J. spoke of the "ultimate dependence" of the legislation on "professional ability and integrity" as a factor to be taken into account in considering the arbitrariness of the detention. With respect, I do not see how professional ability and integrity can operate to save statutory provisions which are inconsistent with the *Charter*. I find support for that conclusion in the comments of Lamer J. in *R. v. Smith, supra*, at pp. 481-2 D.L.R., p. 48 W.W.R.:
>
>> In my view, the section cannot be salvaged by relying on the discretion of the prosecution not to apply the law in those cases where, in the opinion of the prosecution, its application would be a violation of the *Charter.* To do so would be to disregard totally s. 52 of the *Constitution Act, 1982* which provides that any law which is inconsistent with the Constitution is of no force or effect to the extent of the inconsistency and the courts are duty-bound to make that pronouncement, *not to delegate the avoidance of a violation to the prosecution or to anyone else for that matter.*[1039]
>
> (My emphasis.)

In subsequent challenges of mental health legislation, the respective governments were able to demonstrate the statutory provisions in question addressed concerns raised in *Thwaites* regarding “arbitrariness”.[1040] In a B.C. case, the Supreme Court of British Columbia considered the B.C. mental health legislation (which was similar to the updated Manitoba legislation after *Thwaites*) and concluded that:

> As to the standards for committal, I find that they strike a reasonable balance between the rights of the individual to be free from restraint by the state and society's obligation to help and protect the mentally ill. . . Unlike incarceration in the criminal justice system, involuntary committal is primarily directed to the benefit of the individual so that they will regain their health.”[1041]

Arguably, for legislative provisions that authorize detention-like living circumstances to be *Charter* compliant, they have to narrowly define a class of residents with respect to whom the admission criteria may properly be invoked, and must prescribe quite specifically the conditions under which a resident may be admitted. Further, the legislation cannot simply delegate the

---

[1039] *Thwaites v. Health Sciences Centre Psychiatric Facility, supra* note 1038, at paras 34–35.
[1040] Hall, *supra* note 1004 at 20.
[1041] *McCorkell v. Director of Riverview Hospital 1993* CanLII 1200 (BC SC), *supra* note 1038 at 47.

decision to a health care provider without any checks and balances. As well, the court is expected to attend to the question whether the admission to a detention-like environment is *primarily* for the benefit of the individual.

6.2.3 **Summary**

The *Charter* is relevant for the discussion of legislative provisions for risk reduction measures in homes because while well-intentioned, these measures may deprive the life, liberty and security of residents. From a legal drafting perspective, the key is whether such risk reduction provisions include all the necessary safeguards to withstand potential *Charter* challenges. It is not surprising that to avoid claims of arbitrariness, overbreadth, and gross disproportionality, the government has a strong incentive to demonstrate through very prescriptive regulatory requirements (for example, through establishment of a clear threshold) that any deprivation is consistent with the principle of fundamental justice. But it would be utterly wrong to assume that a *Charter*-compliant regulatory regime also promotes all four markers of care.

6.3 Who can be accommodated in a LTC home?

To begin, I summarize changes in LTC regulation that contribute to a home's approach to safety and security of residents and others. While safety is never defined explicitly in legal terms in the LTCHA, it is probably not controversial to assume that safety means absence of physical harms, given the measures explained below. Similarly, security is also not defined legally but one could argue that it implies keeping out external threat or risk of threat or alternatively, keeping a potential threat contained. After laying out the overarching principles about responsibilities of the home, the first issue is how to determine who can be safely accommodated in the home in a non-arbitrary way and under what conditions. The processes for admitting and discharging residents will be discussed in more detail in Chapter 8. Here the concern is how the objective of safety is factored into the processes of admitting and discharging. Such determination is dependent on the "intrinsic factors" (to use Shakespeare's terminology) of residents as well as extrinsic factors, such as the physical design of the home. The tension is to promote safety of residents, employees and others in the home while potentially restricting the liberty of residents who because of their impairments, may pose threats to others. In 2007, the former Parliamentary Assistant Monique Smith articulated this tension during clause-by-clause consideration of the LTCHA: “We believe that by amending the fundamental principle to include the word "primarily," we are acknowledging that it is not just the home of the residents but other things, including a workplace. We acknowledge that those workers are entitled to protection under the *Occupational Health and Safety Act*.”[1042] Negotiation of this tension is even more pressing now as residents are admitted to LTC older and with more profound impairments than before including cognitive impairments (see Chapter 4).

6.3.1 **Overarching principles – the home’s responsibilities**

The LTCHA reiterates the importance of resident safety and security, either as a qualifying condition for various rights, or as justification for additional measures under the new regime. This is not entirely new - as is reflected in the current and previous Residents’ Bill of Rights: “Every resident has the right to live in a safe and clean environment” and “Every resident has the right to keep and display personal possessions, pictures and furnishings in his or her room subject to safety requirements and the rights of other residents.”[1043] The fundamental principle to be applied in the interpretation of the LTCHA and the Regulation is that a home is primarily the home of its residents and is to be operated so that it is a place where its residents may live with dignity and in security, safety and comfort and have their physical, psychological, social, spiritual and cultural needs adequately met.[1044] While the fundamental principle is not new, the reference to “security, safety and comfort” is new and represents the increasing prominence of resident safety and security as a common concern. Similarly, in the Preamble: “. . . care and services provided meet the needs of the resident and the safety needs of all residents . . . quality accommodation that provides a safe, comfortable, home-like environment …”[1045] Last but not least, the most obvious new requirement is that the home must ensure that it is a safe and secure environment for residents.[1046]

These broad principles are more than rhetoric and are important for interpreting the obligations of homes, especially when something goes wrong. In the only two enforcement decisions that have been appealed to the Health Services Appeal and Review Board, these

---

[1042] Ontario, *supra* note 867.
[1043] *Long-Term Care Homes Act, 2007*, *supra* note 425, ss 3(1)5, 3(1)10.
[1044] *Ibid*, s 1.
[1045] *Ibid*, Preamble.
[1046] *Ibid*, s 5.

legislative provisions were cited as relevant to the matters. In *Seniorscare Operations v Director, Performance Improvement and Compliance Branch*, the Health Services Appeal and Review Board cited sections 1, 3 and 5 of the LTCHA[1047] in order to emphasize the importance of the safety of residents. "The Appeal Board finds that the overriding principle to be applied in the interpretation and application of the Act is the best interest of the residents. Although the commercial interests of the licensee must also be taken into account, those interests must take a secondary position to the interests of the residents."[1048] *In Morriston Park Nursing Home v Ontario (Health and Long-term Care)*, the Health Services Appeal and Review Board writes: "Finally, the Appeal Board notes that resident safety is identified as a key concern in sections 1, 3 and 5 of the Act. The provision of very few and narrow exceptions to the requirement for 24/7 RN coverage requirement is consistent with the importance of safety for this vulnerable population."[1049]

These broad principles have ramifications for setting expectations about how the home should influence and shape the behavior of people within the home. The home's general responsibility for a safe and secure environment is translated into more specific requirements. The fulfillment of these requirements can then be measured and documented.

By way of example, the LTCHA attempts to control the risks stemming from interactions between staff and volunteers with residents. A new requirement is prior screening of staff and volunteers, and applicable exemptions from such screening.[1050] Training and orientation have not changed substantively as requirements have been moved from regulation and Program Manual to the LTCHA and its regulation. Many new training requirements are related to new regulatory requirements such as minimization of the use of restraints and confining (to be discussed later in this chapter). Under the LTCHA, every home must ensure that a training and orientation program is developed and implemented.[1051] Additional training requirements are prescribed for direct care

---

[1047] *Seniorscare Operations v Director, Performance Improvement and Compliance Branch,* 2014 CanLII 81247 (ON HSARB*)*, at paras 117–119.
[1048] *Ibid* at para 120.
[1049] *Morriston Park*, *supra* note 875 at para 63.
[1050] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 75. The screening measures must include police record checks, unless the person being screened is under 18 years of age.
[1051] O Reg 79/10, *supra* note 811, ss 216–217. Requirements such as designated lead, topics, record-keeping and evaluation are also provided for.

staff, such as abuse recognition and prevention, mental health issues, including caring for persons with dementia and behaviour management. [1052] But some requirements, such as availability of library resources, have been dropped too.[1053] As well, the home must develop and implement an orientation program for volunteers.[1054] The point is that having properly trained staff and volunteers (facilitated by legally mandated screening, orientation and training) is part of the response to the safety and security of residents and others in the home, considering the specific clinical characteristics of the current and future cohort of residents.

6.3.2 **Admission and discharge of residents**

The LTC admission process is designed to ensure that those who, for a variety of reasons, can no longer reside safely in the community can access LTC. A related consideration is under what condition(s) an applicant may be admitted and an applicant's impairment(s) is clearly implicated. A new requirement is to explicitly address the procedural protections of those who would be confined (a term to be defined in the regulation)[1055] once they are admitted. A placement co-ordinator employed by a LHIN[1056] must consider whether an eligible LTC applicant may need to be confined in the home and must make a recommendation to the home after considering whether (1) there would be a significant risk that the applicant or anyone else would suffer serious bodily harm if the applicant were not confined; (2) confining the applicant would be reasonable in light of the applicant's physical and mental condition and personal history; and (3) a physician or registered nurse in the extended class.[1057] The placement co-ordinator must advise the applicant or the substitute decision-maker of the confinement recommendation prior to authorization of admission.[1058] The home must approve the applicant's admission to the home unless the home lacks, (a) the physical facilities necessary to meet the

---

[1052] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 76(7); O Reg 79/10, *supra* note 811, s 221.

[1053] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 1002-02, page 6.

[1054] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 77. Previously the requirements were in the Program Manual. Now the content is prescribed in the LTCHA and its regulation

[1055] As of September 27, 2019, the provisions related to confinement have not been proclaimed.

[1056] At the time of writing, the LHINs are still responsible for LTC placement. Section 153 of O Reg 79/10 states: "Every person or entity that is not a local health integration network is ineligible for designation as a placement co-rdinator." Therefore, the LHINs are the designated placement co-ordinators.

[1057] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 44(2.1). More providers could be authorized by regulation to recommend confining of a resident.

[1058] *Ibid*, s 44(2.2).

applicant's care requirements; or (b) the nursing expertise necessary to meet the applicant's care requirements.[1059] I will return to the issue of confinement later in the chapter.

To ensure residents are not removed from the home (i.e. discharged) without legitimate reasons while ensuring a safe and secure environment, the law sets out the requirements for and restrictions on discharging residents from a home. The mandatory and permissible grounds for discharge remain the same, such as death and medical and psychiatric absences that exceed the thresholds allowed in the respective regulations.[1060] In general, the LTCHA provides more procedural protections for residents in the form of greater clarity about what the home can and cannot do. For example, it is an offence to discharge or threaten to discharge a resident or to subject a resident to discriminatory treatment (including threatening any family member, substitute decision-maker or person of importance to a resident that such action will be taken) because of anything that is disclosed to the Director or an inspector, or for giving evidence in a legal proceeding, even if the resident or other person acted maliciously or in bad faith. [1061] Another example is the more elaborate notice requirements prior to discharge when a home closes some or all of its beds.[1062]

Under both regimes, a home may discharge a resident because the home can no longer provide a safe and secure environment. In the *Nursing Homes Act*, a home was permitted to discharge a resident if other arrangements were made to provide the accommodation, care and secure environment required by the resident.[1063] However, by contrast, the LTCHA's procedural requirements are more extensive, including: alternatives to discharge must have been considered and tried; alternative arrangements must have been made in collaboration with the appropriate placement co-ordinator and other health service organizations; the resident and the resident's substitute decision-maker, if any, and any person either of them may direct must be kept informed and given an opportunity to participate in the discharge planning and that the resident's wishes are taken into consideration; a written notice must be provided to the resident, the resident's substitute decision-maker, if any, and any person either of them may direct, setting out

---

[1059] *Ibid*, s 44(7). More grounds of refusal could be prescribed in the regulation in the future.
[1060] Reg 832, *supra* note 831, ss 47–49; O Reg 79/10, *supra* note 811, ss 144–146.
[1061] Ministry of Health and Long-Term Care, *supra* note 782 at 2–77.
[1062] O Reg 79/10, *supra* note 811, ss 147, 306.
[1063] Reg 832, *supra* note 831, ss 48(2)(a), 49(2).

a detailed explanation of the home's discharge decision.[1064] That said, under the LTCHA, there is no way for a resident or the substitute decision-maker to challenge or appeal the home's decision other than complaining to the Ministry if the discharge decision is not made in accordance with legislative requirements.

6.3.3 **Physical design of a home**

A variety of rules apply to the physical design of a home. In addition to statutes, the Ministry has published various manuals pertaining to design of LTC homes over the years. The *Long-Term Care Home Design Manual, 2015* (the Design Manual) contains the Ministry's current design standards for LTC homes being developed or redeveloped in Ontario.[1065] The Manual includes design objectives, design standards for LTC homes' resident, staff and public spaces.[1066] The focus here is how statutory requirements about physical design supplement the discussion about safety and security.[1067]

The notion of "safety and security" has been integrated into the requirements for the physical design of homes. These requirements contribute to the configuration of space within the home and provide specifications related to doors, windows, furnishings, elevators, communication and response systems etc.[1068] The majority of the requirements are similar to those in the *Nursing Homes Act,* its regulation and the Program Manual. Some have been updated to articulate more clearly the risks to residents, for example, the risks of bed rails are more clearly articulated.[1069] However, from a law on the books perspective, the LTCHA is not uniformly more prescriptive than the *Nursing Homes Act* as some design requirements have also been removed or scaled back. Some requirements related to elevators and windows have been removed.[1070] These requirements may be experienced as more prescriptive by non-profit and

---

[1064] O Reg 79/10, *supra* note 811, s 148(2).
[1065] Ministry of Health and Long-Term Care, *Long-Term Care Home Design Manual 2015* (Toronto: Ministry of Health and Long-Term Care, 2015).
[1066] *Ibid* at 1.
[1067] An important theme in scholarly debates is the idea of a "home like" environment. See Braedley & Martel, *supra* note 678.
[1068] O Reg 79/10, *supra* note 811, ss 9–23; Ministry of Health and Long-Term Care, *supra* note 782 at 2-7-2–11.
[1069] O Reg 79/10, *supra* note 811, s15.
[1070] *Ibid*, ss 10, 16. For example, section 23 of Reg 832 stated that an elevator must equipped with handrails on the interior walls etc. These types of specificities no longer appear in the LTCHA.

municipal homes who were under *Charitable Institutions Act* and *Homes for the Aged and Rest Homes Act.*

The last point about the physical design of the home is the creation of different types of space within a home that are linked to the biomedical characteristics or needs of residents such as dementia. A new concept, the "specialized unit", is introduced in the LTCHA. It means "any unit designated by or in accordance with the regulations to provide or offer certain types of accommodation, care, services, programs and goods to residents."[1071] The Director is authorized to designate a specialized unit in a home on the recommendation of the LHIN, or alternatively, on his/her own initiative after considering the input of the LHIN and the home.[1072] A specialized unit cannot not be designated without the agreement of the home.[1073] The rules regarding admission to and transfer from specialized units are also provided for.[1074]

6.3.4 **Summary**

Table 20: Key changes related to who can be accommodated under the *Nursing Homes Act* and the LTCHA

	Nursing Homes Act	**LTCHA**
Overarching principles	A home is primarily the home of residents	Home must ensure that it is a safe and secure environment for residents Screening for staff and volunteers Additional training and orientation requirements
Admission and discharge of residents	No reference of confining	More procedural protections for those who would be

---

[1071] *Long-Term Care Homes Act, 2007, supra* note 425, s 39(3).

[1072] O Reg 79/10, *supra* note 811, s 198(2).

[1073] *Ibid*, s 199

[1074] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 39; O Reg 79/10, *supra* note 811, ss 200–205.

	Nursing Homes Act	**LTCHA**
		confined once they are admitted More procedural protections for those who are deemed not safe to remain in the home
Physical design of the home	Specifications related to doors, windows etc	Updated requirements to express the risks to residents New concept of "specialized units"

In sum, the regulatory changes are intended to reinforce the objective of resident safety and security - as evident in the overarching principles of the LTCHA. The first measure is controlling who is allowed to be admitted (under what conditions) and then remain in the home. Having appropriately trained staff and volunteers is another measure. Safety also depends on whether the physical design of the home can meet the needs of all residents and that a subset of residents who are deemed to threaten the safety of themselves and others. The majority of changes are not significant as they are simply changes in legal form. The more significant changes are those related to confinement and discharge of residents. More clarity and certainty about these aspects acknowledge that homes (and those who work in them) have responsibilities[1075] in relation to their residents. The empirical question is whether law can actually enable homes to fulfill their responsibilities to residents while still respecting fundamental justice. I will return to this question in Chapter 9. The next section will turn to the regulatory changes that are intended to strengthen prevention of harm to residents.

6.4 Prevention of physical (bodily) harm to residents

An important consideration in the design of the new regime is that risk-reduction measures authorized by law must be in accordance with the principle of fundamental justice. Since these measures also create situations similar to detention, s.9 of the *Charter* should apply

---

[1075] Herring, *supra* note 112 at 60–62. Recall responsibility is one of the four markers of care.

too. As noted in the previous section, the law clearly establishes who is in charge of safety and security: the home. The focus here is on measures concerning potential physical or bodily harm suffered by residents because of some kind of interference of the body but it is acknowledged that there is always a mental component when a person's bodily integrity is engaged. Note that security of the person is not limited to physical integrity: ". . . security of the person is violated by state action interfering with an individual's mental integrity."[1076] Building on empirical observations from the feminist political economy literature about negotiating the tensions between safety and risks in LTC, I explore what a home must do to prevent harm inflicted on residents by caregivers and other residents. Here, harm is understood in a relational context. By that, I mean the interference or harm occurs between people who are in a care relationship and that trust is integral to this relationship. Herring argues that the nature of power in a caring relationship is not straight forward.[1077] The measures addressed here have to do with the fact that residents and caregivers are interdependent; that is their well-being is mutually dependent on each other's intentions and actions, as explained by Herring's idea of "intermingled interests". As well, a central aspect of a caring relationship is respect for each other.[1078] Three sets of changes are addressed below: the minimization of restraining and confining policy, zero tolerance for abuse and neglect and responsive behaviour. The strengths and weaknesses of these changes can be analyzed from the perspective of promoting respect as a marker of care.

6.4.1 **Minimization of restraining and confining policy**

To be certain, the use of restraints in LTC is not necessarily unlawful. Rather, the law's pre-occupation is to define when restraining is lawful and to establish the appropriate checks and balances. The *Nursing Homes Act* provided very limited guidance with respect to the use of restraints. In fact, there was no definition of "restraint" in the Act. Pursuant to the Residents' Bill of Rights, "[e]very resident who is being considered for restraints has the right to be fully informed about the procedures and the consequences of receiving or refusing them".[1079] The Regulation only provided requirements for the use of physical restraints, including permissible situations where such restraints could be used, authorization, duration, regular

---

[1076] *R v Mills*, [1999] 3 SCR 668, at para 85.
[1077] Herring, *supra* note 112 at 24.
[1078] *Ibid* at 280.
[1079] *Nursing Homes Act*, *supra* note 786, s 2(2)8.

assessment/monitoring, minimal conditions (not to cause harm or the least amount of discomfort), and written policies and procedures on the use of restraints.[1080] The Program Manual provided additional guidance by defining chemical restraint, environmental restraint, and physical restraint.[1081] Policies and/or procedures for ethical issues should include use of chemical, physical and environmental restraints.[1082]

The LTCHA offers more substantive and procedural protections to residents than the *Nursing Homes Act,* and the objective of minimization of confining and restraining of residents is clear. These protections for residents are necessary if we consider the requirements of the *Charter,* in particular, the jurisprudence on sections 7 and 9 of the *Charter*. For care providers, these protections may also be desirable because they provide greater legal certainty about what is permissible and what is not. The new system, which has been updated pursuant to Bill 160 in 2017, sets out the requirements relating to minimizing the restraining and confining of residents, and when and how physical devices and personal assistance service devices (PASDs) are to be used in a home. The LTCHA can be described as more stringent than the *Nursing Homes Act* because the threshold for the lawful restraining and confining residents is higher than it was the previous regime and the concept of confining is also new. The following features are highlighted: common law duty, written policy, checks and balances, confining of residents, PSADs and soft law.

6.4.1.1 LTCHA Requirements

Although a system is in place to address restraining and confining, the common law duty of a caregiver to restrain or confine a person continues to be applicable.[1083] According to the Ministry's guidance on restraining by physical device, the common law duty allows staff to act quickly when immediate action is required to prevent serious bodily harm to the resident or others in an emergency situation. Further, the use of the common law duty should not be a routine part of any plan of care.[1084] The Ministry also points out that both the LTCHA and the

---

[1080] Reg 832, *supra* note 831, s 55.
[1081] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 9901-01, page 6–7.
[1082] *Ibid* at Tab 1001-02, page 6.
[1083] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 36.
[1084] Ministry of Health and Long-Term Care, *supra* note 782 at 2–87. The assumption is that there is no time to meet the requirements specified for restraining using physical device.

Regulation are silent about who may authorize the use of the physical device to restrain a resident under the common law duty. Since certain types of staff may not be in the home at the time of the emergency, the home should consider the relationship between the urgent nature of restraining under common law and the presence of appropriate staff when developing the policy on restraining under the common law duty.[1085]

First and foremost, every home must have a written policy to minimize the restraining and confining of residents, and to ensure that any restraining or confining is done in accordance with the law. The home must ensure that the policy is complied with.[1086] The content of the policy is also prescribed.[1087] The LTCHA also specifies what homes cannot do: no resident can be restrained or confined for the convenience of the home or staff or, as a disciplinary measure.[1088] The home must undertake a monthly analysis of the restraining of residents. The home must evaluate the effectiveness of its policy annually and determine the changes and improvements required and ensure that any restraining that is necessary is done according to law. The home must prepare a written record of its monthly analysis, the evaluation and any changes or improvements.[1089]

The mandatory safeguards clearly indicate how the welfare of caregivers and recipients are intricately related when restraining is used. The Ministry emphasizes that restraining using a physical device is a "last resort" option[1090] and points out that other regulatory requirements support the minimizing of restraining, including developing strategies to address residents' behaviours and developing a falls prevention and management program. Both of these requirements may reduce or eliminate the need for restraining with a physical device.[1091] Some new conditions have to be met before restraints can be used, such as significant risk of serious bodily harm, lack of alternatives, and reasonable and least restrictive method of restraining.[1092]

[1085] *Ibid*; O Reg 79/10, *supra* note 811, s 109(c).

[1086] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 29.

[1087] O Reg 79/10, *supra* note 811, s 109. The policy must deal with specific topics including use of physical devices, duties and responsibilities of staff, restraining under common law, types of permitted physical devices, how consent about the use of physical devices and PSADs is to be obtained and documented, alternatives to the use of physical devices, and evaluation

[1088] *Long-Term Care Homes Act, 2007*, *supra* note 425, ss 30(1)1 and 2.

[1089] O Reg 79/10, *supra* note 811, s 113; Ministry of Health and Long-Term Care, *supra* note 782 at 2–97.

[1090] Ministry of Health and Long-Term Care, *supra* note 782 at 2–89.

[1091] *Ibid*.

[1092] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 31(2).

Additional checks and balances have been introduced to ensure residents are monitored regularly and provided with care such as re-positioning when they are being restrained and afterwards.[1093] Additional requirements such as increased frequency of reassessment of the resident's condition apply when a resident is being restrained under the common law duty.[1094] The rationale is as follows: "A resident being restrained by a physical device under these circumstances may be highly agitated and may require ongoing and heightened monitoring and reassessment."[1095] After a physical device has been used, the reason for using it must be explained to the resident or, to the resident's substitute decision-maker.[1096] Regardless of the type of authority that the home relies on to restrain a resident, there are record-keeping obligations.[1097]

The Ministry provides further guidance on obtaining consent. The home may not ask a resident or the resident's substitute decision-maker for up-front "blanket authority" to restrain a resident using a physical device (or any other permissible type of restraining) should the need ever arise. However, if a resident has been assessed as requiring restraining with a physical device on a continuing basis and consent from the resident or the resident's substitute decision-maker has been obtained, the home is not required to obtain consent every time the physical device is applied. If a resident or the resident's substitute decision-maker refuses to consent to the restraining, the home can only restrain the resident under the common law duty. The home may apply to the Consent and Capacity Board to review whether the substitute decision-maker made the treatment decision in accordance with the *Health Care Consent Act, 1996*.[1098]

The requirements for confining a resident are very similar to those related to restraining using a physical device. The key difference is the additional steps to be taken after a substitute decision-maker has provided consent to confining a resident: the resident is promptly given a written notice and a verbal explanation, and is asked whether he or she wishes to meet with the rights advisor.[1099] The written notice must inform the resident of: reasons for the confining,

---

[1093] O Reg 79/10, *supra* note 811, s 110.

[1094] Ministry of Health and Long-Term Care, *supra* note 782 at 2–92; O Reg 79/10, *supra* note 811, s 110(3).

[1095] Ministry of Health and Long-Term Care, *supra* note 782 at 2–92.

[1096] *Ibid*; O Reg 79/10, *supra* note 811, s 110(4).

[1097] O Reg 79/10, *supra* note 811, ss 110(7)-(8).

[1098] Ministry of Health and Long-Term Care, *supra* note 782 at 2–89.

[1099] At the time of writing, the LTCHA is silent on the qualifications of the rights advisor or any other details. It is expected that the regulation will provide the necessary implementation details when the statutory amendments are proclaimed.

rights to meet with the rights advisor and the contact information, right to apply to the Consent and Capacity Board, and the resident's right to retain and instruct counsel without delay. If the resident wishes to meet with the rights advisor or expresses disagreement with the confining, a rights advisor is promptly notified.[1100] The rights advisor must promptly meet with and explain the right to apply to the Consent and Capacity Board[1101] At the resident's request, the rights advisor must assist with making an application to the Consent and Capacity Board and in obtaining legal services.[1102] The home must ensure that the resident is not confined until the written notice requirement has been satisfied, requirements related to rights advisor (if applicable) have been met or that the resident has refused to meet with the rights advisor.[1103] The rights advisor must promptly notify the home that: 1) the meeting with the resident has occurred or the resident has refused to meet; 2) the rights advisor is aware that the resident or someone acting on the resident's behalf intends to make an application to the Consent and Capacity Board.[1104] Since the confinement provisions have not yet been proclaimed, more requirements may be prescribed in regulation in the future.

The LTCHA also sets out requirements for the use of PASDs. A PASD is a personal assistance services device that is used to assist a person with a routine activity of living. The requirements only apply when a PASD has the effect of limiting or inhibiting a resident's freedom of movement and the resident is not able, either physically or cognitively, to release himself or herself from the PASD.[1105] The conditions that must be met for the lawful use of PASDs are similar to those of restraining by physical device.[1106] A list of prohibited devices (for example, vest or jacket restraints) is also prescribed in the Regulation.[1107] The Ministry provides

---

[1100] *Long-Term Care Homes Act, 2007*, *supra* note 425, ss 30.1(4)1, 30.1(6); Ministry of Health and Long-Term Care, *Compendium to Bill 160, Strengthening Quality and Accountability for Patients Act, 2017* (Toronto: Ministry of Health and Long-Term Care, 2017) at 14–15.

[1101] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 30.1(4)2. The resident could apply for a determination as to whether the substitute decision-maker complied with principles for giving or refusing consent as mandated in the *Health Care Consent Act*. See chapter 7.

[1102] Ministry of Health and Long-Term Care, *supra* note 782, s 30.1(4)3.

[1103] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 30.1(4)6.

[1104] *Ibid*, s 30.1(5).

[1105] *Ibid*, ss 33(1) – (2).

[1106] *Ibid*, ss 33(3) – (5).

[1107] O Reg 79/10, *supra* note 811, s 112.

further guidance on using specific physical devices (which is not a defined term in statute and regulation) and whether they constitute restraining.[1108]

6.4.1.2 Soft law

In soft law, the issue of restraining is usually addressed in conjunction with abuse, fall prevention and medication management. The issue of confining (as used in the LTCHA) is new so soft law does not address that. The guidelines referred to here do not all address restraining in LTC exclusively; rather, they emphasize the role and responsibilities of the care provider in various settings. They are explained here because they bring out some of the relational aspects of prevention of harm in LTC more clearly.

Similar to the direction in the LTCHA, in soft law, the use of restraint is described as a last resort.[1109] Accreditation Canada refers to ‘the least restraint’ approach and the guidance is similar to the legal requirements.[1110] The College of Nurses of Ontario endorses the least restraint approach, which means nurses need to assess and implement alternative measures before using any form of restraint. Further, when restraint is required, the least restrictive form of restraint to meet the client’s needs should be used.[1111] But the College of Nurses of Ontario also provides additional instructions within the context of providing quality care to clients. By way of example, one of the activities is discussing with the client or substitute decision-maker the options and associated risks of using a restraint to enable the client to make an informed decision. It is pointed out that clients will, at times, prefer to accept safety risks rather than be restrained.[1112] The Practice Guide also points out that a least restraint policy does not mean that nurses are required to accept abuse.[1113]

The RNAO also has the most comprehensive guidance on the use of restraints but it is not specifically designed for LTC. The guideline covers strategies for assessment, prevention and use of alternative practices (including de-escalation and crisis management techniques) to prevent the use of restraints, and moves towards restraint-free care in diverse settings such as

---

[1108] Ministry of Health and Long-Term Care, *supra* note 782 at 2-98–2–100.

[1109] College of Nurses of Ontario, *Practice Standard: Restraints (Pub. No. 41043)* (Toronto: College of Nurses of Ontario, 2017) at 3; Accreditation Canada, *supra* note 815 at 57.

[1110] Accreditation Canada, *supra* note 815 at 56–57.

[1111] College of Nurses of Ontario, *supra* note 1109 at 4.

[1112] *Ibid* at 5.

[1113] *Ibid* at 4.

acute, long-term and home health-care.[1114] Many of the steps involved (such as individualized plan of care)[1115] are the same as the requirements in the LTCHA. There are more specific recommendations about the prevention of restraint use and the identification of risk factors. For example, nurses must assess on admission the potential for the presence of predisposing and precipitating factors that put the client at risk for the use of restraints.[1116] The guideline also establishes linkage of restraint use to escalating responsive behaviour and fall management.[1117] But the RNAO also notes that successful implementation of nursing best practices guidelines requires adequate planning, resources, organizational and administrative support, as well as appropriate facilitation.[1118]

6.4.2 **Zero tolerance of abuse and neglect of residents**

Unlike restraining and confining, abuse and neglect of residents are not lawful. The issue is to define what they mean in the LTC setting and who is responsible for taking actions to prevent abuse and neglect and then directing the home to address their consequences. Another layer of complexity is the *Criminal Code* and the responsibilities of respective police forces. The *Nursing Homes Act* and its regulation contained very few references to abuse and neglect, and contained no definitions of “abuse” or “neglect.” However, the *Nursing Homes Act* stated that every resident had the right to be free from mental and physical abuse.[1119] The *Nursing Homes Act* also outlined a reporting duty related to unlawful conduct, improper or incompetent treatment or care, or neglect.[1120] Finally, it stated that no person could be dismissed, disciplined or penalized because a report had been made to the Ministry unless the person acted maliciously or without reasonable grounds.[1121] The Program Manual contained guidance on what constituted resident abuse and neglect, prevention, and actions to be taken by homes[1122] and these were later elevated to formal law. Not surprisingly, the LTCHA requirements are denser and more

---

[1114] Registered Nurses’ Association of Ontario, *supra* note 830 at 17.
[1115] *Ibid* at 5.
[1116] *Ibid* at 23.
[1117] *Ibid* at 19, 24–26 and 38.
[1118] *Ibid* at 50.
[1119] *Nursing Homes Act*, *supra* note 786, s 2(2)1.
[1120] *Ibid*, s 25(1).
[1121] *Ibid*, s 25(2).
[1122] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 0902-01, page 2 and Tab 0902-01, 1 and 4.

technical. As we will see below, many of these requirements can be described as a procedural fix to a very complex and contentious problem.

6.4.2.1 LTCHA requirements

The key provisions in the LTCHA pertaining to abuse and neglect are as follows. The most significant change is a formal duty imposed on the home to protect residents from abuse by anyone and to ensure that residents are not neglected by the home or staff. This duty does not apply when the resident is away from the home. It is an offence when a home has failed to protect residents from abuse by anyone and neglect by staff.[1123] The interpretation of this duty also requires more precise meanings of abuse and neglect. The LTCHA and its regulation include definitions for "abuse", "emotional abuse", "physical abuse", "financial abuse", "sexual abuse", "verbal abuse" and "neglect".[1124] These definitions expand on earlier examples of physical abuse, emotional abuse and financial abuse included in the Program Manual, and some definitions are also new. For example, "sexual abuse" is now a separate category and previously, "physical abuse" included sexual assault or molestation. The regulation also further clarifies what is not sexual abuse, for example, sexual abuse is not touching, behaviour or remarks of a clinical nature.[1125] However, despite the wide range of behaviours captured in the definitions, the Ministry is also careful to point out that resident-on-resident incidents may be outside the scope of the definitions. Altercations and harmful interactions among residents that are not covered under these definitions but could escalate into abusive situations are addressed separately (and this will be discussed later in this chapter). Addressing these situations early should be a key part of preventing abuse in the home.[1126]

Further, every home must have a written policy to promote zero tolerance of abuse and neglect of residents, and must ensure that the policy complies with the LTCHA.[1127] This requirement builds on the Program Manual requirement that every home should have policies on abuse.[1128]The LTCHA also specifies the content of such policy (for example, setting out the

---

[1123] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 19; Ministry of Health and Long-Term Care, *supra* note 1100 at 13. There is no duty to ensure residents are not neglected by volunteers.

[1124] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 2(1); O Reg 79/10, *supra* note 811, s 2(1).

[1125] O Reg 79/10, *supra* note 811, s 2(3).

[1126] Ministry of Health and Long-Term Care, *supra* note 782 at 2–62.

[1127] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 20(1).

[1128] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 0902-01, page 2.

consequences for those who abuse or neglect residents).[1129] However, the LTCHA does not provide very much direct guidance on what the home must do to assist residents affected by abuse and neglect other than noting that procedures and interventions to assist and support residents who have been abused or neglected may include counselling.[1130] The effectiveness of the home's policy must be evaluated at least annually to identify changes and improvements, which must be implemented promptly. A written record of the annual evaluation must be prepared.[1131]

Another key component in the regulatory regime is addressing what homes must do after incidents of abuse and neglect: investigations, actions, reporting and notification. A home must ensure that every incident is immediately investigated and that appropriate action is taken.[1132] The results of every investigation and every action taken must be reported to the Ministry within 10 days of the home becoming aware of the incident.[1133] However, the Ministry also clarifies that not all resident-to-resident interactions that seem abusive require reporting to the Director. Homes and their staff members should ensure that when they consider reporting resident-to-resident interactions that the interactions fall within the definitions of abuse.[1134] The LTCHA also strengthens the reporting requirement by providing enhanced protection for those who make reports by making it an offence to suppress reports.[1135] As well, there are penalties for certain persons (for example, homes, staff and health care providers) who fail to make a report.[1136] The home must ensure that the appropriate police force is immediately notified of any alleged, suspected or witnessed incident of abuse or neglect of a resident that the home suspects may constitute a criminal offence.[1137] Last but not least, if a resident wants a person notified about an incident of abuse or neglect, the home must notify that person (unless there are reasonable grounds to believe that the person is responsible for the incident). The home must notify a resident's substitute decision-maker – even if that person does not wish to be notified (unless

---

[1129] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 20(2); O Reg 79/10, *supra* note 811, s 99.
[1130] Ministry of Health and Long-Term Care, *supra* note 782 at 2–64.
[1131] O Reg 79/10, *supra* note 811, s 99; Ministry of Health and Long-Term Care, *supra* note 782 at 2–64.
[1132] *Long-Term Care Homes Act, 2007*, *supra* note 425, ss 23(1)(a) and (b).
[1133] *Ibid*, s 23(2); O Reg 79/10, *supra* note 811, ss 104 (1) – (3); Ministry of Health and Long-Term Care, *supra* note 782 at 2–71. The content of the report is also mandated
[1134] Ministry of Health and Long-Term Care, *supra* note 782 at 2–70.
[1135] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 24(6).
[1136] *Ibid*, s 24(5).
[1137] O Reg 79/10, *supra* note 811, s 98.

there are reasonable grounds to believe that the person is responsible for the incident). This requirement applies even if the resident does not wish to have the substitute decision-maker notified.[1138]

6.4.2.2 Soft law

The issue of abuse and neglect of patients / residents is also addressed in the guidelines prepared by various regulatory colleges and professional associations but the depth of the discussion of the subject varies. The variation across disciplines is indicative of the range of potential responses to relational wrongs, depending on one's understanding of the importance of responsibilities as a maker of care.[1139] The responses are targeted to individuals and institutions.

At one end of the spectrum, health care providers are reminded of their legal obligations to report different types of abuse, including sexual abuse, and the manner and timing of such reporting under various statutes, such as the *Regulated Health Professionals Act, 1991* and the LTCHA.[1140] Accreditation Canada's LTC service standards include discussion of reporting of resident abuse and these standards frame abuse as one of the issues related to the physical security of residents.[1141] But the guideline also acknowledges that abuse may occur between residents, between residents and family, or between residents and staff.[1142] Other topics include education and training on recognizing, preventing, and assessing risk of abuse,[1143] workplace violence,[1144] information and education for residents and families about recognizing and reporting abuse,[1145] and the organization's abuse prevention strategy.[1146]

At the other end of the spectrum is the Registered Nurses' Association of Ontario's *Preventing and Addressing Abuse and Neglect of Older Adults: Person-Centred, Collaborative,*

[1138] *Ibid*, s 97; Ministry of Health and Long-Term Care, *supra* note 782 at 2–65. A resident is not required to specify a person to be notified.

[1139] Herring, *supra* note 112 at 60–62.

[1140] College of Dietitians of Ontario, *supra* note 918 at 70; College of Physicians and Surgeons of Ontario, *Policy Statement # 6-12: Mandatory and Permissive Reporting* (Toronto: College of Physicians and Surgeons of Ontario, 2012) at 4–5; College of Physicians and Surgeons of Ontario, *Policy Statement #4-08 - Maintaining Appropriate Boundaries and Preventing Sexual Abuse* (Toronto: College of Physicians and Surgeons of Ontario, 2017).

[1141] Accreditation Canada, *supra* note 815 at 12.

[1142] *Ibid* at 21.

[1143] *Ibid* at 20.

[1144] *Ibid* at 29–30.

[1145] *Ibid* at 40.

[1146] *Ibid* at 41.

System-Wide Approaches. For the purpose of this research, it should be noted that the guideline acknowledges that institutions have the responsibility to provide safe, quality care for all residents. Furthermore, older adults living in institutions are in a relationship of trust with the organization, and a trusting relationship is a key element in most definitions of abuse and neglect.[1147] In addition to practice recommendations for registered nurses, the Guideline also includes education and policy/organization/system recommendations. By way of example, the guideline includes a discussion of factors and conditions that contribute to abuse and neglect in institutions to contextualize adoption of a combination of approaches to prevent abuse and neglect of older adults.[1148] In addition, the guideline recommends that nurses, other health-care providers, stakeholders that have advocacy mandates, and other groups can help prevent and address abuse and neglect of older adults through advocacy efforts.[1149]

6.4.3 Responding to responsive behavior and altercations

So far I have explained harm that is most likely to be inflicted by people other than the residents, even though others in the caring relationships can be harmed also. Harm to residents and others can also occur when residents engage in certain types of interactions – intentionally or unintentionally – when they encounter caregivers and residents. Some residents engage in behaviour that may normally be considered socially unacceptable (e.g., aggression) or in actual or potential violence, possibly attributed to an impairment, health condition, or care received by the resident (or lack thereof). Such behaviours are known as responsive behaviours (to be defined below). Law's responses to these behaviours have evolved over time and have been augmented by other non-regulatory initiatives, such as Behavioural Supports Ontario (to be discussed in Chapter 9).[1150] Law's function here is to change the language used to describe those living with significant cognitive impairments and to more formally recognize the responsibility to respond to their needs. The proliferation of guidelines on dealing with dementia is also indicative of how behavioural issues are now perceived and understood. Overall, the new requirements move away from blaming the residents' impairments but at the same time, the

---

[1147] Registered Nurses' Association of Ontario, *supra* note 919 at 6.

[1148] *Ibid* at 52–56.

[1149] *Ibid* at 62.

[1150] Behavioural Supports Ontario, "Background", online: *Behavioural Supports Ontario Soutien en cas de troubles du comportement en Ontario Provincial Website / Site-Web Provincial* <http://www.behaviouralsupportsontario.ca/29/Background/>.

impairments are used to justify more intense monitoring and documentation. There is also the question whether enough resources (human and otherwise) are made available to meet the needs of those who exhibit responsive behaviour as required by hard and soft law and others in the caring relationships.

There was not much guidance on how to deal with residents' behavioural issues under the previous regime. The *Nursing Homes Act* and its regulation did not have any reference to cognitive impairment or behaviour issues. Pursuant to the Program Manual, resident medical care was to include behaviour management of aggressive, agitated residents.[1151] The home was required to provide annual education to staff on, among other things, understanding residents with cognitive impairment and responding to disruptive behavior.[1152] Similarly, orientation was to include understanding disruptive behaviour.[1153] As part of the Ministry's review of the home, focused audits of residents were to include residents who demonstrated disruptive behaviour[1154] and there was a checklist for disruptive behavior focused audit. The standards and criteria to be reviewed in the focused audit were related to the care received by the residents and some were modified to reflect a disruptive behavior emphasis. For example, one of the standards required that policies and procedures be in place for all aspects of behavior management.[1155]

6.4.3.1 LTCHA requirements

The LTCHA represents a different way of formally acknowledging the needs of residents who exhibit behavioural issues and the needs of people around them including other residents and caregivers. These are now described as "responsive behaviours," which means behaviours that often indicate: "(a) an unmet need in a person, whether cognitive, physical, emotional, social, environmental or other, or (b) a response to circumstances within the social or physical environment that may be frustrating, frightening or confusing to a person".[1156] MOHLTC explains: "In the past, these behaviours have often been termed 'disruptive,' 'challenging,' or 'aggressive.' This terminology negatively labels residents".[1157] The significance of the change in

---

[1151] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 1012-02, page 4.
[1152] *Ibid* at Tab 1002-01, page 3.
[1153] *Ibid* at Tab 1002-02, page 2 and Tab 1007-02, page 4.
[1154] *Ibid* at Tab 1101-01, page 6.
[1155] *Ibid* at Tab 1102-02, page 31.
[1156] O Reg 79/10, *supra* note 811, s 1.
[1157] Ministry of Health and Long-Term Care, *supra* note 782 at 2–34.

language is that "[b]y calling these behaviours "responsive", focus is placed on understanding the meaning behind the behaviour and what the resident may be trying to communicate. This focus requires a holistic approach to assessment that takes into consideration physical, cognitive, emotional, social, environmental and other conditions that might be triggering the behaviour."[1158]

New requirements for addressing these behaviours are targeted for individual residents and for the home as a whole. For each resident who demonstrates responsive behaviours, the home must identify the behaviour triggers, must develop and implement strategies to respond to these behaviours, and must take action to respond to the resident's needs.[1159] The home must also develop the following: written approaches to care, such as screening protocols and identification of behavioural triggers; written strategies, including techniques and interventions, to prevent, minimize or respond to the responsive behaviours; resident monitoring and internal reporting protocols; and protocols for referrals to specialized resources.[1160] These tasks must be integrated into the care that is provided to all residents, based on the assessed needs of residents with responsive behaviours, and must be co-ordinated and implemented on an interdisciplinary basis.[1161] They must also be evidence-based, must be evaluated and updated at least annually, and a written record of each evaluation must be kept.[1162]

But not all behaviour issues can be attributed to a resident's reaction to an unmet need. Steps must be taken to minimize the risk of altercations and potentially harmful interactions between and among residents i.e., identifying factors that could potentially trigger such altercations, and identifying and implementing interventions.[1163] The Ministry reiterates that some interactions are not included in the definition of abuse. For example, the actions of a resident who does not understand or appreciate their consequences are not included in the definitions of emotional abuse and verbal abuse. But staff must be proactive in identifying triggers and must deal with potentially harmful interactions before they escalate into a harmful situation.[1164] Further, homes must develop and implement procedures and interventions to assist

---

[1158] *Ibid* at 2–35.

[1159] O Reg 79/10, *supra* note 811, s 53(4); Ministry of Health and Long-Term Care, *supra* note 782 at 2–34.

[1160] *Ibid*, s 53(1); *Ibid* at 2–33.

[1161] *Ibid*, s 53(2); *Ibid* at 2–34.

[1162] *Ibid*, s 53(3); *Ibid* at 2–34.

[1163] *Ibid*, s 54; *Ibid* at 2–36.

[1164] *Ibid*, s 54; *Ibid* at 2–36.

residents and staff who are at risk of harm or who are harmed as a result of a resident's behaviour. All direct care staff must be advised of each resident whose behaviours require heightened monitoring.[1165] The home must address all behaviours, including those that may not be responsive. To help identify residents whose behaviours should be monitored, the home can use information provided by family members and substitute decision-makers as well as admission assessments and any psychogeriatric or other assessments.[1166]

6.4.3.2 Soft law

The legal requirements say very little about what homes actually have to do other than having processes and procedures in place, and that gap is partially filled by soft law. A potentially promising feature in soft law is that it acknowledges the interactional nature of disability: that not only the physical environment but also the social environment can have a profound effect on the quality of life of those who experience behaviour issues. The resident cannot be "fixed"; it is those around the resident with behaviour issues who must change. The guidelines surveyed also devote considerable attention to the needs of those who experience behavioural issues, usually in conjunction with other related topics such as abuse, medication management and use of restraints. Responsive behaviour might also be addressed from the home's perspective through programming. Accreditation Canada's LTC Service Standards require that education and training on preventing and managing residents' responsive behaviours are provided to the team and include examples of training programs and evidence-informed use of pharmaceuticals.[1167]

Responsive behavior might be addressed from the care provider's perspective in the context of providing guidance on a variety of related topics. The Registered Nurses' Association of Ontario's guidance on behavioural issues appears in in the following guidelines: *Promoting Safety: Alternative Approaches to the Use of Restraints*, *Preventing and Addressing Abuse and Neglect of Older Adults: Person-Centred, Collaborative, System-Wide Approaches*, and *Delirium, Dementia, and Depression in Older Adults: Assessment and Care*. It is stated that responsive behavior is a predisposing risk factor for restraint use, and in partnership with the

---

[1165] *Ibid* , s 55; *Ibid* at 2–36.
[1166] Ministry of Health and Long-Term Care, *supra* note 782 at 2–37.
[1167] Accreditation Canada, *supra* note 815 at 21.

inter-professional team nurses should implement de-escalation and crisis management techniques and mobilize the appropriate resources to promote safety and mitigate risk of harm for all in the presence of escalating responsive behaviours.[1168] Having effective strategies for challenging/responsive behaviours is also incorporated into discussions about prevention of abuse and neglect.[1169] Risk factors for abuse and neglect include the presence of responsive behaviour.[1170] Institutions should adopt a combination of approaches to prevent abuse and neglect of older adults, for example supporting the needs of individuals with cognitive impairment, including those with responsive behaviours.[1171] Responsive behaviour is addressed within the context of employing communication strategies and techniques when caring for people with dementia.[1172]

Finally, responsive behaviour could be a standalone topic addressed from multiple perspectives. Health Quality Ontario's *Behavioural Symptoms of Dementia* Quality Standard incorporates 14 quality statements; each statement also explains how its successful delivery impacts people living with dementia, their caregivers, health care professionals, and health care services at large.[1173] To begin with, this Standard is

> underpinned by the principle that people living with dementia have the right to receive services that are respectful of their rights and dignity and that promote self-determination. People living with dementia and symptoms of agitation or aggression are provided service that is respectful of their gender, sexual orientation, socioeconomic status, housing, age, background (including self-identified cultural, ethnic, and religious backgrounds), and disability.[1174]

The majority of the statements are not new in that they reflect existing regulatory requirements under the LTCHA and other legislation.[1175] However, they articulate more

---

[1168] Registered Nurses' Association of Ontario, *supra* note 830 at 28 and 38.

[1169] Registered Nurses' Association of Ontario, *supra* note 919 at 8.

[1170] *Ibid* at 27.

[1171] *Ibid* at 10.

[1172] Registered Nurses' Association of Ontario, *Delirium, Dementia, and Depression in Older Adults: Assessment and Care Second Edition* (Toronto: Registered Nurses' Association of Ontario, 2016) at 63.

[1173] Health Quality Ontario, *Behavioural Symptoms of Dementia Care for Patients in Hospitals and Residents in Long-Term Care Homes* (Toronto: Health Quality Ontario, 2016) at 4. This quality standard focuses on care for those who are in an emergency department, admitted to a hospital, or in a long-term care home. It also provides guidance on the care given when a person is transitioned between these settings; for example, when someone is discharged from a hospital to a long-term care home.

[1174] *Ibid* at 5.

[1175] *Ibid* at 7. The topics include comprehensive assessment, individualized care plan, mechanical restraint, informed consent and provider training and education concretely *how* to meet the expectations of the LTCHA. More importantly, they accept the interactional nature of disability and explain more clearly how others may be affected if this interactional nature is not taken into account. For example, as discussed above, the home must identify the behaviour triggers, develop and implement strategies to respond to the responsive behaviours, and take actions to respond to the resident's needs. Concrete guidance toward meeting this requirement can be seen in Quality Statement 13: An appropriate environment that is calm with minimal potentially disturbing stimuli helps prevent retriggering of behavioural symptoms related to the physical environment (e.g., overcrowding, lack of privacy, loud noise levels). This also benefits other service users who might experience violence or harm when witnessing the behavioural symptoms of the person with dementia.[1176] Some are new in the sense that they go beyond the scope of the LTCHA, for example, recommending training and education for caregivers (defined as paid or unpaid people who help a family member, friend, or another person in need of assistance or support with daily living).[1177]

6.4.4 **Summary**

Table 21: Key changes about prevention of harm under the *Nursing Homes Act* and the LTCHA

	Nursing Homes Act	**LTCHA**
Minimization of restraining and confining of residents	Resident's right to be fully informed of the procedures and the consequences of receiving or refusing restraints Requirements for the use of physical restraints	More substantive and procedural protections Explicit reference to the common duty to restrain and confine New concept of "confining" and related protections

---

[1176] Health Quality Ontario, *supra* note 1173.

[1177] *Ibid* at 33–34.

	Nursing Homes Act	**LTCHA**
Prevention of abuse and neglect of residents	Resident right to be free from mental and physical abuse Guidance on what constitutes resident abuse and neglect Prevention and actions to be taken by home	Duty of home to protect residents from abuse and neglect Policy of zero tolerance of abuse and neglect Strengthened reporting requirements
Responsive behaviour and altercations	Yes –reference to what the home must do for residents with cognitive impairments and disruptive behaviour	New language – responsive behaviour New requirements to deal with altercations and other harmful interactions

This section is premised on the assumption that the safety of residents must be understood with respect to the relationships in the home. The changes are intended to protect the safety of residents and others in the home by avoiding certain types of risk or reducing its impact, although not necessarily consistently or to the same extent. Very few references are made to the safety of workers. The risk of physical harm that may occur in a caring relationship in LTC is addressed in three key categories of the requirements of the LTCHA: minimization of restraining and confining of residents, zero tolerance of abuse and neglect of residents and management of responsive behaviour and altercations. Together, they represent a trend in understanding and responding to risks in LTC homes: the impairments and health status of residents make them susceptible to intentional and unintentional harm inflicted by others in the home. At the same time, certain types of impairments, such as dementia, also justify restrictions on liberty, more intense monitoring and targeted measures to prevent harm to residents and others in the home. These techniques make regulation of LTC homes appear to be more "rational, analytical, and orderly,"[1178] however caring relationships are messy in LTC. Law also serves the function of ensuring that any infringement of life, liberty and security by the government is in accordance with the principle of fundamental justice. Arbitrariness is of particular concern and the requirements in the LTCHA may take away some discretion that caregivers once had over certain types of interactions. The question is whether the degree of discretion that caregivers still have is adequate to give them the flexibility to respond to the needs of individual residents.

6.5 Acknowledging the challenges of communal and congregate living

In this last section, I will explore three sets of changes that illustrate how the law responds to other harms that may occur in LTC as a communal or congregate living setting. This is an interesting setting through which to understand relationality as a marker of care. This section highlights the fact that it is more meaningful to talk about the safety of all individuals present in a home. While resident health and safety are also the primary policy objectives addressed by the changes discussed below, a less obvious objective is to protect the safety of caregivers, albeit marginally. Keeping in mind the interdependences of residents and their caregivers and among residents continues to be important in the interpretation of these changes. Autonomy is also engaged in the discussion below. The regulatory changes concern fall prevention, medication management, infectious diseases control and dining. The feminist political economy literature has commented on the medicalized nature of care within homes and the discussion below will also illustrate such concerns.

6.5.1 **Medication management**

The Regulation under the LTCHA establishes requirements relating to the home's medication management system.[1179]According to the Ministry, the purpose of the system is to ensure medication requirements of residents are met in a safe and timely manner and to ensure the best health outcomes for residents. The Regulation also includes requirements for addressing

---

[1178] Windholz argues that the rise of risk-based regulation is part of broader efforts to make regulations more rational, analytical, and orderly. Windholz, *supra* note 50.

[1179] O Reg 79/10, *supra* note 811, ss 114–117; Ministry of Health and Long-Term Care, *supra* note 782 at 2–101 to 2–102.

medication incidents, adverse drug reactions, and the use of any drug or drug combinations, including psychotropic drugs, which could potentially put residents at risk.[1180] The majority of the LTCHA requirements build on the previous regime, where the bulk of the requirements were in the Program Manual and the *Nursing Homes Act* and its regulation provided less guidance. Under the LTCHA, the components of the medication management system are similar to those in the Program Manual, such as inter-disciplinary review and written policies and procedures.[1181] The following new requirements will be addressed here: use of chemical restraints, administration of drugs and medication incidents.

Restraining a resident by the administration of a drug is prohibited under the LTCHA with only one exception: under the common law duty of a caregiver to restrain a person when immediate action is necessary to prevent serious bodily harm to the person or to others. In this situation, the administration of the drug must be ordered by a physician or a Registered Nurse.[1182] The regulatory requirements focus on what the home must do after restraining. The home must document each incident.[1183] It is also made clear that physical abuse includes administering or withholding a drug for an inappropriate purpose.[1184] And the administration of a drug as a treatment set out in a plan of care is not considered as restraining a resident.[1185] In contrast, the *Nursing Homes Act* and its regulation did not address restraining by administration of a drug and the Program Manual included only a definition of chemical restraint.[1186]

The requirements related to administration of drugs involve the following changes: self-administration of drugs, destruction of controlled substances and use of natural health products. The requirements are undoubtedly complex and can be partly explained by the fact that LTC is a

---

[1180] Ministry of Health and Long-Term Care, *supra* note 782 at 2–101.

[1181] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 1016-01.

[1182] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 36(3); Ministry of Health and Long-Term Care, *supra* note 782 at 2–112; O Reg 79/10, *supra* note 811, s 137.

[1183] O Reg 79/10, *supra* note 811, s 137(2). The documentation must include all of the following: the circumstances precipitating the administration of the drug; who made the order, what drug was administered, the dosage given, how the drug was administered, the time or times when the drug was administered and who administered the drug; the resident's response to the drug; assessments, reassessments and monitoring of the resident; and discussions with the resident or, the resident's substitute decision-maker (following administration of the drug) to explain the reasons for using the drug.

[1184] *Ibid*, s 2(1).

[1185] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 30(4); Ministry of Health and Long-Term Care, *supra* note 782 at 2–113.

[1186] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 9901-01, page 7.

communal setting. In this particular communal setting, the challenge is to allow general patient safety principles to apply while respecting autonomy. There is now more clarity about self-administration of drugs whereas the Program Manual simply noted that self-administration must be permitted when specifically ordered by the physician in consultation with the care team.[1187] Under the new regime, a resident may self-administer a drug if approved by the prescriber in consultation with the resident. There must be written policies to ensure that the resident who self-administers understands: the use and need for the drug; monitoring and documentation of the use of the drug; and safekeeping.[1188] The processes and procedures about destruction of drugs including documentation, especially with respect to controlled substances have been expanded.[1189] Another new requirement addresses the use of natural health products. The home must ensure that when a resident wishes to use a drug that is a natural health product and that has not been prescribed, there are written policies and procedures.[1190] The Ministry further clarifies that the level of staff involvement in administering natural health products that have not been prescribed for a resident is at the discretion of the home. The home's policies and procedures should not be overly restrictive or prevent a resident from using the products given the fundamental principle and the Residents' Bill of Rights of the LTCHA.[1191]

Last but not least, more extensive requirements about medication incidents and adverse drug reactions are now in place. The previous regime simply required a system for immediate reporting of each medication error and adverse drug reaction, with specific follow-up actions to be taken.[1192] The new requirements in the LTCHA are as follows. The definitions of medication incident and adverse drug reactions are provided for. The scope of reporting is broader. A medication incident involving a resident or adverse drug reaction must be reported to the resident or the resident's substitute decision-maker. All medication incidents (whether involving a

---

[1188] O Reg 79/10, *supra* note 811, s 131(6).
[1189] *Ibid*, s 136; Ministry of Health and Long-Term Care, *supra* note 782 at page 2-111. For example, any controlled substance that is to be destroyed and disposed must be stored in a double-locked area separate from any controlled substance that is available for administration to residents.
[1190] O Reg 79/10, *supra* note 811, s 132.
[1191] Ministry of Health and Long-Term Care, *supra* note 782 at 2–108.
[1192] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 1016-01, page 9.

resident or not) and adverse drug reactions must be documented, reviewed and analyzed. Corrective action must be taken and a written record must be kept. The home is required to review all medication incidents and adverse drug reactions quarterly. Any changes and improvements identified in the review must be implemented and a written record must be kept.[1193]

The soft law on medication management is extensive. The emphasis is on patient safety and appropriateness of medication, including the use of anti-psychotics. Medication is addressed in almost all topic-specific guidelines[1194] as well as in sector-specific guidelines.[1195] These guidelines overlap with each other and with the LTCHA but they also add to the hard law, for example, resident engagement (including families) in medication reconciliation, risks of using psychotropic medications and alternatives to such medications, and appropriateness of long-term medications.[1196]

6.5.2 **Fall prevention and management**

The risk of falls is one of the safety issues addressed in the LTCHA and even more guidance is included in soft law. While falls can happen in other care settings, the potential implications of a fall extend beyond the person who fell such as liability for the home. Another way of thinking about this is how to support residents and/ or their substitute decision-makers to make decisions about balancing the safety risks and the values of the residents.

One of the required programs under the LTCHA (see Chapter 5) is falls prevention and management. While “falls” were mentioned sporadically in the Program Manual,[1197] this new required program must, at minimum, provide strategies to reduce or mitigate falls. These strategies must include monitoring residents, reviewing residents’ drug regimes, implementing restorative care approaches, and using equipment, supplies, devices and assistive aids, which

---

[1193] O Reg 79/10, *supra* note 811, s 135; Ministry of Health and Long-Term Care, *supra* note 782 at 2–110.

[1194] For example see Registered Nurses Association of Ontario, *Prevention of Falls and Fall Injuries in the Older Adult* (Toronto: Registered Nurses’ Association of Ontario, 2005) at 8; Health Quality Ontario, *supra* note 1173 at 13–24.

[1195] For example see Accreditation Canada, *supra* note 815 at 41–46, 59; Long Term Care Medical Directors Association of Canada, *Long Term Care: Six Things Physicians and Patients Should Question* (Toronto: Choose Wisely Canada, 2017).

[1196] Canadian Patient Safety Institute, *supra* note 849 at 31; Long Term Care Medical Directors Association of Canada, *supra* note 1195; Health Quality Ontario, *supra* note 1173 at 16–24.

[1197] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 1012-02.

must be readily available at the Home. After a fall, the resident must be assessed and, when the resident's condition or circumstances requires it, a post-fall assessment must be conducted.[1198]

Soft law overlaps with the LTCHA. For example, Accreditation Canada's LTC Service Standards require a documented and coordinated approach to falls prevention.[1199] But there are some differences too. In contrast to the LTCHA and its regulation, the guidance in various guidelines is more contextualized in the sense of referring to other values (e.g. a resident's autonomy) and attends to other social-economic and environmental aspects of falls and fall prevention. For example, according to the Registered Nurses' Association of Ontario, the client's perspective, risk-taking, autonomy, and self-determination are supported, respected, and considered in the plan of interventions. Further, clients, their significant other(s) and the care team engage in assessment and interventions through a collaborative process.[1200] It is also acknowledged that interventions also must occur at the organization level. For example, organizations should review the communication processes between interdisciplinary team members especially between regulated and non-regulated staff.[1201]

6.5.3 **Infection control**

Every home must ensure that there is an infection prevention and control program for the home.[1202] This simply formalizes and expands on the Program Manual's requirements for an organized program of infection control.[1203] The only significant changes are the immunization and screening measures provisions.[1204] The soft law surveyed complements the LTCHA by giving more guidance on what individual providers should do. By way of example, the College of Nurses of Ontario's *Practice Standard: Infection Prevention and Control* requires that nurses reduce the risk to self and others by appropriately handling, cleaning and disposing of materials and equipment.[1205] As well, nurses should use appropriate and timely communication strategies

---

[1198] O Reg 79/10, *supra* note 811, s 49; Ministry of Health and Long-Term Care, *supra* note 782 at 2–29.

[1199] Accreditation Canada, *supra* note 815 at 46–47.

[1200] Registered Nurses Association of Ontario, *supra* note 1194 at 8.

[1201] Canadian Patient Safety Institute, *supra* note 849 at 40.

[1202] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 86.

[1203] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 1011-01, page 9–10.

[1204] O Reg 79/10, *supra* note 811, s 229(10)–(12). The provisions specify: 1) which types of immunization must be offered to residents and screening residents for tuberculosis; 2) staff immunization program and screening for staff for tuberculosis and other infectious diseases; and 3) up-to-date immunizations for pets.

[1205] College of Nurses of Ontario, *Practice Standard: Infection Prevention and Control (Pub. No. 41002)* (Toronto: College of Nurses of Ontario, 2009) at 5.

with clients and their significant others, the health care team and the community when discussing infection prevention and control issues.[1206] These examples illustrate the inter-dependency of caregivers and residents, and among residents and family members when dealing with infectious diseases. As Chapter 9 will show, the importance of balancing the needs and rights of various people living / working in a home is evident.

6.5.4 **Dining and nutrition**

In the previous chapter, I briefly discussed nutrition care as part of quality care. A closely related matter is the regulation of residents' dining experiences. This area has always been highly prescriptive, in part due to safety reasons because residents must eat in a congregate setting under both regimes. The Program Manual included requirements about meal services, such as supervision of residents, meal times, location, and assistance to be provided to residents.[1207] These requirements are elevated to regulation[1208] with small modifications. The only difference is that some of the context and guidance have not been incorporated into the new regime. For example, the Program Manual referred to the goals of meal service, such as providing meal service as a pleasurable dining experience, focusing on eating as a social experience, providing special meals to increase pleasure and creating happy memories and pleasant meal time ambience.[1209]

6.5.5 **Summary**

Table 22: Key changes to communal living under the *Nursing Homes Act* and the LTCHA

	Nursing Homes Act	**LTCHA**
Medication management	Yes	Added restraining by administration of drugs, consumption of natural health products

---

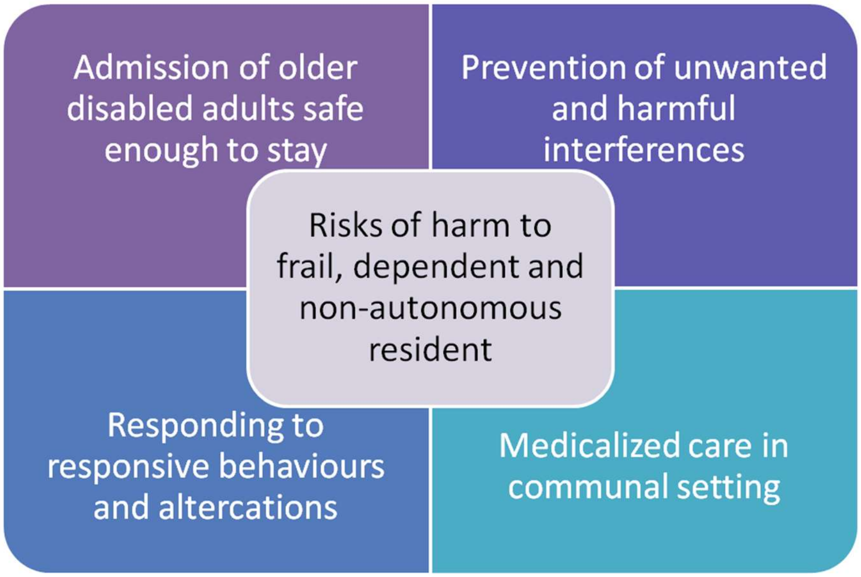
[1206] *Ibid*.
[1207] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 1014-01, page 3–4.
[1208] O Reg 79/10, *supra* note 811, s 73; Ministry of Health and Long-Term Care, *supra* note 782 at 2–46.
[1209] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 1014-02, page 2.

	Nursing Homes Act	**LTCHA**
		Modified requirements about self-administration of drugs, destruction of controlled substance and medication incidents and adverse drug reactions
Fall prevention	Yes	Formalized as a program and added strategies
Infection control	Yes	Formalized in law and added immunization and screening measures provisions
Dining	Yes	Formalized in law but omitted some of the context

All the topics discussed in this section share a common theme: they are perceived to be necessary for prevention of harm because LTC is a communal or congregate setting. The point is that the safety is translated into detailed legal rules for activities that may be deemed potentially more risky in a communal setting. With more rules come the challenge of respecting the autonomy of residents when they take medications, attempt to reduce the risk of fall (or not), make decisions about immunization or dining.

6.6 Conclusion

Illustration 4: Means to Protect Safety and Security of Residents



This chapter illustrated the changes to the process of admitting and discharging residents, physical design of the home, the minimization of restraining and confining of residents, the policy of zero tolerance of abuse and neglect, the management of responsive behaviour and altercations and other care practices. The changes are mostly requirements elevated from the Program Manual but some are expansions too. They have important ramifications for protecting the autonomy of residents and for defining the caring relationship.

Similar to the previous chapter, this chapter is also informed by the debates about criticisms of care, including the contributions from Herring[1210] as well as contributions of the feminist political economy literature.[1211] It is hard to argue with the observation that the safety and security of residents is prioritized by measures that are intended to minimize certain types of risks. Not interfering in abusive or harmful situations can leave residents without protection and therefore the *Charter*-protected right to life may be engaged. Our understanding of risk of harm is central to law's response to residents' impairments. The law is built around the image of a

---

[1210] Herring, *supra* note 112.
[1211] Armstrong, *supra* note 655; Armstrong, *supra* note 1003; Braedley & Martel, *supra* note 678.

frail, dependent and non-autonomous resident, in contrast to the autonomous individual as explained by Herring. The current regulatory tools available to protect the typical resident include enhanced monitoring, documentation and minimization of risks to physical safety. It is evident that some discretion is taken away from caregivers in the process of providing care. These tools are designed to keep the resident free from harm inflicted by workers, volunteers and other residents but could also interfere with the autonomy of residents. The sum of these observations reinforces the importance of analyzing safety and security measures from the perspective of promoting caring relationships.

The promotion of caring relationships entails careful consideration of potential for harm in care but user involvement is also important. The next chapter will turn to another important theme in the disability scholarship: inclusion and participation. This theme is also informed by the insights advanced by New Governance scholars and the counter-arguments of their critics. In Chapter 8, I will return to the issue of harms in a caring relationship by examining what the state has to do to protect its vulnerable citizens, including enforcement and compliance.

7 Inclusion and Participation

7.1 Introduction

The purpose of this chapter is to flesh out what inclusion and participation mean in LTC homes. My starting point is that from a disability perspective, autonomy is still an important concept in studying care, regardless of where it is offered.[1212] The purpose here is to explore how participation mechanisms, especially those mandated by law, support or frustrate autonomy in the LTC context. In Chapter 2, I explained the significance of the idea of inclusion to the Canadian Disability Movement. I have also argued that there is a case for close examination of the techniques used to promote inclusion and participation in LTC as well as the purposes of and meanings attributed to such techniques. In Chapters 5 and 6, I examined how the law constructs care and what has changed in the regulation of LTC between 2004 and 2018. I have described the caring relationship as unidirectional as the law focuses on giving directions about what care providers have to do for the residents and how. If implicit in the scholarly criticisms of care is lack of meaningful user involvement, then reforming care in LTC will require a different understanding of how residents should participate in their own care, individually, as well as collectively, as a group, in homes.

Inclusion and participation of LTC residents are enabled by a variety of rights, duties and safeguards enshrined in the *Charter,* the Ontario Human Rights Code, common law as well as in statutes. The following dimensions of inclusion and participation are explored in this chapter: the equality guarantee under the *Charter*, autonomy in decision-making at the individual level, and collective rights of residents to participate in the operation of home. This chapter will proceed as follows: the first section will summarize some of the recent s.15 cases; the second section will explain the changes to the *Health Care Consent Act* and *Substitute Decisions Act* in relation to residents' autonomy in making and executing decisions at the point of care; the last section will explore how residents and their families and friends – as a group – participate in their homes under the LTCHA.

[1212] Boyle, *supra* note 154; Kröger, *supra* note 156.

From exploring these three dimensions of inclusion and participation, it becomes clear that there is no shortage of tools available to residents and to those in caring relationships with them. However, it is also the case that not all of these tools are equally useful. I question the utility of arguments based on the equality guarantee of the *Charter* and the *Human Rights Code* in order to generate changes to ameliorate some of the shortcomings in the LTC system that are directly related to the personal characteristics of residents. A greater emphasis on procedural fairness and due process in involuntary committal, capacity and consent matters may better support individual autonomy but says little about supporting caring relationships. If properly understood and implemented, the new or strengthened participation mechanisms at the individual and collective levels are significant for residents as they encourage residents to decide for themselves and collaborate with each other. These mechanisms also attend to the reality that families and friends continue to constitute part of the web of relationships of residents. It is my view that these mechanisms have the potential to reconcile dependence and autonomy in caring relationships in LTC. If LTC residents, even if they are dependent on others for meeting their needs, are not to be treated as objects of care or passive recipients of care, it follows that there must be mechanisms to empower and enable all parties in a caring relationship to seek out the wishes and needs of each other. Participation mechanisms are concrete ways of promoting autonomy at the individual and collective levels in LTC.

7.2 Section 15 of the *Charter*

The Charter provisions regarding liberty and security of the person (section 7), arbitrary detention (section 9) and equality (section 15) are especially relevant for LTC residents. In chapter 6, I discussed section 7 and section 9 jurisprudence in relation to bodily integrity as part of safety and security of the person. Section 7 is also relevant to consent and capacity law in this chapter. According to D'Arcy Hiltz, Anita Szigeti and Ruby Dhand, "statutory provisions setting out the requisite elements of informed consent constitute expressions of the constitutional right against unwanted or unwarranted interference with personal autonomy and dignity by way of unauthorized medical treatment, which are protected by s. 7."[1213] Here I will briefly outline the section 15 jurisprudence in this period. I adopt Robert Leckey and Régine Tremblay's idea that a

---

[1213] Halsbury's Laws of Canada (online), *Mental Health*, "II. Consent and Capacity 1. Overview of Consent and Capacity" at HMN-7 "Consent to treatment and refusal" (2019 Reissue).

judgment, law, or other measure should not be taken as an end; rather, legal reforms in equality's name invite fresh lines of inquiry.[1214] I focus on several aspects of the key judicial decisions that are relevant to my case study –not because they involve LTC residents. I am incorporating a short discussion about equality here because ultimately, freedom from discrimination often finds expression in government benefit schemes that may include or exclude a group of beneficiaries from enjoying a benefit or protection conferred by law based on one or more personal characteristics.

In terms of equality jurisprudence, there has not been much progress[1215] – if judged solely by the outcomes of the cases – in terms of using the *Charter* to advance social justice. Jennifer Koshan and Jonnette Watson Hamilton express a view not uncommon among scholars and activists: "although the Court continually describes its goal as one of substantive equality, it has yet to develop an approach that truly embraces that notion."[1216] In the landmark 2007 decision *R v. Kapp*,[1217] the Supreme Court did indeed rework and provided important clarifications to the analytical framework for applying the equality guarantee provided for in s. 15(1) of the Charter.[1218] For example, *Kapp* marked the end of the *Law* approach and a return to *Andrews*.[1219] The Supreme Court was aware of criticisms about the resurfacing of formalism in the form of an artificial comparator analysis which focused on treating likes alike in some of the Court's post-*Andrews* jurisprudence.[1220] However, besides acknowledging the criticisms about formalism, the Supreme Court said nothing about comparator groups. This left unsettled the issues surrounding comparator groups that had been raised in the academic literature the Court

---

[1214] Robert Leckey & Régine Tremblay, "Introduction: After Equality" (2015) 27:1 Can J Women & L i at i.
[1215] Jena McGill & Daphane Gilbert, "Of Promise and Peril: The Court and Equality Rights" (2017) 78 SCLR(2d) 235; Jennifer Koshan & Jonnette Watson Hamilton, "Meaningless Mantra: Substantive Equality after Withler" (2011) 16 Rev Const Stud 31; Hester Lessard, "'Dollars Versus [Equality] Rights': Money and the Limits on Distributive Justice" (2012) 58:1 SCLR (2d) 299; David Wiseman, "The Past and Future of Constitutional Law and Social Justice: Majestic or Substantive Equality?" (2015) 71:1 SCLR (2d) 563; Jennifer Koshan, "Redressing the Harms of Government (In)Action: A Section 7 Versus Section 15 Charter Showdown" (2013) 22:1 Constitutional Forum 31; John David Lee, C Tess Sheldon & Roberto Lattanzio, "Law and Ordered C.H.A.O.S.: Social Science Methodology, and the Charter Claims of Persons with Disabilities" (2013) 32:1 NJCL 61 at 101–104; Ena Chadha & C Tess Sheldon, "Promoting Equality: Economic and Social Rights for Persons with Disabilities Under Section 15" (2004) 16:1 NJCL 27 at 71–72.
[1216] Jennifer Koshan & Jonnette Watson Hamilton, "The Continual Reinvention of Section 15 of the Charter Forum Topic Articles" (2013) 64 UNBLJ 19 at 21.
[1217] *R v Kapp,* 2008 SCC 41, [2008] 2 SCR 483 [Kapp].
[1218] McGill & Gilbert, *supra* note 1215 at 246.
[1219] *Ibid*.
[1220] *Kapp, supra* note 1217, at para 22.

cited, and the impact of cases such as *Auton* where the Supreme Court's choice of comparators precluded the establishment of the equality claims.[1221] In the discussion of the 2011 *Withler* decision*,* this issue of comparator groups would be addressed again to reiterate the analysis is contextual and not formal.

Despite the Supreme Court's apparent willingness to move away from formalism in *R v. Kapp*,[1222] subsequent decisions were subject to considerable scholarly criticisms.[1223] The lack of progress in s.15 jurisprudence may prompt equality-seeking groups to bring claims under s.7.[1224] The problem with such an approach is that it would appear that some types of harm (e.g. those related to physical safety and security) are more worthy of *Charter* protection than others (e.g. those flowing from membership in disadvantaged groups).[1225] The Supreme Court's apparent unwillingness to engage s.15 arguments such as those advanced by LEAF will inform our analysis in chapter 9.

7.2.1 **Age, gender and entitlement to public benefits**

In *Withler v. Canada (Attorney General)*, the appellants, representative plaintiffs in two class actions, were widows whose federal supplementary death benefits were reduced because of the age of their husbands at the time of death.[1226] Federal civil servants and members of the Canadian Forces, and their families are provided with a suite of benefits both during employment and after retirement, including a package of survivor benefits for the surviving spouse and for dependents of a plan member after his or her death.[1227] The two-part test for assessing a s. 15(1) claim as described in *Kapp* is as follows: "(1) Does the law create a distinction based on an enumerated or analogous ground? (2) Does the distinction create a disadvantage by perpetuating prejudice or stereotyping?"[1228] With respect to the first stage of the analysis, the Supreme Court stated that "provided that the claimant establishes a distinction based on one or more enumerated or analogous grounds, the claim should proceed to the second step of the analysis. This provides

---

[1221] Jonnette Watson Hamilton & Jennifer Koshan, "Courting Confusion? Three Recent Alberta Cases on Equality Rights Post-Kapp" (2010) 47 Alta. L. Rev. 927 at para.6 (QL).
[1222] *Kapp*, *supra* note 1217.
[1223] For example, see Koshan & Hamilton, *supra* note 1216.
[1224] Koshan, *supra* note 1215 at 41.
[1225] *Ibid* at 41.
[1226] *Withler v Canada (Attorney General),* 2011 SCC 12 at para 1, [2011] 1 SCR 396 [*Withler*].
[1227] *Ibid* at para 4.
[1228] *Ibid* at para 30.

the flexibility required to accommodate claims based on intersecting grounds of discrimination."[1229] The Supreme Court of Canada agreed that the Reduction Provisions at issue in this case were age-related; and they constituted an obvious distinction on an enumerated ground.[1230] At the second stage of the analysis, factors such as those developed in *Law* — pre-existing disadvantage, correspondence with actual characteristics, impact on other groups and the nature of the interest affected — may be helpful but need not be expressly canvassed in every case in order to fully and properly determine whether a particular distinction is discriminatory.[1231] The heart of the issue is "whether, having regard to the relevant context, the impugned law perpetuates disadvantage or prejudice, or stereotypes the claimant group."[1232] However, because the age-based rules are, overall, effective in meeting the actual needs of the claimants and in achieving important goals such as ensuring that retiree benefits are meaningful, they do not violate s. 15(1).[1233]

For the purpose of my case study, the most relevant aspect of *Withler i*s the Supreme Court's treatment of the comparator analysis. The acknowledgement of the problems associated with comparator group figures prominently in the decision: ". . . A formal equality analysis based on mirror comparator groups can be detrimental to the analysis. Care must be taken to avoid converting the inquiry into substantive equality into a formalistic and arbitrary search for the "proper" comparator group."[1234] Further, "the analysis involves looking at the circumstances of members of the group and the negative impact of the law on them. The analysis is contextual, not formalistic, grounded in the actual situation of the group and the potential of the impugned law to worsen their situation."[1235] The inquiry should take "full account of social, political, economic and historical factors concerning the group."[1236] Despite these seemingly encouraging paragraphs, the judgment actually did not address an obvious fact about the claimants: they were

---

[1229] *Ibid* at para 63.
[1230] *Ibid* at para 69.
[1231] *Ibid* at para 66.
[1232] *Ibid* at para 70.
[1233] *Ibid* at para 74.
[1234] *Ibid* at para 2.
[1235] *Ibid* at para 37.
[1236] *Ibid* at para 39.

predominantly older widows. Other than criticizing the B.C. Court of Appeal's dissent opinion, the Supreme Court did not conduct any contextual analysis regarding the claimants.[1237]

The Supreme Court's continued focus on prejudice and stereotyping rather than on a broader range of harms of discrimination, such as marginalization, oppression and deprivation of significant benefits is problematic.[1238] The law is often neutral on its face and rarely singles out women or men for differential treatment.[1239] The troubling aspect here is the fact that the inequalities the claimants face flow from laws that fail to take their needs and circumstances into account.[1240] As I will show later in this dissertation, the problems with many legal protections pertaining to those in caring relationships is that the law rarely considers their specific needs and circumstances, which result from an "intermeshing"[1241] of gender, disability, age, immigration status and other grounds, as factors that contribute to the realization of these protections.

7.2.2 **Marital status and claim for patrimonial and support rights**

In *Quebec (Attorney General) v A*, the applicant (A) challenged the constitutionality of several provisions of the Civil Code of Québec in order to obtain the same legal regime for de facto spouses that existed for married spouses.[1242] More specifically, the Supreme Court was asked to decide whether the exclusion of *de facto* spouses from patrimonial and support rights granted to married and civil union spouses violated the right to equality guaranteed by s. 15 of the *Charter*.[1243] The majority of the Supreme Court ultimately did not find A's arguments to be persuasive.[1244]

[1237] *Ibid* at para 80; Koshan & Hamilton, *supra* note 1215 at 57–58.

[1238] Koshan, *supra* note 1215 at 32–33.

[1239] Kimberly Potter, "The Role of Choice in Claims under Section 15 of the Charter: The Impact of Recent Developments in Section 7 Jurisprudence" (2016) 35:2 NJCL 181 at 184.

[1240] Koshan, *supra* note 1215 at 33.

[1241] Thomas, *supra* note 96.

[1242] *Quebec (Attorney General) v A*, 2013 SCC 5 at para 6, [2013] 1 SCR 61. A and B separated after living together for a total of seven years. In 2002, A filed a motion in the Quebec Superior Court seeking custody of the children, support, a lump sum, use of the family residence, a provision for costs and an interim order. A also challenged the constitutionality of several provisions of the Civil Code of Quebec. When the matter finally reached the Supreme Court of Canada, the only unresolved aspect of the matter was the constitutionality of the impugned provisions. Other issues (such as child support and custody) were resolved in the lower courts.

[1243] *Ibid* at para 1.

[1244] This is a complicated decision. While the majority agreed that the impugned provision violated s.15(1), Abella J was the only justice who argued that the impugned provisions could not be saved by s.1. The Chief Justice stated that the impugned provisions could be saved by s.1. Deschamps, Cromwell and Karakatsanis JJ. concluded that only the exclusion of de facto spouses from support is not justified under s. 1 of the Charter.

The issue from this case that is of particular relevance to this research is the notion of choice.[1245] It was stated by the then Chief Justice that the Quebec law falls within a range of reasonable alternatives for maximizing choice and autonomy in the matter of family assets and support.[1246] When she applied the s.15 framework to A's claim, McLachlin C.J (as she then was) explained: "In its effect, the Quebec scheme denies separated *de facto* partners important protections that it accords to separated married and civil union partners, despite the fact that they may not have meaningfully exercised a choice of regime. It is reasonable to infer from this, subject to a full analysis of the relevant contextual factors, that the law that denies them these protections treats them as less deserving of concern, respect and consideration."[1247] However, at the s.1 analysis stage, she concluded that the objective of the law, which is to promote choice and autonomy for all Quebec spouses with respect to property division and support", is sufficiently important to justify an infringement of the right to equality.[1248] When applying the minimum impairment test, she agreed that availability of judicial recourse for *de facto* spouses would obviously be less impairing of their equality right than the Quebec regime. However, she noted that there would be a trade-off in diminished choice and autonomy. In the Quebec scheme, partners choose whether to opt into the mandatory regime and have the discretion to manage their independence if they do not opt in. If judges were allowed to make orders that would limit those choices, individuals who thought they were free to structure their affairs would find themselves bound by judicially imposed obligations.[1249]

In contrast, Abella J (dissenting in result) took the position at the section 1 analysis stage that "[t]he harm of excluding all de facto spouses from the protection of the spousal support and family property regimes is clearly profound."[1250]In her view, the analysis should recognize protection "of those spouses for whom the choices to marry are illusory and who are left economically vulnerable at the dissolution of their relationship."[1251] Further, "the salutary impact of the exclusion . . . is the preservation of *de facto* spouses' freedom to choose not to be in a

---

[1245] More generally on the topic of choice in judicial decisions see Young, *supra* note 1011; Potter, *supra* note 1239; Koshan, *supra* note 1215.

[1246] *Quebec (Attorney General) v. A*, *supra* note 1242, at para 447.

[1247] *Ibid* at para 426.

[1248] *Ibid* at paras 435 and 437.

[1249] *Ibid* at para 445.

[1250] *Ibid* at para 377.

[1251] *Ibid* at para 376.

formal union. . . this freedom would be equally protected under a presumptive scheme. Those for whom a *de facto* union is truly a chosen means to preserve economic independence can still achieve this result by opting out."[1252]

The prioritization of an idealized version of choice over equality[1253] – a constitutional guarantee – is puzzling and troubling. In contrast to s.7 cases such as *PHS Community Services Society*,[1254] *Bedford*[1255] and *Adams*,[1256] where the respective governments' arguments about choice were not successful, the Supreme Court found the Quebec government's reliance on the notion of choice in the justification of impairing equality to be persuasive.[1257] I am not calling for an end to the preservation of choice and autonomy, rather, that "the context in which those choices are exercised"[1258] must be scrutinized carefully. In particular, it is argued by Potter, that equality is a pre-condition for the exercise of choice.[1259] My position is that meaningful exercise of choice is denied to those who are excluded from the protection of substantive equality. Without advancing substantive equality concurrent with initiatives to promote choices in care, it is unlikely that autonomy in decision-making can be fostered for those who experience the effects of "intermeshing" (to use the terminology of Carol Thomas) of gender, disability and other grounds. As Chapter 9 will show, some residents and their families are not able to exercise choices with respect to accommodation, despite the rhetoric of choice in the LTC sector.

7.2.3 Disability and autonomy in assisted dying

The last case is the 2015 Supreme Court of Canada decision *Carter v. Canada (Attorney General)*,[1260] which was about *Criminal Code* provisions that prohibited the provision of assistance in dying in Canada. This meant that a person could not legally seek the option of a

---

[1252] *Ibid* at para 379.

[1253] Potter, *supra* note 1239 at 188.

[1254] *Canada (Attorney General) v. PHS Community Services Society* 2011 SCC 44, *supra* note 1011.

[1255] *Canada (Attorney General) v. Bedford*, *supra* note 1012.

[1256] *Victoria (City) v Adams*, 2009 BCCA 563.

[1257] Koshan, *supra* note 1215 at 38.

[1258] Potter, *supra* note 1239 at 181.

[1259] *Ibid*.

[1260] *Carter*, *supra* note 1007. The appellants are Lee Carter, Hollis Johnson, William Shoichet, British Columbia Civil Liberties Association and Gloria Taylor. Gloria Taylor was diagnosed with a fatal neurodegenerative disease, amyotrophic lateral sclerosis (or ALS). Lee Carter and Hollis Johnson, who had assisted Ms. Carter's mother in achieving her goal of dying with dignity by taking her to Switzerland to use the services of an assisted-suicide clinic.

physician-assisted death.[1261] The Supreme Court held that the impugned provisions infringed s. 7 of the *Charter* and are of no force or effect to the extent that they prohibited physician-assisted death for a competent adult who (1) clearly consents to the termination of life and (2) has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition. The declaration of invalidity was suspended for 12 months.[1262]

This decision is important in terms of understanding how the Court interprets autonomy in the context of health care decision-making. It should be stressed that the Supreme Court was careful to point out the diverse views about autonomy in relation to the assisted dying debate since *Rodriguez*.[1263] The Supreme Court maintained that liberty and security rights deal with concerns about autonomy and quality of life.[1264] Liberty protects the right to make fundamental personal choices free from state interference while security of the person involves control over one's bodily and psychological integrity free from state interference.[1265] The law has long protected patient autonomy in medical decision-making.[1266] This is how the Supreme Court explained autonomy in medical decision-making:

> . . . An individual's response to a grievous and irremediable medical condition is a matter critical to their dignity and autonomy. The law allows people in this situation to request palliative sedation, refuse artificial nutrition and hydration, or request the removal of life-sustaining medical equipment, but denies them the right to request a physician's assistance in dying. This interferes with their ability to make decisions concerning their bodily integrity and medical care and thus trenches on liberty.[1267]

This case is also significant for our purpose because the Supreme Court declined to opine on the s.15 part of the claim.[1268] David Lepofsky argues that disability equality should have been the judicial focus of this case.[1269] The *Carter* claimants contended that because of their

---

[1261] *Ibid* at para 5.
[1262] *Ibid* at paras 127–128.
[1263] *Ibid* at paras 6, 10 and 59.
[1264] *Ibid* at paras 62 and 64.
[1265] *Ibid* at para 64.
[1266] *Ibid* at para 67.
[1267] *Ibid* at para 66.
[1268] *Ibid* at para 93.
[1269] David Lepofsky, "Carter v. Canada (Attorney General), The Constitutional Attack on Canada's Ban on Assisted Dying: Missing an Obvious Chance to Rule on the Charter's Disability Equality Guarantee" (2016) 76 SCLR(2d) 89 at 91.

disabilities they would not be able to end their own lives and needed help to carry out that wish.[1270] Lepofsky asserts that prior to *Carter*, the Supreme Court had failed to explore disability equality violations in *R. v. Swain* and *Rodriguez v. British Columbia (Attorney General)*.[1271] Lepofsky's critique of *Carter* also relates to his (and other disability scholars'[1272]) disappointment concerning the realization of disability rights in general: "The Supreme Court of Canada has made some great pronouncements about the Charter's disability equality guarantee. Yet governments too readily disregard them. Consequently, the lives of Canadians with disabilities are full of accessibility barriers, many of which are a government responsibility. All violate the Charter / human rights statutes."[1273]

Carter may indicate the Supreme Court's willingness to engage in *Charter* analysis of state interferences with an individual's ability to make decisions concerning their bodily integrity and medical care. The problem for LTC residents is that some of the interferences such as the use of physical and chemical restraints and confinement (see Chapter 6), are more likely to be disability-related. The government's justification is grounded in the need to protect vulnerable persons and those around them. It is not clear if the Supreme Court will be willing to accept arguments that are based on the relationship between liberty and equality.[1274] For LTC residents, the "totality of their lived reality"[1275] may need to be brought forward by claims that engage both s.7 and s.15.

7.2.4 **Summary**

To recap, the rights of residents that are created by various statutes must be considered in relation to the equality guarantee of the *Charter* as all laws must comply with the *Charter*. For many legal scholars, the post-*Kapp* legal landscape is not promising for equality-seeking groups. Although the cases discussed above do not involve LTC residents, they can illuminate a few important concepts related to the discussion below, including autonomy and choices. Governments have found courtroom success in defending their own characterizations of the

---

[1270] *Ibid*.
[1271] *Ibid* at 95–97.
[1272] Mary Ann McColl et al, "People with Disabilities and the Charter: Disability Rights at the Supreme Court of Canada Under the Charter of Rights and Freedoms" (2016) 5:1 Canadian Journal of Disability Studies 183.
[1273] Lepofsky, *supra* note 1269 at 109.
[1274] For example, see Sheldon, Spector & Perez, *supra* note 14.
[1275] *Ibid* at 232.

purposes of statutory schemes in s.15 cases, for example, by using a decontextualized notion of choice. These cases and their legal commentaries show that legal expression of substantive equality may not provide better prospects for challenging systemic discrimination in the s. 15 context and is unlikely to generate systemic changes in the LTC sector.

7.3 Autonomy in receiving care (decision and execution)

This section is intended to build on the discussion about care in Chapter 5 by explaining how individual residents exercise control over decisions about their own admission to or being confined in LTC, medical treatments, personal care and property matters. To understand why some residents may not be able to decide or influence their own care, it is important to address how law recognizes autonomy in making health care decisions. As Joan Gilmour explains, the law's strong support for an individual's right to autonomy is not extended to everyone. In particular, people with disabilities, seniors and minors are most at risk of being deprived of the power and authority to make their own decisions about health care.[1276] Recall that autonomy is a concept that has attracted criticisms from Nedelsky and Herring (see Chapter 2). At the core of their work is the concept of the "relational self". In consent and capacity law, the relational context in situations where a person lacks or may lack capacity (a term to be defined below) is frequently at the forefront of legal and factual analysis. The concept of the relational self allows me to focus on consent and capacity law issues that are most pertinent to the lives of LTC applicants and residents. The insights of Nedelsky and Herring will also help us understand how relationships may affect a person's ability or inability to exercise autonomy in practice (see Chapter 9).

This section will begin by unpacking some of the policy and legal considerations around autonomy in decision-making,[1277] followed by an overview of changes to consent and capacity law in Ontario. The law has not changed significantly – the elements of informed consent remain the same but there are some procedural changes that may be relevant to LTC residents

---

[1276] Joan Gilmour, "Legal Capacity and Decision Making" in Joanna N Erdman, Vanessa Gruben & Erin Nelson, eds, *Canadian Health Law and Policy*, fifth ed (Toronto, Ontario: LexisNexis Canada, 2017) 351 at 352.

[1277] I should note that for reasons of space, I exclude other relevant legal devices such as *parens patriae* for in-depth discussion. *Parens Patriae* refers to the state's responsibility to protect persons who are deemed incapable of protecting their own interests by reason of their particular personal characteristics. Margaret Hall, "The Vulnerability Jurisdiction: Equity, Parens Patriae, and the Inherent Jurisdiction of the Court" (2016) 2 Can J Comp & Contemp L 185; Sheldon, Spector & Perez, *supra* note 14 at 203.

and potential applicants to LTC, including substitute decision-makers. The professional guidelines will also be referenced as they guide the conduct of health care providers at the point of care. This section will end with a discussion about human rights cases involving LTC residents, which will add some nuances to the discussion about autonomy in decision-making when disability is engaged.

7.3.1 Achieving a balance between autonomy and protection

My starting point is to unpack the concept of "capacity" because as the Law Commission of Ontario argues, it is foundational to the law related to decision-making.[1278] The concept of capacity is associated with autonomy because capacity is "intimately tied to the ability to make independent decisions and take responsibility for their consequences."[1279] For Clíona de Bhailís, the right to legal capacity "encompasses both the ability to be the holder of rights (including legal standing) and the ability to be an actor in law (legal agency) … this can be categorized as the right to make decisions which have legal consequences and to have those decisions respected by the law."[1280] The threshold test that must be met to establish capacity varies depending on the context.[1281]

Law governing involuntary committal and capacity and consent matters attempts to balance individual rights against the interest of the state. Citizens have certain rights to liberty, autonomy and self-determination and the state also has the right as well as obligations to protect the safety of the community and to protect incapable individuals from self-harm, exploitation by others or unnecessary suffering.[1282] Ontario's attempt to achieve an appropriate balance between these competing interests and rights is evident in the four inter-related statutes that govern involuntary committal, capacity and consent matters: the *Mental Health Act*, *Health Care Consent Act, 1996*, *Substitute Decisions Act, 1992*, and the *Personal Health Information*

[1278] Law Commission of Ontario, *Discussion Paper: Legal Capacity, Decision Making and Guardianship* (Toronto: Law Commission of Ontario, 2014) at 4.

[1279] *Ibid*.

[1280] Clíona de Bhailís, "Theoretical framework for the VOICES Project" in Eilionóir Flynn et al, eds, *Global Perspectives on Legal Capacity Reform: Our Voices, Our Stories* (Abingdon, Oxon ; Routledge, 2019) 1 at 1.

[1281] Gilmour, *supra* note 1276 at 353.

[1282] D'Arcy Hiltz & Anita Szigeti, *A Guide to Consent and Capacity Law in Ontario*, 2017 edition. ed (Markham: LexisNexis, 2017) at xiii. See also Jane Meadus & Mary Jane Dykeman, *Health Care Consent and Advance Care Planning in Ontario: Legal Capacity, Decision-Making and Guardianship* (Toronto: Law Commission of Ontario, 2014) at 32.

Protection Act, 2004.[1283] All four statutes engage individual liberty and autonomy; the intent is to enhance autonomy and self-determination as much as possible while using the principle of minimal restrictions on liberties. Since the principle of fundamental justice must be adhered to, all four statutes are replete with procedural safeguards, checks and balances.[1284] It should be emphasized that even when a person is no longer capable, the intent of the law is to maximize personal autonomy for the incapable person by allowing for prior expressed wishes, values and beliefs to guide substitute decision-making.[1285] These statutes are of general application, so the discussion below is not limited to LTC applicants or residents but as I will show in Chapter 9, capacity issues are much debated in the LTC sector.

The general principle in consent and capacity law is that capable people have the right to take risks, whereas incapable people have the right to informed decision-making by others based on their prior capable wishes or best interests. Capable individuals enjoy decision-making autonomy in the broad areas of "property", "treatment/placement", "detention", and "personal health information" regardless of the wisdom of the choices.[1286] More importantly, we are all presumed to be capable in these areas.[1287] However, the state owes us a duty to protect our interests and those of the community if and when we become sufficiently incapacitated that we, or others, are at serious risk of harm. The law is about setting out the circumstances wherein others can take over making important decisions on behalf of incapable persons and detailing the protections afforded to incapable persons.[1288] Guardianship, as a legal option, should only be used as a last resort; indeed, the *Substitute Decisions Act* specifically prohibits court appointment

---

[1283] Hiltz & Szigeti, *supra* note 1282 at xiii to xiv. For a more comprehensive background on Ontario's history regarding guardianship and related issues, see Israel Doron, *From Guardianship to Long -Term Legal Care: Law and Caring for the Elderly* (D.Jur., York University (Canada), 2000) [unpublished].

[1284] Hiltz & Szigeti, *supra* note 1282 at xiv.

[1285] Hall, *supra* note 1004 at 16. See also Halsbury's Laws of Canada (online), *Mental Health*, "II. Consent and Capacity, 4. Substitute Consent, (4) Hierarchy of Substitute Decision-Makers (a) General" at HMN-41 "Overview" (2019 Reissue).

[1286] Hiltz & Szigeti, *supra* note 1282 at 1. See also CD Freedman, "Misfeasance, Nonfeasance, and the Self-Interested Attorney" (2010) 48 Osgoode Hall LJ 457, para 26.

[1287] *Health Care Consent Act, supra* note 490, s 4; *Substitute Decisions Act, 1992,* SO 1992, c 30, s 2.

[1288] Hiltz & Szigeti, *supra* note 1282 at 1. For a history on the old concept that a public obligation of some kind is owed to persons whose processes of thought and mind are seen to create or exacerbate vulnerability see Margaret Isabel Hall, "Dementia, Decision-Making, and the Modern (Adult) Guardianship Paradigm: Bentley v. Maplewood Seniors Care Society" (2015) 1 Can J Comp & Contemp L 293.

of a guardian if less restrictive alternatives exist.[1289] Procedural safeguards enshrined in other legislation, such as the *Statutory Powers Procedures Act* which applies to Ontario tribunals including the Consent and Capacity Board,[1290] are also relevant to the protection of incapable persons.

7.3.1.1 *Health Care Consent Act*: decisions about LTC admission, confinement to a care facility, medical treatments and personal care

The *Health Care Consent Act, 1996* largely codifies the common law. It also codifies principles of assessing capacity. Further, it establishes a framework for substitute decision-making, including a hierarchy of substitute decision-makers and rules applicable for consenting to or refusing treatment, personal assistance services, admission to or confinement in LTC.[1291] The Consent and Capacity Board, which adjudicates a variety of matters under a number of statutes, is also established by the *Health Care Consent Act*.[1292] A quick clarification about the structure of the *Health Care Consent Act* is in order. The *Health Care Consent Act* is divided into six parts dealing with, among other subjects, legal tests for capacity to make health care decisions, treatment, admission to care facilities and personal assistance services. Each type of decision has its own part, which covers common topics such as decisions on behalf of incapable persons and application to the Consent and Capacity Board. It should be noted that the LTC admission provisions mirror the treatment provisions, with some differences.[1293] Similarly, the personal assistance services provisions mirror the treatment provisions, with differences in the decision-making by substitute decision-maker.[1294]

The role of the concept of best interests in substitute-decision making is important for my research. The concept of best interests highlights how the law regulates the complex interplay of relational selves and need for protection. The hierarchy of substitute decision-makers[1295] indicates that most of the time, substitute decision-makers have continuing relationships with the incapable person (such as spouses, parents, children and siblings). Other types of relationships

---

[1289] Capacity Assessment Office, *Guidelines for Conducting Assessments of Capacity* (Toronto: Ministry of the Attorney General, 2005) at I.3.

[1290] Hiltz & Szigeti, *supra* note 1282 at 593–597; *Statutory Powers Procedure Act,* RSO 1990, c. S.22, s 3(1).

[1291] Hiltz & Szigeti, *supra* note 1282 at 165.

[1292] *Health Care Consent Act, supra* note 490 at Part V. See also Hiltz & Szigeti, *supra* note 1282 at 198.

[1293] Hiltz & Szigeti, *supra* note 1282 at 192.

[1294] *Ibid* at 197–198.

[1295] *Health Care Consent Act, supra* note 490, s 20.

between the incapable person and public institutions are created by law, such as the appointment of the Public Guardian and Trustee as guardian. A person who gives or refuses consent on an incapable person's behalf for his or her admission to a care facility must be in accordance with prior capable wishes.[1296] If there are no prior expressed capable wishes expressed, then the person must act in the incapable person's best interests.[1297] In deciding what the incapable person's best interests are, the following must be considered:

- the values and beliefs that the person knows the incapable person held when capable and believes he or she would still act on if capable;
- any prior capable wishes expressed by the incapable person with respect to admission to a care facility that are not required to be followed;
- Whether admission to the care facility is likely to improve the quality of the incapable person's life, prevent the quality of the incapable person's life from deteriorating, or reduce the extent to which, or the rate at which, the quality of the incapable person's life is likely to deteriorate;
- whether the quality of the incapable person's life is likely to improve, remain the same or deteriorate without admission to the care facility;
- whether the benefit the incapable person is expected to obtain from admission to the care facility outweighs the risk of negative consequences to him or her; and
- Whether a course of action that is less restrictive than admission to the care facility is available and is appropriate in the circumstances.[1298]

One could interpret from the above discussion that the law assumes a family member or friend appointed through a substitute-decision making process is best placed to: 1) know the individual's "prior intentional states" (i.e., reference to "values and beliefs" in s. 42(2)(a) of the *Health Care Consent Act*) and to effect the decision that the incapable person would have made if able to do so;[1299] 2) determine other factors that contribute to the determination of the best interests of the incapable person, such as the quality of life of the incapable person.

[1296] *Ibid*, s 42(1)1.

[1297] *Ibid*, s 42(1)2.

[1298] *Ibid*, s 42(2).

[1299] Margaret Hall argues that pursuant to modern guardianship paradigm, the assumption is that persons generally make decisions like those they have made in the past, the substitute is able to maintain the identity of the incapable individual by perpetuating this kind of consistent decision-making. Hall, *supra* note 1288 at 296–301.

7.3.1.2 Substitute Decisions Act, 1992: decisions about property and personal care

The *Substitute Decisions Act* governs what may happen when someone is not mentally capable of making certain decisions about their own property or personal care (health care, accommodation, safety, nutrition, hygiene and clothing).[1300] Similar to the law regarding consent to health care, "[g]uardianship laws continue to grapple with the competing values and interests of individual autonomy and self-determination vs. the best interests of the individual."[1301] The *Substitute Decisions Act* applies to both court appointed personal and property guardianship and to powers of attorney for personal care and otherwise.[1302] The procedures to be followed depend on the type of decision the person is unable to make i.e., property or personal matters.[1303] The Public Guardian and Trustee may also be appointed by the court as the guardian of an incapable person, if there is no one else willing, suitable, and available to take on the responsibility.[1304]

For the purpose of this chapter, incapacity for personal care is particularly relevant. If the court makes an order for full guardianship of the incapable person, the guardian may have a wide range of powers, including powers to:

- determine his or her living arrangements and provide for his or her shelter and safety;[1305]
- on behalf of the person, make any decision to which the *Health Care Consent Act, 1996* applies;[1306] and
- make decisions about the person's health care, nutrition and hygiene.[1307]

There is overlap and similarity between the *Health Care Consent Act* and *Substitute Decisions Act.* The *Substitute Decisions Act* mandates the guardian to make decisions to which the *Health Care Consent Act* applies in accordance with that Act.[1308] For decisions to which the

---

[1300] Ministry of the Attorney General, *A Guide to the Substitute Decisions Act* (Toronto: Ministry of the Attorney General, 2000) at 2.
[1301] Halsbury's Laws of Canada (online), *Mental Health*, "II. Consent and Capacity 1. Overview of Consent and Capacity" at HMN-108 "Overview" (2019 Reissue).
[1302] Hall, *supra* note 1004 at 22. For a history of power of attorney, see C.D. Freedman, *supra* note 1286.
[1303] Ministry of the Attorney General, *supra* note 1300 at 2.
[1304] *Ibid* at 6. See also C.D. Freedman, *supra* note 1286 at para 26.
[1305] *Substitute Decisions Act, supra* note 1287, s 59(2)(a).
[1306] *Ibid*, s 59(2)(e).
[1307] *Ibid*, s 59(2)(e.1).
[1308] *Ibid*, s 66(2.1).

Health Care Consent Act does not apply, if the guardian does not know of a wish or instruction applicable to the circumstances that the incapable person expressed while capable, or if it is impossible to make the decision in accordance with the wish or instruction, the guardian must make the decision in the incapable person's best interests.[1309] In deciding what the incapable person's best interests are, the guardian must consider factors such as the values and beliefs that the guardian knows the person held when capable and believes the person would still act on if capable.[1310]

7.3.1.3 Amendments to the *Health Care Consent Act* and *Substitute Decisions Act* between 2004 and 2018

To briefly recap the legislative developments in this period, I did not note any fundamental changes to consent and capacity law outside of the *Mental Health Act*.[1311] Similarly, I found no significant developments in common law either, except for the few cases noted here.

With respect to the *Health Care Consent Act*, the key provisions about consent and capacity with respect to treatment have not changed: these include elements of informed consent,[1312] presumption of capacity,[1313] principles for giving or refusing consent on behalf of an incapable person,[1314] application of review of finding of incapacity.[1315] The changes that did occur were the result of other legislative initiatives: *Personal Health Information Protection Act, 2004*,[1316] *Regulated Health Professions Statute Law Amendment Act, 2009* (Bill 179),[1317] *Good Government Bill 2009* (Bill 212)[1318], the *Long-Term Care Homes Act, 2007*, and more recently, *Strengthening Quality and Accountability for Patients Act, 2017* (Bill 160).[1319] In what follows, I will first address the more substantive changes specific to LTC residents and then other types of changes.

[1309] *Ibid*, s 66(3).

[1310] *Ibid*, s 66(4)(a).

[1311] Hiltz & Szigeti, *supra* note 1282 at 289–291.

[1312] *Health Care Consent Act*, *supra* note 490, s 11.

[1313] *Ibid*, s 4(2).

[1314] *Ibid*, s 21.

[1315] *Ibid*, s 32.

[1316] *Personal Health Information Protection Act,* 2004, SO 2004, c 3, Sched A.

[1317] *Regulated Health Professions Statute Law Amendment Act,* 2009, SO 2009, c 26.

[1318] The author was involved in Bill 212.

[1319] *Strengthening Quality and Accountability for Patients Act, 2017*, *supra* note 625. Schedule 5 of Bill 160 includes amendments to the Health Care Consent Act. This Schedule comes into force on a day to be named by proclamation of the Lieutenant Governor (see s.70 of Bill 160). I am assuming the amendments will be proclaimed.

Similar to the *Health Care Consent Act*, the *Substitute Decisions Act*[1320] was amended by a number of omnibus bills. In addition, the capacity assessment regulation[1321] and the Guidelines for Conducting Assessments of Capacity[1322] have been updated also. None of these changes were major changes for residents or their substitute decision-makers. They were more procedural in nature and did not fundamentally change the existing ways of dealing with incapacity and its legal consequences.

7.3.1.4 Highlights of the statutory amendments and case law

The developments in law are intended to ensure due process and procedural fairness and can be grouped into the following themes. First, the jurisdiction of the Consent and Capacity Board was clarified. Second, more checks and balances were introduced into the capacity evaluation process. Third, how substitute decision makers give or refuse consent was clarified. Fourth, minor procedural changes were made to the consent process.

Jurisdiction of the Consent and Capacity Board

The first set of changes concerned the jurisdiction of the Consent and Capacity Board. The *Health Care Consent Act* was amended to clarify that the Consent and Capacity Board cannot adjudicate on constitutional issues.[1323] In *Ontario (Attorney General) v. Patient*, the Attorney General applied for judicial review of a decision of the Consent and Capacity Board in which the Board held that it had jurisdiction to hear and determine the constitutional validity of its enabling legislation.[1324] The Superior Court concluded that the majority of the Consent and Capacity Board erred in law in holding that the Board had implied jurisdiction to deal with questions of law arising from the impugned provisions of the *Mental Health Act* and was therefore presumed to have jurisdiction to determine the constitutional validity of those provisions.[1325] The Superior Court stated that the legislature in this case had ensured that patients have an expedited opportunity to have their Charter rights addressed by a court.[1326] In 2006, the

---

[1320] *Substitute Decisions Act*, *supra* note 1287.
[1321] *Capacity Assessment,* O Reg 460/05.
[1322] Capacity Assessment Office, *supra* note 1289.
[1323] *Health Care Consent Act, 1996, supra* note 490, s 70.1(1).
[1324] *Ontario (Attorney General) v Patient*, 2005 CanLII 3982 (ON SCDC) at para 1, 250 D.L.R. (4th) 697.
[1325] *Ibid* at para 7.
[1326] *Ibid* at para 53.

Health Care Consent Act was amended to clarify that the jurisdiction of the Consent and Capacity Board does not include the consideration of constitutional questions.[1327]

The Supreme Court of Canada decision *Cuthbertson v. Rasouli*[1328] is the most recent decision about Ontario's statutory scheme (i.e., *Health Care Consent Act*) to deal with a dispute between next of kin and physicians over consent regarding life support and other forms of medical treatment for incapable patients.[1329] Writing for the majority, McLachlin C.J. stated: ". . . The simple fact is that appropriate medical care at the end of life, including palliative care, is closely tied to the withdrawal of life support."[1330]Provision of palliative care requires consent: ""Treatment" is "anything that is done" for one of the enumerated purposes (therapeutic, preventive, palliative, diagnostic and cosmetic) or "other health-related purpose". Under the HCCA, only acts undertaken for a health-related purpose constitute treatment, and therefore require consent."[1331] The Supreme Court confirmed that withdrawal of life support constitutes treatment requiring consent under the *Health Care Consent Act*.[1332] However, the Supreme Court was careful to point out that this case does not mean consent is required under the *Health Care Consent Act* for withdrawals of other medical services or in other medical contexts.[1333]

Further, McLachlin C.J noted: "[i]n summary, the HCCA contemplates disputes between physicians and substitute decision-makers over the care of incapable patients, and provides for their resolution by the Board, an independent, quasi-judicial body with specialized jurisdiction over matters of consent to medical treatment."[1334] The Supreme Court explained the role of the Consent and Capacity Board as follows: "Bringing its expertise to the issue, the Board's decisions may be expected to bring consistency and certainty to the application of the statute, thereby providing essential guidance to both substitute decision-makers and health care providers

---

[1327] This was amended as part of the *Good Government Act, 2006*, SO 2006, c 19. See the explanatory note of the Bill.
[1328] *Cuthbertson v Rasouli,* 2013 SCC 53, [2013] 3 SCR 341. Mr. Rasouli was unconscious and on life support. The physicians responsible for Rasouli's care believed that he was in a persistent vegetative state. In their opinion, continuing life support would not provide any medical benefit to Rasouli and may cause harm. They sought to remove his life support and to provide palliative care until his expected death. Ms. Salasel, Rasouli's wife and substitute decision-maker, refused to provide her consent.
[1329] *Ibid* at para 2.
[1330] *Ibid* at para 67.
[1331] *Ibid* at para 37.
[1332] *Ibid* at para 76. See also Meadus & Dykeman, *supra* note 1282 at 49-50.
[1333] *Cuthbertson v. Rasouli, supra* note 1328 at para 70.
[1334] *Ibid* at para 28.

in this difficult area of the law."[1335] According to Hiltz and Szigeti, this case has had a profound impact on litigation of end of life cases, encouraging greater use of the Consent and Capacity Board as the forum where substitute decision-making processes may be reviewed..[1336]

Capacity evaluation process

In both the *Health Care Consent Act* and the *Substitute Decisions Act*, there are provisions about evaluating or assessing capacity. Another significant change with respect to health care consent concerns assessment of capacity by an evaluator, which may lead to substitute decision-making. An evaluator[1337] must now provide information about consequences of findings of incapacity regarding admission to LTC, personal assistance and confining to a care facility to a person found incapable in accordance with guidelines established by the governing body of the evaluator's profession.[1338] Previously the requirement to provide information about the consequences of findings of incapacity was only applicable to a finding of incapacity regarding treatment decision.[1339] All the regulatory colleges surveyed address the issue of finding of incapacity, but their respective guidelines are slightly different. The College of Physicians and Surgeons of Ontario and College of Dietitians of Ontario direct their respective members to inform the client of the right to appeal the finding of incapacity to the Consent and Capacity Board for review if the client disagrees with the finding of incapacity.[1340] The College of Nurses of Ontario stipulates that nurses are professionally accountable for helping clients understand the information relevant to making decisions to the extent permitted by the client's capacity. If there is an indication that the client is uncomfortable with the finding of incapacity, or objects to the choice of substitute decision-maker, then the nurse informs the client of his/her options to apply to the Consent and Capacity Board for a review of the finding of incapacity, and/ or for the appointment of a representative of the client's choice.[1341]

[1335] *Ibid* at para 103.

[1336] Hiltz & Szigeti, *supra* note 1282 at xi.

[1337] *Health Care Consent Act, supra* note 490, s 2. See also *EVALUATORS,* O Reg 104/96. Evaluation of capacity may be made "evaluators" entitled to make such determination, such as physicians, social workers, nurses and psychologists.

[1338] *Health Care Consent Act, supra* note 490, ss 47.1, 54.11, 62.1.

[1339] *Ibid*, s 17. This provision has been in place 1996.

[1340] College of Dietitians of Ontario, *supra* note 918 at 82. College of Physicians and Surgeons of Ontario, *supra* note 813 at 7.

[1341] College of Nurses of Ontario, *Practice Guideline: Consent (Pub. No. 41020)* (Toronto: College of Nurses of Ontario, 2017) at 3 and 9.

Assessments of legal capacity are undertaken under the *Substitute Decisions Act* in situations where, in order to protect an individual from personal or financial harm, it may be appropriate to change his / her legal status or to restrict his/her legal rights.[1342] Under the *Substitute Decisions Act,* only a qualified assessor can conduct assessments of capacity for purposes such as creating a statutory guardianship.[1343] According to the Ministry of the Attorney General, the *Substitute Decisions Act* "creates the opportunity for a standard assessment protocol, which reduces bias and introduces consistency in the way that mental capacity assessments are conducted."[1344] The regulation governing assessors under the *Substitute Decisions Act* was also updated in 2005; Ontario Regulation 460/05 replaced Ontario Regulation 293/96. The rules concerning assessors have been modified to make assessments more professional by introducing a new continuing education requirement[1345] and requiring a minimum annual number of assessments.[1346] As well, the content of the qualifying course has been modified: instead of giving instructions about procedures for the conduct of capacity assessments, there will be instructions on best practices in completing forms and reports, and on standards for the performance of capacity assessments.[1347] Other minor changes include clarification about liability insurance[1348] and about which classes of nurses can perform capacity assessments.[1349]

The key tenets and methodologies of capacity assessments are provided in the 2005 *Guidelines for Conducting Assessments of Capacity*, which replaced the 1995 *Manual for Capacity Assessments – Section R*.[1350] The highlights are as follows. The Guidelines emphasize procedural protections: for example, assessors have to explain the purpose of the assessment and the need for reviewing documentation.[1351] An assessor has to make a determination of whether

---

[1342] Capacity Assessment Office, *supra* note 1289 at I.1.
[1343] Hiltz & Szigeti, *supra* note 1282.
[1344] Capacity Assessment Office, *supra* note 1289 at I.1.
[1345] O Reg 460/05, *supra* note 1321, s 5(1).
[1346] *Ibid*, s 6.
[1347] *Ibid*, ss 4(a)2 and 3.
[1348] *Ibid*, s 2(1)(e). The new regulation clarifies that the $1million liability insurance requirement is satisfied if the assessor belongs to an association that is specified in the by-laws of the regulated health profession of which the assessor is a member, and provides protection against professional liability, in respect of assessments of capacity, in an amount not less than $1M.
[1349] *Ibid*, s 2(2)5. The new regulation just allows Registered Nurses and Registered Nurses (Extended Class) to perform assessments. The old regulation allowed Registered Practical Nurses to conduct assessments (see Ontario Regulation 293/96, s 1(1.1)5.
[1350] Capacity Assessment Office, *supra* note 1289 at iii.
[1351] *Ibid* at III.1.

the person's decisions or actions are reasoned, not whether the decisions or actions are reasonable.[1352] The Guidelines provide an explanation as to how capacity (as a socio-legal concept) has evolved over time.[1353] A medical condition or disability does not mean incapacity.[1354] Part VII of the Guidelines addresses special populations: the elderly, Focal Neurological Disorders, The Psychiatrically Disabled and People with Intellectual Disabilities. This part addresses disability, including intellectual disability, from various perspectives and includes special considerations and implications for each special population. Some examples of the considerations are as follows. Past experience of institutionalization will affect how a person may react to the assessor.[1355] Family members do not necessarily want rights or autonomy for the disabled person.[1356] The assessor must be alert to bias and prejudice against disabled people.[1357] It should be noted that the Guidelines also address the intersection of aging and disability. In particular, it is suggested that various deficits do not mean incapacity.[1358]

The more recent Consent and Capacity Board decisions and the handful of appellate level cases can shed light on the importance of procedural fairness for individuals who may be incapable. Since the 1997 decision *Re Koch*,[1359] which was the first consideration of consent and capacity issues with respect to admission to LTC, the Consent and Capacity Board and the courts have pondered what types of procedural safeguards are necessary and the consequences if the process is somehow tainted. The overarching theme is that some protections and due process rights must be afforded to individuals when the implications of determinations of capacity have such fundamental impact on the liberty of the person.[1360] In the cases reviewed, procedural fairness played a critical role in the Board's or the court's decision about an evaluator's finding of incapacity. For example, in *MN (Re)*:

[1352] *Ibid* at II.4.
[1353] *Ibid* at II.1.
[1354] *Ibid* at Part VII.
[1355] *Ibid* at VII.10.
[1356] *Ibid*.
[1357] *Ibid* at VII.9.
[1358] *Ibid* at VII.2 to VII.5.
[1359] *Koch (Re),* 1997 CanLII 12138 (ON SC), [1997] 33 OR (3d) 485; [1997] OJ No 1487 (QL). The appellant suffered from multiple sclerosis and was separated from her husband. The husband made a complaint about his wife's capacity. The appellant appealed from the Consent and Capacity Board's findings that she was incapable of managing her affairs and incapable of consenting to placement in a care facility. The appeal was allowed.
[1360] Hiltz & Szigeti, *supra* note 1282 at 196.

> However, the *Health Care Consent Act* is replete with provisions designed to protect the legal rights of the individual and provides for due process where those rights are to be protected. Procedural fairness, like natural justice, is impliedly, however, required by the statute, since the end result for the individual is a denial of his or her fundamental rights to make one's own choices in life. That right of the individual places an onus on the capacity assessor or evaluator to establish that the process of evaluation or assessment was procedurally fair.[1361]

In these decisions, the Board or the court was critical of certain aspects of the processes that led to the hearing (in other words, capacity assessment), including detailed notes or documentation of the process i.e., completeness of the evidence,[1362] whether the evaluator informed the patient of the consequences of a finding of incapacity,[1363] and how the evaluator reached his/her conclusion in particular whether the evaluator started with the presumption of capacity.[1364] The Board was also critical of an evaluator who misunderstood the legal test for capacity.[1365] By the same token, the Board or court also took note when an evaluation was done properly.[1366] The rules can be summarized as follows. The individual must be informed of the fact that a capacity assessment for the purpose of LTC admission is going to be undertaken, the purpose of the assessment and the significance of a finding of incapacity. The individual must be informed as soon as a decision to assess capacity is made as well as on an on-going basis.[1367]

Giving consent by capable person or substitute decision-maker

In 2017, the *Health Care Consent Act* was amended mainly to provide for rules with respect to confining in a care facility, including rules for who may give consent to confining on behalf of an incapable person, and respecting reviews by the Consent and Capacity Board.[1368] These amendments are consequential amendments to the provisions in the LTCHA about restraining and confining residents, which I addressed in Chapter 6. More specifically, because

---

[1361] *MN (Re),* 2010 CanLII 70783 (ON CCB) at 11.
[1362] *FK (Re),* 2013 CanLII 73956 (ON CCB). see also *Ibid*.
[1363] *AB (Re),* 2004 CanLII 34873 (ON CCB).
[1364] *FK (Re), supra* note 1362; *RTC (Re),* 2007 CanLII 20001 (ON CCB).
[1365] *C (Re),* 2005 CanLII 57860 (ON CCB).
[1366] *AM (Re)*, *supra* note 570.
[1367] Hiltz & Szigeti, *supra* note 1282 at 196. See also *Saunders v Bridgepoint Hospital*, 2005 CanLII 47735 (ON SC).
[1368] *Strengthening Quality and Accountability for Patients Act, 2017*, *supra* note 625. See explanatory note of Schedule 5 of the Bill.

the concept of "confining in a care facility" has to be incorporated,[1369] the *Health Care Consent Act* had to be amended throughout so that the application of the Act is extended beyond treatment, admission to LTC, and personal assistance services to include "confining in a care facility". The most significant change is the addition of a new part (Part III.1 Confining in a Care Facility). The steps of consenting to confinement are basically the same as other types of decisions, but a few requirements are important to note. It is made clear that the common law duty of a caregiver to confine a person when immediate action is necessary to prevent serious bodily harm to the person or to others continues to apply, and therefore the home does not necessarily have to wait 48 hours or until any appeal is disposed of.[1370] The majority of the changes involve striking out "admission to a care facility", and substituting "admission to or confining in a care facility" so they are not necessarily substantive. For example, one of the purposes of the *Health Care Consent Act* has been updated to state: "to permit intervention by the Public Guardian and Trustee only as a last resort in decisions on behalf of incapable persons concerning treatment, admission to or *confining in a care facility* or personal assistance services" [my emphasis].[1371] As well, the 2007 amendments were never proclaimed so the provisions unrelated to the secure unit provisions have to be reintroduced. For example, one of the new (but never proclaimed) requirements in the 2007 amendments was that the person responsible for authorizing admission must take reasonable steps to ensure that the incapable person's admission is only authorized when the substitute decision-maker has given consent in accordance with the Act. Previously the *Health Care Consent Act* stated consent may be given or refused on the incapable person's behalf by his or her substitute decision-maker in accordance with the Act.[1372]

Procedural changes

The *Health Care Consent Act* was amended to introduce procedural changes. The Consent and Capacity Board now has four business days to release its reasons for a decision after

---

[1369] Confinement is not a completely new concept in the *Health Care Consent Act*. See s.7: "This Act does not affect the common law duty of a caregiver to restrain or confine a person when immediate action is necessary to prevent serious bodily harm to the person or to others." Also, s.59(3) states that "the person shall not give consent on the recipient's behalf to the use of confinement, monitoring devices or means of restraint, unless the practice is essential to prevent serious bodily harm to the recipient or to others, or allows the recipient greater freedom or enjoyment."

[1370] *Health Care Consent Act*, *supra* note 490, s 54.10(6).

[1371] *Ibid*, s 1(f).

[1372] *Ibid*, s 40(1). It is amended by s.59 of Bill 160.

receipt of a request[1373] instead of two days.[1374] Further, there were changes related to arranging counsel for incapable persons. While the Consent and Capacity Board has always been able to arrange for legal representation for a person who is or may be incapable regarding treatment, admission to a care facility or a personal assistance service, the Consent and Capacity Board can now arrange legal representation for a person who is or may be incapable with respect to managing property.[1375] The Consent and Capacity Board may direct Legal Aid Ontario - instead of the Public Guardian and Trustee Office or the Children's Lawyer - to arrange for legal representation to be provided for the incapable person.[1376] The *Health Care Consent Act* was further amended to include specific authority for an incapable person's attorney or guardian of property to assess, review and challenge a solicitor's bill under the *Solicitors Act*.[1377]

The key changes to *Substitute Decisions Act* are as follows. There is a new requirement that the resigning statutory guardian of property or attorney under a continuing power of attorney or a power of attorney for personal care must provide an accessible copy of their notice of resignation to any entitled recipient who requests it in an accessible format. The accessible copy must also be provided if the guardian or attorney has reason to believe that the recipient needs an accessible copy. The guardian or attorney is also required to explain their resignation on request or if there is reason to believe that an explanation is necessary.[1378] Further, previously, there were a number of requirements related to the Public Guardian and Trustee. The *Substitute Decisions Act* now places responsibility for enforcement on the applicant in the proceeding in which the assessment order is made, rather than on the Public Guardian and Trustee.[1379] The Public Guardian and Trustee must reasonably believe a record relating to a person who is alleged to be incapable to be relevant to an investigation arising from the allegation in order to be entitled to have access to the record.[1380] A duty is created for the Public Guardian and Trustee to provide notice of the access to the person alleged to be incapable, unless notice is not appropriate in the

---

[1373] *Ibid*, s 75(4).

[1374] This was amended by the *Good Government Bill 2009,* SO 2009, c 33.

[1375] *Health Care Consent Act, 1996, supra* note 490, s 81(1).

[1376] *Ibid*, s 81(1)(a).

[1377] *Ibid*, s 81(2.1).

[1378] *Substitute Decisions Act, 1992, supra* note 1287, ss 11(3), 4, 20(2)-(3). See the explanatory note of Bill 173. *Jobs for Today and Tomorrow Act (Budget Measures),* 2016, SO 2016, c 5.

[1379] *Substitute Decisions Act, 1992, supra* note 1287, s 81.

[1380] *Ibid*, s 83(1).

circumstances.[1381] The court must not appoint the Public Guardian and Trustee as a guardian unless the application is accompanied by the Public Guardian and Trustee's written consent to the appointment. [1382] Also, provisions about requiring the disclosure of certain categories of personal information about an incapable person to his or her guardian were added.[1383]

In sum, this brief overview of the changes to the consent and capacity law above set the stage for understanding decision-making autonomy that residents may enjoy. They very much correspond to Herring's comments: ". . . medical law is built around highly individualised concepts of what are people, what are bodies and what our rights are."[1384] The legal safeguards are created to enhance the protection of persons who appear to be of limited or marginal capacity. Sometimes problems may arise in determining the responsibilities and rights of those in caring relationships. As Nedelsky explains, relationships are not necessarily benign, and it is important to understand what kinds of relationships foster—and which undermine— autonomy and other core values.[1385] This discussion on capacity also helps us understand how caring relationships may be factored into the lives of incapable LTC applicants and residents when decisions about property, treatment and LTC admission, including confinement, must be made. In Chapter 9, the exercise of these rights will be examined.

7.3.2 *Asserting Rights at the Human Rights Tribunal of Ontario*

Sometimes decisions about treatment, LTC admission and property also engage other legislation. In Chapter 5, I discussed the recent changes to the *Ontario Human Rights Code*. Here I will describe three human right cases[1386] involving LTC residents to illustrate some nuances around autonomous decision-making. I take no position with respect to the adjudicative facts in these cases.

[1381] *Ibid*, s 83(9).

[1382] *Ibid*, s 24(2.1). See Bill 190. *Good Government Act, 2006,* SO 2006, c 19.

[1383] *Substitute Decisions Act, 1992, supra* note 1287, ss 31.1, 59.1. See explanatory note of Bill 190. *Good Government Act*, *2006*, *supra* note 1382.

[1384] Herring, *supra* note 112 at 186.

[1385] Nedelsky, *supra* note 248 at 39.

[1386] These three cases involve multiple decisions including interim decisions from the Human Rights Tribunal of Ontario.

7.3.2.1 Lack of capacity to conduct litigation and accessing tribunals

Since capacity is domain-specific, it is possible to be competent in one domain but not others. The challenge for those who lack litigation capacity is the appointment of a litigation guardian if they want to assert their rights in more formal forums. This may be further complicated by the fact that they may have given power of attorney to others who do not act in their best interests to manage their affairs. In *Romanchook v. Garda Ontario*, the Human Rights Tribunal of Ontario was asked to decide "whether and when the Tribunal should use its powers to control its process to require the appointment of a litigation guardian for a party who may not be competent to make decisions about the litigation, and to disqualify a licensed member of the Law Society of Upper Canada from continuing to act as a party's representative."[1387] It was alleged that the claimant, Mr. Romanchook, had not obtained placement at the LTC home of his choice because of a priority given to married couples.[1388] Mr. Romanchook was represented by a paralegal, R.J. Potomski, at this proceeding. In an earlier court proceeding, the court declared that Mr. Romanchook was incapable of managing property and that the Public Guardian and Trustee was appointed guardian of property for Mr. Romanchook. Further, the court terminated the Power of Attorney of Robert Joseph Potomski and Norma Johns over the property of Mr. Romanchook.[1389] The Consent and Capacity Board determined that Mr. Romanchook was capable of making treatment decisions regarding mental stimulation and socialization.[1390] The Chair conducted a preliminary investigation into Mr. Romanchook's capacity to make decisions about the litigation and found strong reasons to believe that he did not have capacity to conduct the litigation without a litigation guardian.[1391]

One of the issues that was litigated at the proceeding was legal capacity. Citing a 1997 decision *Calvert (Litigation Guardian of) v. Calvert*, the Human Rights Tribunal of Ontario stated that instructing counsel requires a relatively high level of competency.[1392] "The capacity to instruct counsel involves the ability to understand financial and legal issues. This puts it

---

[1387] *Romanchook v. Garda Ontario*, *supra* note 986 at para 1. There were six applications filed by the paralegal and the Tribunal ordered them to be heard together. See also Tess Sheldon & Ivana Petricone, *supra* note 978 at 48–49.

[1388] *Romanchook v. Garda Ontario*, *supra* note 986 at para 3.

[1389] *Ibid* at para 21.

[1390] *Ibid* at para 13.

[1391] *Ibid* at paras 50–51.

[1392] *Ibid* at para 36.

significantly higher on the competency hierarchy."[1393] The conduct of court litigation on behalf of incapable parties is governed by comprehensive schemes contained in the Rules of Civil Procedure and the Rules of the Small Claims Court. Both Rules define a person under a disability to include a person or party who is "mentally incapable within the meaning of section 6 or 45 of the *Substitute Decisions Act, 1992* in respect of an issue in the proceeding, whether the person or party has a guardian or not." Both sets of Rules require that, with limited exceptions, a proceeding must be commenced, continued or defended on behalf of a person under a disability by a litigation guardian. The courts have powers to appoint, remove, and substitute litigation guardians in certain circumstances, and, in particular, to appoint the Public Guardian and Trustee or Children's Lawyer as litigation guardian. Courts must approve settlements and give leave (permission) for discontinuances. For proceedings under the Rules of Civil Procedure, a litigation guardian must be represented by a lawyer.[1394] Also, courts of inherent jurisdiction (in Ontario the Superior Court of Justice) have *parens patriae* jurisdiction to make orders to protect children and others under legal disabilities.[1395]

The gap, as pointed out by the Human Rights Tribunal of Ontario, is that the Tribunal has no *parens patriae* jurisdiction and the *Statutory Powers Procedure Act*, which addresses tribunals' procedural powers, contains no provisions regarding proceedings on behalf of children or individuals who are not legally capable of conducting litigation on their own behalf: "In our contemporary justice system, in which many important decisions that affect the lives of individuals are often made by administrative tribunals and not courts, this is a significant, and in my view, unfortunate, gap."[1396] The results are as follows:1) the Tribunal's proceedings were suspended unless and until a litigation guardian is appointed or there is new evidence that Mr. Romanchook was competent to make decisions about the litigation; 2) R.J. Potomski was disqualified from acting as representative for Mr. Romanchook or as his litigation guardian.; 3) If no party communicates with the Tribunal in one year, the Applications may be dismissed as withdrawn.[1397]

[1393] *Ibid* at para 59.
[1394] *Ibid* at para 37.
[1395] *Ibid* at para 38.
[1396] *Ibid* at para 39.
[1397] *Ibid* at para 68.

7.3.2.2 Executional autonomy and disability

Sometimes a LTC resident may require assistance to execute his / her decision because of a disability. As Boyle argues, the decisional autonomy of older disabled people may be ignored or overridden because they lack the ability to execute their decisions.[1398] But the question is to what extent others must assist the disabled person to execute his / her decision. In *TenBruggencate v. Elgin (County),* the application was filed by the son (Roeland) of a LTC resident (Albert TenBruggencate) against the home (institutional respondent) and the medical director (personal respondent).[1399] The applicant told nursing staff at home that a specialist in Chinese medicine and acupuncture was recommending that the applicant's father take some homeopathic drops including Pimpinella (an over-the-counter medication) to help alleviate his cough. The applicant's father could not self-administer this medication because of his physical disabilities. However, nursing staff were not permitted to administer any medication without a physician's order.[1400] The home's medical director maintained that Chinese medicine was outside the scope of his practice and that he did not have sufficient knowledge about Pimpinella to order this treatment for the applicant's father.[1401] The applicant submitted that the LTC home was his father's home and that he should be able to take over-the-counter medications if he so wishes, as he would be able to if he was living in a private home.[1402] It was alleged that the respondents have a duty to assist him. The refusal of the respondents to do so would constitute discrimination based on disability.[1403] The respondents principally argue that administering a herbal remedy is not a service the respondents provide to anyone.[1404]

The Human Rights Tribunal of Ontario dismissed the application as there was no *prima facie* case of discrimination. Further, the Vice-Chair stated that even if the applicant's allegations were accepted to be true, he did not find that the refusal to administer Pimpinella to the applicant's father constitutes discrimination based on disability.[1405] Specifically, the Vice-Chair

---

[1398] Boyle, *supra* note 154 at 303.
[1399] *TenBruggencate v. Elgin (County)*, *supra* note 987 at para 2. The respondents were the County of Elgin as it operated the LTC home and the medical director of the home.
[1400] *Ibid* at paras 3, 6.
[1401] *Ibid* at para 4.
[1402] *Ibid* at para 16.
[1403] *Ibid* at para 6.
[1404] *Ibid* at para 7.
[1405] *Ibid* at para 11.

found the physical disabilities of the applicant's father were not a factor in the medical director's decision.[1406] With respect to the institutional respondent, the policy requiring a doctor's order for residents to self-administer over-the-counter medications can be said to restrict the "rights" of residents to take over-the-counter medications. However, under this policy everyone is expected to have a doctor's order in order to self-administer medications. With a doctor's order, the respondents would assist the applicant's father in administering the Pimpinella.[1407] Further, this was not a case of adverse impact discrimination.[1408] In sum: " . . . that the service that the respondents provide in this regard is medical treatment when ordered by a doctor. I do not see a positive obligation on the respondents' part to provide a service beyond this established policy and practice by being required to assist the applicant's father in self-administering a medication he wishes to take. . . "[1409]

7.3.2.3 Challenges of family members as advocate for disabled resident

The last group of decisions also concerns a LTC resident who may lack capacity in making certain decisions. The most troubling aspect of these decisions is that the disabled resident in question may have experienced discrimination in accessing services, but her relative (daughter) was not able to make a case (or cases) without counsel. The daughter clearly lacked understanding of disability as a ground of discrimination and of the Tribunal's process. This resulted in the disabled resident being involved (unwillingly) in a series of Tribunal decisions that unavoidably exposed her private information, such as health records.

By way of background, the applicant (Ms. Gan) was a LTC resident and was non-verbal, non-mobile and completely dependent on others for all activities of daily living.[1410] She was being fed through a gastrostomy feeding ("G feeding") tube.[1411] Ms. Gan and her daughter (Ms. He) have had a history of difficulties with the LTC care home.[1412] It appears that the cases can be traced to an incident involving the daughter (Ms. He) being removed from the home because Ms.

[1406] *Ibid* at para 27.
[1407] *Ibid* at para 29.
[1408] *Ibid* at para 31.
[1409] *Ibid* at para 34.
[1410] *Public Guardian and Trustee v Gan et al*, 2014 ONSC 2145 at para 3.
[1411] *Gan v Sergeant Gowan,* 2013 HRTO 2080 (CanLII) at para 10.
[1412] *Ibid*.

He removed the feeding tube with Ms. Gan's consent but without the home's permission.[1413] Ms. He complained to a number of bodies, including the College of Physicians and Surgeons of Ontario and Toronto Police, about this incident. Then Ms. Gan and Ms. He made a variety of allegations of discrimination with respect to goods, services and facilities against several respondents, including the College of Physicians and Surgeons of Ontario, Toronto Police, and the LTC home.[1414] It should be noted that in a separate proceeding, the Superior Court refused to allow Ms. He to be Ms. Gan's guardian of the person and appointed the Public Guardian and Trustee as the guardian.[1415] Due to space constraints, instead of summarizing all the cases, I will only highlight a few pertinent legal points.

For the allegation against the College of Physicians and Surgeons of Ontario, the issue was whether the respondent infringed Ms. Gan's right to equal treatment without discrimination by refusing to allow her to file a complaint about a doctor because of disability.[1416] The vice-chair found that:

> Ms. He misinterpreted Mr. Bellefontaine's [the College's investigator] words that he used to explain his inability to obtain the applicant's consent for the release of medical information. I find that Mr. Bellefontaine reasonably understood that it was Ms. He who filed a complaint against the doctor on her mother's behalf, that he reasonably understood that the applicant was unable to provide consent for the release of her medical information, and that he reasonably understood that Ms. He could provide consent because she was the applicant's next-of-kin. The respondent obtained Ms. He's consent and processed the complaint filed by her against the doctor treating the applicant. There was no evidence at the hearing to establish that Mr. Bellefontaine was aware that Ms. He wanted her mother recognized as the complainant.[1417]

For the case against a Toronto Police Sergeant, it was claimed that the respondent discriminated against Ms. Gan by failing to take action in relation to a complaint letter she had signed.[1418] In brief, the letter (signed by Ms. Gan) stated that Ms. He had disconnected her G feeding tube with her consent. Also, by asking her daughter to leave the home's premises, the

---

[1413] *Ibid* at para 11.

[1414] *Gan v. College of Physicians and Surgeons*, *supra* note 988. As of August 17, 2018, there are at least 13 decisions related to Ms. Gan and her daughter, Ms. He. Ms. He filed parallel applications along Ms. Gan's applications with similar allegations. Some applications were about discrimination on the basis of creed. All Human Rights applications were dismissed.

[1415] *Ibid* at para 4. See also *Public Guardian and Trustee v. Gan et al.*, *supra* note 1410.

[1416] *Gan v. College of Physicians and Surgeons*, *supra* note 988 at para 8.

[1417] *Ibid* at para 43.

[1418] *Gan v. Sergeant Gowan*, *supra* note 1411 at para 1.

police were assisting the home to breach the LTCHA. The letter quoted a section of the Act that provides, among other things, that every resident has the right to receive visitors of their choice. The letter also stated that, due to their actions, the home and the police had discriminated against the Ms. Gan because of disability.[1419] The Vice-Chair found that the allegation had no reasonable prospect of success:

> . . . The issue is whether there is any information from which the Tribunal could reasonably conclude that the applicant's disability was a factor in the respondent's decision not to deal with her complaint. In my view, there is not. I find that the applicant has provided no information from which the Tribunal could reasonably infer that her disability tainted the respondent's judgment regarding the scope of the police's power to intervene in this case.[1420]
>
> …
>
> there is no basis on which the Tribunal could reasonably find that the respondent's actions constituted a reprisal under the Code. . . [1421]

In sum, these Human Rights Tribunal of Ontario cases raise questions about the underlying tensions inherent in on the one hand respecting the desires and preferences of LTC residents (or their representatives), and on the other recognizing the support, including enabling relationships, required by residents. First, when LTC residents require assistance to execute their decisions because of their disabilities, others may not be obligated to assist them, and such refusal is not necessarily discrimination. Second, the state has a duty to ensure that the legal system (in this case, the human rights tribunal) is accessible to hear any allegations of right violations, including from those whose capacity, including legal capacity, may be in question. At the same time, there must be safeguards (such as those provided by the *Rules of Civil Procedures* for court proceedings) to protect those who may be incapable from their relatives, representatives and people in their lives generally, so that they are not subject to unnecessary litigations that only benefit their relatives (for example, financial gains). The *Health Care Consent Act* prescribes the principles for giving or refusing consent by substitute decision-makers[1422] and provides for application to the Consent and Capacity Board to determine compliance with such principles.[1423] Outside of the issues covered by the HCCA, the safeguards are hit and miss. Last but not least,

---

[1419] *Ibid* at para 11.
[1420] *Ibid* at para 19.
[1421] *Ibid* at para 20.
[1422] *Health Care Consent Act, 1996, supra* note 490, s 21.
[1423] *Ibid*, s 37.

while the claimants in these cases were disabled, they were not necessarily completely incapable with regard to all decisions. These claimants were not assisted by counsel at their respective hearings. One could ask how much support they received (if any) in making decisions about these applications.

7.3.3 Summary

In this section, I have considered how law is used to protect the autonomous individual in decision-making. Our law is predicated on the belief that capable individuals are free to make unwise choices. Substitute decision-making is available to protect us when we become incapable in specific domains. Legal safeguards are in place to ensure individuals are not unnecessarily denied opportunities to make decisions concerning healthcare, financial and personal matters. Human rights claims can be initiated to address discrimination as a form of barrier to autonomous decision-making. Being attentive to the relational context of persons who may lack capacity in one or more domain gives us insights as to why autonomy in decision-making is not always possible. More procedural safeguards have been introduced to respond to the need for protection of individual autonomy in situations where caring relationships may be detrimental to the exercise of autonomy without interventions from the state, for example, by rejecting an incapacity finding at the Consent and Capacity Board. The problem is that the law is silent on promoting caring relationships so that individuals can exercise their autonomy.

7.4 How do residents (as a group) and their families and friends influence the activities within homes?

Respecting the autonomy of LTC residents requires a variety of legal and non-legal responses. Thus far I have examined how individuals (not just LTC residents) may be able to enjoy autonomous decision-making in specific domains. But living in a communal setting comes with restrictions (as previous chapters have demonstrated) and compromises. In Chapter 5, I described how residents may exercise control at point of care, such as maintaining a resting routine or meal choices. With this in mind, I turn to the more specific mechanisms that are available to LTC residents – individually and collectively – in order to reflect the notion that the LTC home is primarily the home of residents. Formal and informal caregivers also have access to participation mechanisms that allow them to influence certain activities within homes such as quality improvement initiatives. More importantly, I believe that participation mechanisms have the potential to reconcile dependence and autonomy in caring relationships in LTC.

The participation mechanisms described here will be analyzed using insights from the New Governance literature. Recall that participation is an important principle in the New Governance literature, and scholars have debated about incorporating traditional legal approaches to promote accountability, while using New Governance approaches to stimulate innovation and collaboration.[1424] There have always been formal (legally mandated) and informal mechanisms enabling residents and their families and friends to have some role to play in the homes. In recent years, "patient", client or family engagement is the buzz word in the health care system, usually in the context of promoting quality care. Using examples of New Governance approaches, I have argued elsewhere that the changes brought by the LTCHA since 2010 are about strengthening existing or creating additional processes and procedures for participants – homes, residents, families, advocacy groups, industry organizations and government - to problem-solve challenges in the sector. One could view these approaches as recognition that while state involvement continues to be necessary in the governance of LTC, participants in the sector need to play a more active role in problem-solving – arguably in an attempt to broaden the scope of possible solutions and changes that could be implemented in the sector.[1425] By acknowledging and promoting residents' capacity for problem-solving, we can make space for residents – even those with profound disabilities - to express autonomy collectively. This section is a more comprehensive review of changes to the inclusion and participation mechanisms in LTC. I will add more nuances to my claim in Chapter 9. To do so, I will first discuss the Residents' Councils and Family Councils, which are autonomous bodies in LTC homes empowered by law. Then I will explain other participation mechanisms – of various degrees of legal formality - that are intended to promote problem-solving at the home level.

[1424] Alexander, *supra* note 339.

[1425] Poland Lai, "How New Governance Shapes Changes in the Long-Term Care Sector in Ontario, Canada" (2015) 20:1 The Innovation Journal: The Public Sector Innovation Journal Article 4.

7.4.1 **Residents' Councils**

The establishment of Residents' Council has become mandatory under the LTCHA.[1426] Under the *Nursing Homes Act*, a Residents' Council was optional: if three residents, substitute decision-makers, or persons selected by residents made a request then the home was obligated to assist in terms of logistical support and was required to advise the Ministry.[1427] The Program Manual stated that residents were to be given the opportunity and supports to establish and maintain an organized Residents' Council.[1428] In absence of a Residents' Council, the home was required, at least once a year, to convene a meeting of residents and substitute decision-makers to advise them of their right to establish a Residents' Council and then notify the Ministry of the results of the meeting.[1429] This annual general meeting also provided an opportunity for residents, families and representatives to express suggestions or concerns and for the facility to report on the status of services in the facility.[1430]

The Residents' Council's membership has also changed. Under the *Nursing Homes Act*, the substitute decision-maker or someone designated by the substitute decision-maker could also be a member of the Residents' Council. As well, the Minister was authorized to appoint members to the Residents' Council.[1431] Under the LTCHA, only residents of the home can be members of the Residents' Council.[1432]

The scope of the powers of the Residents' Council has not changed significantly. There are two new powers under the LTCHA: Residents' Council may sponsor, plan and collaborate with community groups and volunteers activities for residents.[1433]There are broader powers to advise and make recommendations about operations to the home.[1434] Homes also have an obligation to respond in writing to such concerns or recommendations within 10 days of receipt (instead of the 21 days required by the *Nursing Homes Act*). The Residents' Council may report

---

[1426] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 56(1).
[1427] *Nursing Homes Act*, *supra* note 786, s 29. Reg 832, *supra* note 831, ss 73(6)(a)-(c).
[1428] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 0902-01, page 7.
[1429] *Nursing Homes Act*, *supra* note 786, s 29(3).
[1430] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 0902-01, page 7.
[1431] *Nursing Homes Act*, *supra* note 786, s 29(5).
[1432] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 56(2).
[1433] *Ibid*, ss 57(1)4-5.
[1434] *Ibid*, ss 57(1)6-7.

to the Ministry's Director of LTC program (rather than to the Minister under the *Nursing Homes Act*) about its concerns.[1435]

7.4.2 **Family Councils**

Family Councils have always existed as well, but they are now legally recognized in the LTCHA. The *Nursing Homes Act* did not contain any reference to Family Councils, but the Program Manual made references to Family Council and Family advisory organizations.[1436] Under the LTCHA, if there is no Family Council, a family member or person of importance to a resident may request the establishment of a Family Council.[1437] The home must then assist and notify the Director within 30 days of the establishment of the council.[1438] Subject to exceptions allowed in the LTCHA, a family member or person of importance (for example, a friend or a significant other) to a resident has the right to be a member of the Family Council. A person can no longer be a member of the Family Council after the death or transfer of the resident, unless the person is a person of importance to another resident in the Home.[1439] If there is no Family Council, the Home must advise residents' families and persons of importance on an ongoing basis of their right to establish a Family Council and must convene semi-annual meetings to advise these persons of this right.[1440] The powers of the Family Council are similar to those possessed by the resident council. The Family Council may:

- provide assistance, information and advice to residents and their families, including the rights and obligations of residents, families and homes under the LTCHA;
- attempt to resolve disputes between the Home and residents;
- sponsor, plan and collaborate with community groups and volunteers regarding activities for residents;
- advise and make recommendations to the home; and
- review inspection reports, the home's written plan for achieving compliance, financial statements and operations of the home.[1441]

[1435] *Ibid*, s 57(2).

[1436] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 0902-01, page 10, 11, 14.

[1437] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 59.

[1438] *Ibid*, s 59(1)-(5).

[1439] Ministry of Health and Long-Term Care, *supra* note 782 at 4–3.

[1440] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 59(7)(b).

[1441] *Ibid*, s 60(1).

7.4.3 Home's relationships with the Councils

The relationship between the home and the Councils can be described in a number of ways. There are formal responsibilities, obligations and rights assigned to each party under the LTCHA. In general, they build on the requirements in the *Nursing Homes Act* and the Program Manual. At the same time, some requirements have been eliminated too. For example, the home is no longer required to consult its residents to determine optional services to be made available to residents[1442] nor to consult residents and families on the development of facility-specific admission agreement.[1443]

Firstly, the home is expected to provide staffing support to the councils. Specifically, an assistant must be made available to the Residents' Council[1444] and may be available to the Family Council (if requested).[1445] The council assistants must take instructions from the respective councils, ensure confidentiality where requested and report to the respective councils.[1446] Under the previous regime, there was no obligation on the home's part to appoint any assistant to assist the councils; however, the Minister had the authority to appoint a Residents' Council assistant who would then take instructions from and report to the Residents' Council.[1447] Secondly, the home was always expected to co-operate with the councils and the respective assistants (if any).[1448] The LTCHA imposes a duty on the home to consult regularly with the councils, or at least every three months, rather than merely requiring the administrator to hear suggestions or complaints from the Residents' Council and to act on them where practicable, as was the case under the *Nursing Homes Act*.[1449] The home must meet with the Residents' Council or the Family Council if invited to do so.[1450]Thirdly, while the home has always been expected to respect the autonomy of the councils, under the LTCHA this expectation is more formalized in law. Attendance of home staff at Resident Council meetings

---

[1442] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 0608-02, page 1.
[1443] *Ibid* at Tab 0902-01, page 9-11.
[1444] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 58(1).
[1445] *Ibid*, s 61(1).
[1446] *Ibid*, ss 58(2), 62(2).
[1447] *Nursing Homes Act*, *supra* note 786, ss 31(1)-(2).
[1448] *Ibid*, s 32(1). *Long-Term Care Homes Act, 2007*, *supra* note 425, s 62.
[1449] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 67.
[1450] *Ibid*, s 63.

was by invitation only[1451] and this requirement now applies to meetings of both councils under the LTCHA.[1452] The *Nursing Homes Act* also prohibited anyone from refusing a Resident Council assistant entry to the home or otherwise hindering, obstructing or interfering with a Residents' Council assistant in carrying out his/her duties.[1453] The Program Manual also directed the home to refrain from any involvement in the Residents' Council's commercial activities (e.g. fund-raising, craft sales and bazaars).[1454] This has been replaced by more general non-interference provisions in the LTCHA. Specifically, the home must not interfere with the meetings or operation of the councils, must not prevent a member of either Council from entering the Home to attend a meeting or performing any functions as a member, and must not hinder, obstruct or interfere with the member carrying out those functions. The home must not prevent a Council assistant from entering the home to carry out his or her duties or otherwise hinder, obstruct or interfere with the assistant in carrying out those duties.[1455]

7.4.4 **Resident and Family Participation in the Ministry's Annual Inspections of Homes**

It should be noted that the Ministry is also mandated to engage Residents' and Family Councils. For example, the Councils are involved in the Ministry's enforcement and compliance activities. Under the new legal requirements, all LTC homes are subject to the Resident Quality Inspection (RQI), an annual unannounced comprehensive inspection that assesses residents' satisfaction and homes' compliance with legislative requirements (see Chapter 8).[1456] Residents' and Family Councils have a formal right to participate in the RQIs, and the LTCHA requires that Ministry inspectors meet with the Family and Residents' Councils if they are willing to participate.[1457] In other words, residents and families are co-regulating LTC homes in the sense that they contribute their expertise and knowledge to monitor their homes.

[1451] Reg 832, *supra* note 831, s 73(7).

[1452] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 64.

[1453] *Nursing Homes Act*, *supra* note 786, s 32(2).

[1454] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 0603, page 5–6.

[1455] *Long-Term Care Homes Act, 2007*, *supra* note 425, ss 65(a)-(d). see also Ministry of Health and Long-Term Care, *supra* note 782 at 4–7. This requirement applies to those involved in the management or operation of the Home as well

[1456] Standing Committee on Public Account, *Long-Term Care Home Quality Inspection Program (Section 3.09 of the Auditor General's 2015 Annual Report)* (Toronto: Legislative Assembly. Standing Committee on Public Accounts, 2017).

[1457] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 145; Ministry of Health and Long-Term Care, *Inspection Protocol - Resident Council Interview* (Toronto: Ministry of Health and Long-Term Care, 2013); Ministry of Health

The table below summarizes the various features of both councils and indicates whether any of the features are new (in the sense of having not been included in the *Nursing Homes Act*):

Table 23: Summary of the provisions related to Residents' Council and Family Council

	Residents' Council	**Family Council**
Establishment	Mandatory (new)	Home must assist if requested by a family member or person of importance (new)
Scope of Powers	Expanded modestly (amended)	Similar to Residents' Council (new)
Membership	Residents only (amended)	A family member of a resident or person of importance (for example, a friend or a significant other) to a resident (new)
Council Assistant	Home must provide (new)	Home must provide if requested (new)
Council Meetings	General obligation that home must not interfere with the Council and staff must attend if invited (amended)	General obligation that home must not interfere with the Council and staff to attend must be invited (new)
Ministry inspector meetings with councils	Yes	Yes

---

and Long-Term Care, *Inspection Protocol - Family Council Interview* (Toronto: Ministry of Health and Long-Term Care, 2013). The procedures and processes for the inspector's interviews with the respective councils are prescribed in the inspection protocols.

7.4.5 Other mechanisms to promote participation and inclusion

In addition to formalizing the roles of the Family and Residents' Councils, the LTCHA expanded or formalized a number of mechanisms to promote participation and inclusion: distribution and posting of information, development of the home's mission statement, quality improvement and satisfaction surveys, quality improvement plans, immunity provisions and whistleblower protection. These mechanisms are available not just to residents, but also to their families and friends. They reflect the approaches advanced by New Governance scholars, in particular, participation of non-state actors; flexibility and non-coerciveness (softness in law); collaboration and collaborative process; decentralization; fallibility, adaptability and dynamic learning; and enforced self-regulation.[1458] At the same time, they still retain characteristics of law and legal processes, such as rights.

7.4.5.1 Distribution and posting of information

The home has always been required to post information to ensure residents and others are aware of the services provided in the home, the rights and obligations of different parties and the government's activities and relationship with the home. The only change under the LTCHA is that more information items have to be posted in the home. Examples of such items are the home's mission statement, its zero tolerance of abuse policy, the duty to make mandatory reports, the minimization of use of restraints policy, the Ministry's toll-free numbers, inspection reports from the past two years (rather than the most recent report), orders made by the Ministry and decisions from the Health Services Appeal and Review Board.[1459] This is in addition to information posted on-line by the Ministry, such as inspection reports.[1460]

7.4.5.2 Development of Mission statement

Having a mission statement is a new concept in the LTCHA; it was not mentioned in the *Nursing Homes Act* or its regulation, but is based on the Program Manual, which required a statement of mission and a resident-focused service philosophy to guide the operation of the home. Long-term goals and short-term objectives must be developed to support the home's

---

[1458] Lobel, *supra* note 319.

[1459] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 79; O Reg 79/10, *supra* note 811, s 225.

[1460] Ministry of Health and Long-Term Care, "Find long-term care homes in Ontario", (2019), online: <http://www.health.gov.on.ca/en/public/programs/ltc/home-finder.aspx>.

mission statement.[1461] Under the LTCHA, there must be a mission statement that sets out the principles, purpose and philosophy of care of the Home. The principles, purpose and philosophy of care set out in the mission statement must be put into practice in the day-to-day operation of the Home. Further, the Home's mission statement must be consistent with the fundamental principle set out in section 1 of the LTCHA, and with the Residents' Bill of Rights.[1462] There are also more directions regarding the process of developing and revising the mission statement. The Program Manual simply required the mission statement to be developed and approved by the board/owner/governing body and reviewed, at a minimum, every three years.[1463] In contrast, the LTCHA stipulates that the mission statement must be developed and revised as necessary, in collaboration with the Residents' Council and the Family Council, if any. Further, staff and volunteers must be invited to participate in the development and revision of the mission statement. At least once every five years after a mission statement is developed, the home must consult with the Residents' Council and the Family Council, if any, as to whether revisions are required, and must invite the Home's staff and volunteers to participate.[1464]

7.4.5.3 Continuous Quality Improvement and Satisfaction surveys

The practice of conducting satisfaction surveys is not new in the LTC sector. Under the previous regime, a quality management system had to be developed and implemented[1465] and there were requirements for regular monitoring of the satisfaction of residents and families[1466] and references to satisfaction questionnaires.[1467] In contrast, under the LTCHA, the emphasis on participation is more prominent. Each home must develop and implement a quality improvement and utilization review system concerning the quality of the accommodations, care, services, programs and goods.[1468] In addition, each home must conduct a satisfaction survey of residents and their families at least once a year. In developing and carrying out the survey, and in acting on

---

[1461] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 1011-01, page 1.

[1462] Ministry of Health and Long-Term Care, *supra* note 782 at 2–6; *Long-Term Care Homes Act, 2007*, *supra* note 425, ss 4(1), 4(2).2-6, 4(1)-(2).

[1463] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 1011-02, page 1.

[1464] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 4; Ministry of Health and Long-Term Care, *supra* note 782 at 2–6.

[1465] *Nursing Homes Act*, *supra* note 786, s 20.11.

[1466] Reg 832, *supra* note 831, s 128.

[1467] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 1011-02, page 5.

[1468] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 84.

its results, homes must seek the advice of both the Residents' and the Family Councils. Documentation about the survey and any actions taken must be made available to residents, families, Residents' Councils and Family Councils. Homes must make every reasonable effort to act on the survey results and to improve their homes.[1469]

7.4.5.4 Quality Improvement Plans

As noted elsewhere in this dissertation, Health Quality Ontario is the provincial advisor on the quality of health care.[1470] The *Excellent Care for All Act 2010* and other accountability agreements require all public hospitals, primary health care organizations (e.g. family health teams), and LTC homes to create a Quality Improvement Plan every year. Each organization develops a plan including specific targets and actions that reflect the province's health care improvement priorities, as well as the quality issues that are locally relevant.[1471] 2015-16 was the first year that the LTC sector was required to make annual submissions.[1472] For LTC homes, the priority indicators are: prescribing of antipsychotic medications, falls, pressure ulcers, restraints use and urinary incontinence, Emergency Department visits and resident experience. Homes may choose one or more of these indicators to work on.[1473] It is evident that these indicators also correspond to the programs mandated by the LTCHA (see Chapter 5). To put it differently, one could argue that these indicators are also used to measure how effective the regulatory provisions are. I will return to this subject in Chapter 9.

Homes are increasing their efforts to engage the Residents' and Family Councils in quality improvement and the development of their Quality Improvement Plans.[1474] In a memo to the health sector, Health Quality Ontario explains its expectation about engagement as follows:

> It has been impressive to see the increased engagement and involvement of patients and those with lived experience in quality improvement in Ontario, and the active measurement of patient experience. . . indicators related to patient/resident relations processes have been added for the hospital, home care, and long-term care sectors,

---

[1469] *Ibid*, s 85.
[1470] Health Quality Ontario, *Insights into Quality Improvement: Long-Term Care: Impressions and Observations – 2016/17 Quality Improvement Plans* (Toronto: Health Quality Ontario, 2017) at 2.Impressions, page 2
[1471] "Quality Improvement Plan Guidance", online: <http://www.hqontario.ca/Quality-Improvement/Quality-Improvement-Plans/Quality-Improvement-Plan-Guidance>.
[1472] Health Quality Ontario, *supra* note 1470 at 7.
[1473] *Ibid* at 8.
[1474] *Ibid* at 6.

> reflecting the important role of good patient relations programs on quality of care and patient experience.[1475]

In the Quality Improvement Plan Guidance Document, the justification for engagement is to ensure that the Quality Improvement Plan includes targets and Quality Improvement activities that are meaningful to patients, clients, and residents. Further, Quality improvement plans are designed to create a system that provides care *with* patients/clients/residents rather than *for* them. Health sector organizations are encouraged to engage their communities through established formats, such as patient, resident and Family Councils; town halls; or focus groups.[1476] Similarly, in a guidance document for patients and families, Health Quality Ontario explains why they should get involved in quality improvement: "You are an expert in your health experiences, and bring valued insights to the table. By taking part in quality improvement, you are using your experience to help fix a problem. Your voice can improve the health system for future patients and caregivers."[1477] A variety of resources has also been made available to address the techniques of engagement.[1478] By way of example, Health Quality Ontario proposes a list of orientation and follow-up questions that patients and caregivers can ask of staff at their organizations. Also, Health Quality Ontario suggests some key points for patients and caregivers to consider when they are invited to review a Quality Improvement Plan that has already been written.[1479]

Each year, Health Quality Ontario publishes a report that analyzes LTC Quality Improvement Plans across the province. It should also be noted that Health Quality Ontario posts all Quality Improvement Plans on its website, along with statistics about the sector, such as wait times for LTC beds.[1480]

[1475] Health Quality Ontario, *Annual Memo re 2018/19 Annual Priorities for Quality Improvement Plans (Novemebr 27, 2017)* (Toronto: Health Quality Ontario, 2017).

[1476] Health Quality Ontario, *Quality Improvement Plan (QIP) Guidance Document for Ontario's Health Care Organizations* (Toronto: Health Quality Ontario, 2017) at 17.

[1477] Health Quality Ontario, *Engaging with Patients and Caregivers about Quality Improvement A Guide for Health Care Providers* (Toronto: Health Quality Ontario, 2016) at 38.

[1478] Health Quality Ontario, "Patient Engagement Tools and Resources - Health Quality Ontario (HQO)", online: <http://www.hqontario.ca/Engaging-Patients/Patient-Engagement-Tools-and-Resources>.

[1479] Health Quality Ontario, *supra* note 1477 at 43–44.

[1480] Health Quality Ontario, "Long-Term Care Home Performance in Ontario - Health Quality Ontario (HQO)", online: <http://www.hqontario.ca/System-Performance/Long-Term-Care-Home-Performance>.

7.4.5.5 Immunity provisions

The immunity from actions or other proceedings offered to Residents' Council members and Resident Council assistants has been expanded to Family council members and Family Council assistants, but the conditions have been changed. Under the *Nursing Homes Act*, protection would be available unless the act was done maliciously or without reasonable grounds. Under the LTCHA, no action or other proceeding can be commenced against a member of a Residents' Council or Family Council, or a Residents' Council assistant or Family Council assistant for anything done or omitted to be done in good faith in his or her capacity as a member or assistant.[1481]

7.4.5.6 Whistleblower protection

Previously, legal protection from reprisals was offered to anyone who made a disclosure to an inspector, so long as the disclosure was made in good faith.[1482] As well, there was limited protection for persons reporting various information to the Director at MOHLTC, such as harm to residents as a result of improper or incompetent treatment.[1483] Expanded whistle-blowing protections have been included in the LTCHA to protect anyone from retaliation as a result of disclosing information to an inspector, making a report to MOHLTC, or providing evidence in a legal proceeding. The definition of retaliation includes, but is not limited to: dismissing, disciplining or suspending a staff member; imposing a penalty upon any person; and intimidating, coercing or harassing any person. More importantly, a resident cannot be discharged from a LTC home, threatened with discharge, or in any way be subjected to discriminatory treatment. Further, no family member, substitute decision-maker, or person of importance to a resident shall be threatened with retaliation against the resident.[1484]

The table below summarizes the changes to various participation mechanism under the LTCHA:

[1481] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 66. Ministry of Health and Long-Term Care, *supra* note 782 at 4–6.

[1482] *Nursing Homes Act*, *supra* note 786, ss 24.3(1)-(2).

[1483] *Ibid*, ss 25(1)-(2).

[1484] *Long-Term Care Homes Act, 2007*, *supra* note 425, ss 26(1)-(3); Meadus, *supra* note 793.

Table 24: Summary of other mechanisms to promote participation under the *Nursing Homes Act* and the LTCHA and other means

	Nursing Homes Act	**LTCHA and other means**
Distribution and posting of information	Yes	Expanded
Development of Mission Statement	Yes	Formalized in law and more prescriptive in terms of process
Continuous Quality Improvement and Satisfaction surveys	Yes	Formalized in law and more prescriptive in terms of process
Quality Improvement Plans	None	New but by way of soft law
Immunity for Councils	Yes	Expanded
Whistleblower protection	Yes	Expanded

7.4.6 Summary

This section has explained how residents, families and friends may participate in the operation of the home. I analyzed participation mechanisms from the perspective of reconciling dependency and autonomy. The Residents' Council became mandatory under the new LTCHA. With powers and functions authorized by the LTCHA, Family Councils assume a more formalized role in LTC homes. There are additional mechanisms that could promote problem-solving at the home level. Working together, these participation mechanisms allow residents and their families to access more information relevant to the operation of the home, to have the means to communicate their concerns and suggestions to the home on a regular basis and to have the protected spaces in which residents and their families can collaborate with one another. If properly understood and implemented, these mechanisms could play an important role in correcting some of the power imbalances inherent in caring relationships.

Many of the mechanisms explained above are related directly or indirectly to quality of care—in particular, the notion of continuous quality improvement, which is formalized in law as a mandatory requirement.[1485] The notion of "quality improvement" has always been a part of the LTC system; what varies is how formalized it is, whether resident and family participation is mandated, and protection available to those who speak up. Because annual health expenditure increases are expected to be modest in the foreseeable future (see Chapter 4), a cynical interpretation of these new (or enhanced) approaches might be to suggest that the government is simply looking for ways to improve the experience of residents and their families and friends that do not require additional government funding. While this could very well be the motivation of the government, it does not negate the fact that various forms of participation are occurring as part of the problem-solving process. As well, these approaches could simply be New Public Management techniques dressed up as "user involvement" and "empowerment". In Chapter 9, the findings from my key informant interviews will help us decipher some of the practical implications of these approaches.

The above is not a comprehensive analysis of inclusion and participation under the LTCHA. There are other additional mechanisms that are not exclusive to residents and their families and friends. These are designed to allow a broader range of stakeholders influence policy on LTC in Ontario, such as mandatory consultation on proposed regulation,[1486] public consultation regarding licensing,[1487] and complaints procedures.[1488] They will be addressed in Chapter 8.

7.5 Conclusion

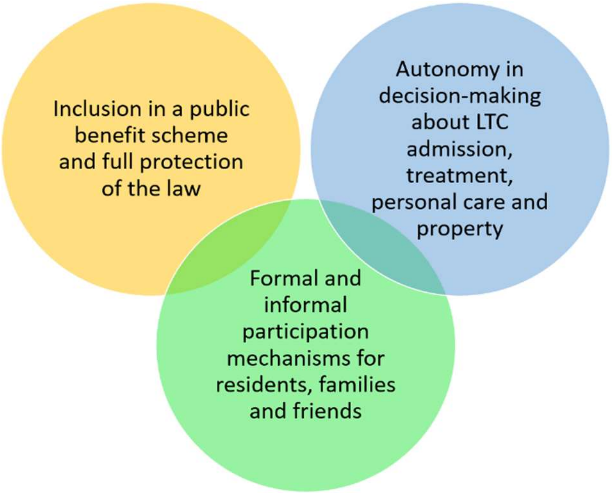
[1485] The *Excellent Care for All Act* states that one of the functions of HQO is "to support continuous quality improvement". See *Excellent Care for All Act 2010*, *supra* note 906, s 12(1)(b).

[1486] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 184.

[1487] *Ibid*, s 106. O Reg 79/10, *supra* note 811, s 273.

[1488] *Long-Term Care Homes Act, 2007*, *supra* note 425, ss 21–24.

Illustration 5: The three dimensions of participation and inclusion



Throughout this chapter, I have sought to flesh out how different dimensions of inclusion and participation (see Illustration 5) matter from the perspective of promoting autonomy in LTC. The first dimension concerns the equality guarantee under s.15 of the *Charter*. It is important to remember that the purpose of s. 15 is to ensure equality in the formulation and application of the law.[1489] The recent Supreme Court decisions – *Withler*, *Carter*, and *Quebec (Attorney General) v A* – illustrate how exclusion from a legal benefit or protection may be based on one or more enumerated or analogous grounds. The second dimension concerns an individual's autonomy in decision-making in matters such as health care, property and personal matters. I have examined how the law protects a capable individual's right to be free from unwanted interference. The statutory scheme was outlined to explore the legal considerations in substitute-decision making. I have focused on the *Health Care Consent Act* but also attended to the issues of guardianship and powers of attorney under the *Substitute Decisions Act*. The human rights cases have been included to give us a glimpse of the ways in which LTC residents may or may not be able to execute their decisions. The third dimension concerns participation in the everyday activities in LTC homes. The emphasis has been on the participation and inclusion mechanisms that are mandated by hard law and soft law. Unlike the other two dimensions, which are about individuals, the third dimension also entails a collective component. Together, these new or formalized mechanisms allow LTC residents and their families and friends to have some

---

[1489] *Andrews v Law Society of British Columbia*, [1989] 1 SCR 143.

influence over the activities in their respective homes and to try to problem-solve issues that arise in the home. The significance is that acknowledging the problem-solving capacity of residents can potentially reconcile the tensions between dependency and autonomy. This inquiry is very timely as residents are admitted older and with more profound disabilities. Respecting the autonomy of residents requires drawing on criticisms of the concept of autonomy (such as those articulated by Herring and Nedelsky). The question of how these mechanisms are implemented on the ground is one to which I will return in Chapter 9. The next chapter will shift the focus to the structural issues inherent the sector (such as the size of the sector) and how law is implicated in those issues, which will contextualize the changes to the regulation of LTC discussed in Chapters 5, 6 and 7.

8 Tensions in the state / citizen (consumer?) relationship

8.1 Introduction

In the context of care, the role of the state is an important area of contention.[1490] In chapter 2, I made the case that there are follow-up questions about the nature and rationale of the state's relationship with disabled citizens that need to be addressed. In previous chapters, I demonstrated how law articulates expectations about what care is and how it is supposed to be delivered. I also explained how caring relationships look and the different ways in which residents and the home may be connected, for example by formal and informal participation mechanisms. The goal in this chapter is to unpack some of the regulatory changes not directly related to hands-on care. Nonetheless, they create conditions that make care possible (or not) because they concern some of the structural issues of the sector, such as adequate public funding, equitable access, affordability, the oversight role of the government and the appropriate role of the market in delivering care. As well, the secondary objectives of social regulation,[1491] such as economic efficiency and value for money in our case, are more apparent in the changes discussed in this chapter. It is important to identify these secondary objectives because they make the state / citizen relationship more complicated. The state attempts to regulate caring relationships indirectly by creating legal constraints in relationships of those involved in care - from officers and directors of the home to suppliers. These constraints acknowledge that certain business relationships or transactions (e.g. non-arms' length transactions) matter because residents' experiences are shaped by "patterns of economic relationships"[1492] and business law.

The first section will demonstrate the ways in which the government attempts to deploy and privilege regulation in order to control access to the LTC sector while searching for ways to make the system financially sustainable (from the government's perspective). I focus on the following areas of law: eligibility, admission and placement, affordability, and licensing of LTC homes. The second section will show the extent to which the state (in conjunction with other bodies) can intervene in order to protect residents from different forms of harm in care such as

---

[1490] Banerjee, *supra* note 301 at 213; Armstrong, Armstrong & Daly, *supra* note 163 at 52.

[1491] Windholz & Hodge, *supra* note 86.

[1492] Nedelsky, *supra* note 248 at 31.

abuse and to a much more limited extent, safety of workers. It will include both the coercive and the more informal and flexible means of intervention. The last section will concentrate on protection of residents as consumers, including corporate governance requirements and market-like mechanisms. What I hope to illustrate is that from examining these regulatory changes, a number of tensions can be identified, which in turn are critical to understanding the implications of these changes.

I argue that the state supports caring relationships by establishing LTC as a way to reallocate dependencies and protect those in caring relationships. There is certainly a sufficiently wide range of activities – from licensing of homes to restrictions on fees - that the state undertakes in order to make LTC available to those needing care. It is probably not controversial to say that the state's responses recognize the consequences of dependencies for residents, their families, providers and the home. The state's responses highlight the legal and economic complexity in the LTC system.

8.2 Capacity of the LTC sector: Control over demand and supply of beds

This section will illustrate how the law has changed by examining examples of new requirements related to the purpose, scope, and capacity of the LTC system. Timely access to LTC depends on the availability and affordability of beds. In Chapter 4, I explained how the sector is funded and the distribution of for-profit, non-profit and municipal homes in Ontario. The level of government funding obviously directly affects the capacity of the sector to respond to those needing care. For economic reasons, the government also uses social regulation (see Chapter 2) to control the growth of the sector in terms of quantity of care. For example, rules are in place to ration available beds and prioritize certain residents over others i.e., who are more "deserving" of state support. This prioritization logic inevitably raises difficult questions about how the state decides on questions of access to LTC beds. The affordability of beds is dependent on both the amount of public funds available and on restrictions as to how much homes are permitted to charge residents for accommodation. Rules governing affordability raise questions about the determination of individuals' responsibility towards providing for their own care needs. The supply of beds is also controlled by the licensing system in the shadow of market forces explained in the feminist political economy literature.

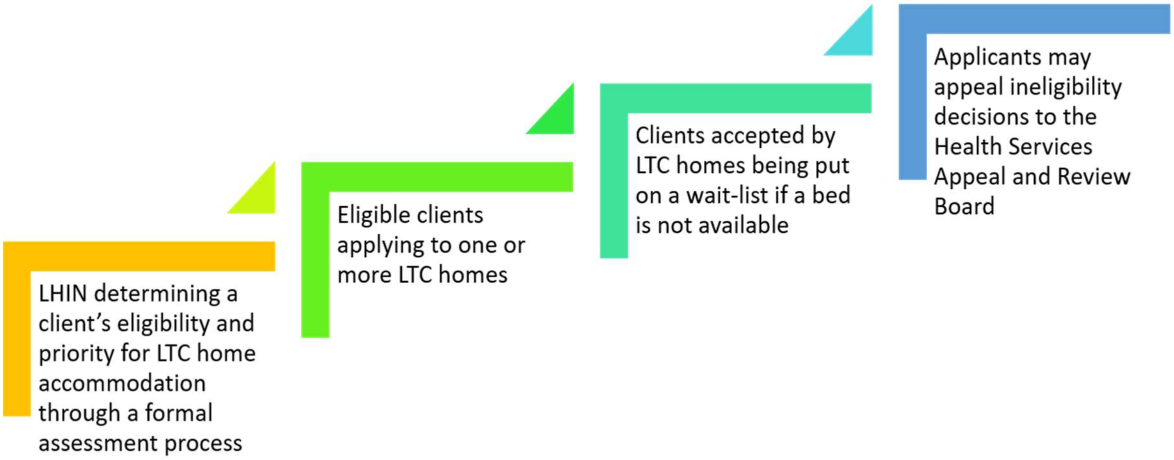
8.2.1 **Who are more "deserving" of state support?**

Recall that disability scholars such as Hughes, Soldatic and Meekosha have analyzed the logic of dividing, sorting and classifying bodies into distinct classes of the "deserving" and "undeserving" in the neoliberal capitalist state.[1493] In Ontario, LTC applicants and residents are deemed as "really disabled" and "deserving of state welfare" by the application process but at the same time, have witnessed tighter and tighter resources in the LTC sector. Scholars have criticized the fact that in Canada, the number of beds has not kept up with the number of people defined as needing care, even though eligibility has become more and more restricted to people with complex health issues combined with dementia and little possibility for receiving care in their own homes.[1494] In Chapter 4, I presented some of the statistics about wait times for LTC admission in order to provide a glimpse of the consequences of government decisions about rationing care. Here, I will consider how the law reflects the state's responsibilities to those who are in caring relationships, and in particular, government responses to those who are considered to be "deserving"[1495] of state support.

One way to limit access to LTC is to control the demand for beds and guide applicants towards home or community-based services by establishing eligibility requirements. As of January 2019, MOHLTC provides access to LTC beds through the 14 LHINs, which manage the LTC admission and placement processes and access to other home and community care.[1496] The underlying assumption is that a LTC applicant's publicly-funded community-based services and other caregiving, support or companionship arrangements available to the person are not sufficient, in any combination, to meet the person's requirements.[1497] A standardized and centralized admission process is necessary to ensure that "only the most appropriate candidates for long-term care are prioritized for admission".[1498] The key steps for placing a client in a LTC home are enumerated in the illustration below.[1499]

[1493] Hughes, *supra* note 18; Soldatic & Meekosha, *supra* note 116.
[1494] Armstrong & Daly, *supra* note 163 at 17.
[1495] Hughes, *supra* note 18; Soldatic & Meekosha, *supra* note 116.
[1496] Until recently, the CCACs were the designated placement co-ordinator. *Local Health System Integration Act, 2006, SO 2006, c 4*, *supra* note 591, s 5(m.2). In April 2017, the Minister of Health and Long-Term Care made the necessary orders to transfer staff from CCACs to LHINs.
[1497] O Reg 79/10, *supra* note 811, s 155(1)(d); Reg 832, *supra* note 831, s 130(3)1.
[1498] Ministry of Health and Long-Term Care, *supra* note 562 at 136.
[1499] Auditor General of Ontario, *supra* note 575 at 189–190 and 193.

Illustration 6: LTC admission process



While these steps have not changed as a result of the implementation of the LTCHA, a number of changes have been made to manage the demand for LTC. It should be noted that the admission and placement process is also engaged when residents have to be relocated for other reasons, such as home closure due to re-development however, I will concentrate on new applicants in this section. I contend that despite the rhetoric of "person-centred care" (see Chapter 5) and "assessed need", the changes deem fewer people to be "deserving" of LTC and much later (therefore they are sicker when they enter LTC) and the changes are intended to deal with pressures on the health care system and to balance other priorities.

The most significant change introduced by LTCHA is the stricter eligibility criteria for LTC home placement.[1500] Accessing LTC appears to be based on needs: "The people of Ontario and their Government: . . . Recognize the principle of access to long-term care homes that is based on assessed need".[1501] However, defining and prioritizing those needs is fraught with tensions, as recent thinking in feminist political economy shows. For example, under the new eligibility criteria of the LTCHA, it is not enough that an applicant requires assistance each day with activities of daily living;[1502] he/she must require such assistance at frequent intervals

---

[1500] *Ibid* at 189. See also *GM v North Simcoe Muskoka Community Care Access Centre,* CanLII 73121, 2013 ON HSARB.
[1501] *Long-Term Care Homes Act, 2007*, *supra* note 425 at Preamble.
[1502] Reg 832, *supra* note 831, s 130(2)2.

throughout the day.[1503] In addition, the new regime no longer permits people access based solely on:

- whether they would be financially, emotionally, or physically harmed if they stayed in their current residence;
- whether they are at risk of suffering harm due to environmental conditions that cannot be resolved if the applicant remains in their residence; or
- whether they may harm someone else if they remain in their own residence.[1504]

Previously, under the *Nursing Homes Act,* there was explicit recognition of a community-based applicant whose condition was expected to deteriorate within three months, or whose care needs were jeopardizing the health and well-being of their caregiver (category 2).[1505] This condition is no longer present in the description of any category in the LTCHA.

Once they are deemed eligible and their applications accepted by their chosen homes, LTC applicants are put on the homes' wait lists based on priority levels. There are rules to rank applicants within each category.[1506] The categories have been modified and the table below compares the current and previous regimes for some of the categories:

Table 25: Select priority categories under the *Nursing Homes Act* and the LTCHA

Type (in order of priority)	***Nursing Homes Act***	**LTCHA**
Readmission	N/A	New - Re-admission after a prolonged medical or psychiatric leave or a stay at a specialized unit[1507]
Crisis (immediate admission is required as a result of a	1A[1508]	1[1509] - similar to the previous regime with a

---

[1503] O Reg 79/10, *supra* note 811, s 155(1)(c)(ii).
[1504] Reg 832, *supra* note 831, ss 130(2)4, 5 and 6.
[1505] *Ibid*, s 128.1.
[1506] Auditor General of Ontario, *supra* note 575 at 194–195; O Reg 79/10, *supra* note 811, s 182.
[1507] O Reg 79/10, *supra* note 811, s 177.
[1508] Reg 832, *supra* note 831, s 143.
[1509] O Reg 79/10, *supra* note 811, s 171.

Type (in order of priority)	***Nursing Homes Act***	**LTCHA**
crisis arising from the applicant's condition or circumstances)		clarification about those applicants from hospitals
Spousal reunification (when both partners want to reside in the same home)	1A1[1510] - two spouses can apply at the same time or one spouse is a resident	2[1511]- similar to the previous regime, but one of the spouses must be a current resident New requirements - reunification priority access beds
Cultural, religious, and ethnic (a home that is primarily engaged in serving the interests of persons of a particular religion, ethnic origin or linguistic origin)	1B[1512]	3A and 3B[1513] - similar to the previous regime, but this group is now divided into those who need admission more urgently for different reasons (3A) and those less urgently (3B)
Other (applicants who do not fit into any other categories such as transfer from another home)	2 and 3[1514]	4A and 4B[1515]

The prioritization of eligible applicants denotes a significant change. The management of waiting lists has been modified to deal with a number of pressures within the health care system.

[1510] Reg 832, *supra* note 831, s 143.1.
[1511] Reg 79/10, *supra* note 811, s 172.
[1512] Reg 832, *supra* note 831, s 144.
[1513] O Reg 79/10, *supra* note 811, s 173.
[1514] Reg 832, *supra* note 831, ss 145 and 148.3.
[1515] O Reg 79/10, *supra* note 811, s 174.

The crisis category has been clarified to refer specifically to applicants in hospitals that are facing significant pressures on capacity if certain conditions are met, such as the placement co-ordinators employed by the relevant LHIN verifying these pressures.[1516] This change was likely made to formalize the practices at that time, as the CCAC Client Services Program Manual provided extensive guidance on when to expedite the admission of Alternative Level of Care patients to LTC homes if there is a systemic crisis.[1517] In addition, to facilitate the flow of residents across the continuum of care, a new "re-admission" category was created to allow persons who were discharged from a home due to a medical or psychiatric leave longer than the permitted time to be readmitted, and except for special categories, such as veteran, individuals in the re-admission category are placed before those in all other categories.[1518]

Another group of changes was intended to encourage applicants to be more knowledgeable about LTC and more flexible in the placement process. The LTCHA increased the number of LTC homes to which an individual may apply if they are not in crisis from three to five.[1519] While CCACs have always provided information to potential applicants, as per the *Nursing Homes Act*[1520] and the CCAC Client Service Manual,[1521] the LTCHA formalized some of the information requirements previously in soft law, such as a resident's responsibility to pay, how to apply for a rate reduction and documents required, and length of wait-lists and approximate time to admission.[1522] Some of the rights associated with the assessment process (e.g., to be informed of the use of the assessment) are also formalized in law.[1523] The LTCHA decreased the wait to reapply for admission from six months to 12 weeks in cases where the client refuses a bed at a LTC home to which they applied.[1524]

The priority categories illustrate that the notion of "assessed needs" is intended to encompass other public policy considerations in the prioritization process, such as familial

---

[1516] *Ibid*, s 171(2); Meadus, *supra* note 793.

[1517] Ministry of Health and Long-Term Care, *CCAC Client Services Policy Manual* (Toronto: Ministry of Health and Long-Term Care, 2007) at Chapter 12, 10-14.

[1518] O Reg 79/10, *supra* note 811, s 177; Meadus, *supra* note 793 at 14.

[1519] O Reg 79/10, *supra* note 811, s 164.

[1520] Reg 832, *supra* note 831, s 154.

[1521] Ministry of Health and Long-Term Care, *supra* note 1517 at Chapter 11, page 1, 8 and 12.

[1522] O Reg 79/10, *supra* note 811, s 154.

[1523] *Long-Term Care Homes Act, 2007*, *supra* note 425, ss 43(4) – (7).

[1524] O Reg 79/10, *supra* note 811, s 167(4).

relationships and membership in a cultural or religious group, in addition to medical and nursing needs. The change concerning spousal or partner reunification is indicative of the difficulties of prioritizing needs among those who urgently require care. The Director of the MOHLTC's LTC program may designate reunification priority access beds for persons who meet the requirements to be placed in category 1 (crisis) on the waiting list for admission and are seeking to be reunified in a home with their spouse/partner. Placement co-ordinators (i.e., LHINs) must keep separate waiting lists for these beds. Requirements to be placed on the waiting lists and priority for admission to these beds are set out. As among those waiting for the reunification priority access bed, applicants must be ranked for admission according to the date on which their spouses or partners were admitted to the long-term care home.[1525] These beds have been created so that those who have a spouse or partner in a LTC home and who have also been designated as crisis can be reunited more quickly.[1526]

The last group of changes concern how safety and security issues are addressed in the admission and placement processes. In Chapter 6, I explained the requirements around confinement of residents. While an assessment is always required, the new regime is more precise about what that assessment entails, and specifically refers to an applicant's mental health, current behavior and behaviour during the year preceding the assessment.[1527] The regulation under LTCHA also makes it explicit that a home can request additional information about an applicant from the LHIN within five days of receiving the application and then make a decision within three days of receiving that information.[1528] Finally, the Director may deem that residents of a home urgently need to be relocated to another home to protect their health or safety. Certain administration requirements (e.g. resident making an application to the second home) are exempted to facilitate the transfer of residents.[1529]

So far I have only described access to LTC in terms of the supply of beds. It is evident that formal legal rules are increasingly used to serve two purposes: to restrict access to LTC to

---

[1525] *Ibid*, ss 206.1–206.2; Service Ontario, "Amendments to Ontario Regulation 79/10 under the Long-Term Care Homes Act, 2007", online: <http://www.ontariocanada.com/registry/view.do?postingId=26226&language=en>.
[1526] Advocacy Centre for the Elderly, *Newsletter (Spring/Summer 2018) Vol. 15, No. 1* (Toronto: Advocacy Centre for the Elderly, 2018) at 8.
[1527] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 43(4).
[1528] Reg 832, *supra* note 831, ss 162(4) and (5).
[1529] O Reg 79/10, *supra* note 811, s 208.

those with the most profound impairments and to delay their admission for as long as possible. This affects the experiences of residents, workers and family members as the LTC population as a whole gradually becomes older and residents live with more profound impairments. In Chapter 9, I will return to this topic. I will now turn to the other part of the access equation in LTC: affordability.

8.2.2 **Is LTC affordable?**

Similar to other Canadian provinces, Ontario's LTC system is financially supported by a mix of public and private contributions (see Chapter 4). The usual argument, MacDonald writes, is that a LTC facility is a principal residence, and people are normally expected to pay for their primary room and board.[1530] Here, there is an underlying tension: on the one hand, the government relies on private contributions in the form of resident charges and other fees that homes retain to help ensure the financial sustainability of the LTC system; on the other hand, the system has to remain affordable for all eligible Ontarians regardless of income. The result is a complex web of rules that dictate how much homes can charge residents and for what. The maximum rates for basic, as well as private accommodation are set by the government (from $1,891 to $2,702 per month). Those who cannot afford to pay the maximum rate for basic accommodation can apply for a rate reduction. The government provides subsidies for residents who are eligible for the rate reduction.[1531] Legal rules about how to measure ability to pay and at what level to set the resident charges can reveal what the state considers to be "care"[1532] and therefore should be paid for by the state.

While the accommodation cost structure (resident charges) remains the same for most people under the LTCHA, there have been some changes that affect the affordability of LTC. First, one substantial change is the prohibition of any bed-holding fees following medical or psychiatric leave. Previously, a resident could hold a bed for up to 30 days in addition to the available 21-day medical or 45-day psychiatric leave under the *Nursing Homes Act*.[1533] During

---

[1530] Martha MacDonald, "Regulating Individual Charges for Long-Term Residential Care in Canada" (2015) 95 Studies in Political Economy 83 at 88.

[1531] Government of Ontario, "Find a long-term care home", (7 November 2017), online: *Ontario.ca* <https://www.ontario.ca/page/find-long-term-care-home>; Ministry of Health and Long-Term Care, *supra* note 611. The rates are as of July 1, 2019.

[1532] MacDonald, *supra* note 1530 at 90.

[1533] Reg 832, *supra* note 831, s 47.

the bed-holding period, the resident would continue to pay accommodation charges and bed-holding fee ($53 per day).[1534] The LTCHA has prohibited such holding fees[1535] and increased the duration of medical and psychiatric leave,[1536] which means a resident can no longer extend a medical or psychiatric leave by paying extra. The second substantial change is the calculation of the accommodation charge. Effective from July 1, 2017, the annual adjustment to the accommodation charge is determined by applying the Consumer Price Index, and any increase is subject to a ceiling of 2.5%.[1537] The third substantial change is modification of the rate reduction scheme for residents who may be supporting dependents in the community.[1538] Under the previous regime, a resident could apply for a rate reduction if his or her spouse resided in the community.[1539] The LTCHA allows for rate reduction if the resident has other dependents, such as children under 18 or under 25 and enrolled in full-time study at a secondary or postsecondary institution, in addition to a spouse residing in the community.[1540] Finally, upon the request of a resident, the home is required to assist with completing applications for rate reductions, which was previously a requirement in the Program Manual.[1541] If the maximum amount is calculated incorrectly as the result of a false or incomplete application, the home is liable for the difference.[1542]

8.2.3 **How many beds can be licensed, where and at what cost?**

By establishing a licensing and approval program, the Ministry currently regulates activities such as changes in bed capacity, buying/selling of homes, relocation of a LTC home for re-development, purchase or sale of shares in a LTC home, hiring a management company and closing of a home.[1543] The licensing and approval program serves multiple objectives, such

---

[1534] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 0803-01; Reg 832, *supra* note 831, ss 47(4) and 117.
[1535] Meadus, *supra* note 793 at 18; O Reg 79/10, *supra* note 811, s 245.5.
[1536] O Reg 79/10, *supra* note 811, s 146.
[1537] *Ibid*, s 247.5.
[1538] Meadus, *supra* note 793 at 18.
[1539] Reg 832, *supra* note 831, s 116.1(1)2; Ministry of Health and Long-Term Care, *supra* note 545 at Tab 0607-07, page 1–2.
[1540] O Reg 79/10, *supra* note 811, s 251.
[1541] *Ibid*, s 253(3); Ministry of Health and Long-Term Care, *supra* note 545 at Tab 0607-07. page 2.
[1542] O Reg 79/10, *supra* note 811, s 253(6).
[1543] Ministry of Health and Long-Term Care Act, *Long-Term Care Homes Licensing Overview: Prepared for the Ministry-LHIN-LTC Operator Education Sessions March-April 2015* (Toronto: Ministry of Health an Long-Term Care, 2015) at 6.

as ensuring that homes are operated by suitable people. But also, since homes are not owned or directly operated by the provincial government, one way to control the size of the sector (and hence the public expenditures for it) is to manage the supply of beds via licensing. Under the current and previous regimes, it is prohibited to operate residential premises where nursing care is provided except in accordance with applicable legislation (certain entities such as hospitals are exempted).[1544] Licences are issued by the Director of the MOHLTC based on what the Minister considers to be the public interest.[1545] Criteria are also set for who is ineligible to be issued a licence.[1546] All LTC homes must comply with any licensing conditions.[1547]

However, despite the similarities between the old and new regimes, there are significant changes under the LTCHA. Changes to the licensing system are one of the key areas of change in the LTCHA[1548] and represent an important milestone in the evolution of the sector. First, the licensing term was increased from one year[1549] to a fixed term of maximum of 30 years.[1550] The term is tied to structural compliance of the home, depending on its type of beds.[1551] Similar to the previous regime, a licence can be revoked in cases of non-compliance and for other reasons.[1552] The much longer licensing term necessitates a number of new corresponding safeguards to ensure sufficient government control over homes, such as:

[1544] *Nursing Homes Act*, *supra* note 786, s 4; *Long-Term Care Homes Act, 2007*, *supra* note 425, s 95; O Reg 79/10, *supra* note 811, s 268.

[1545] *Nursing Homes Act*, *supra* note 786, ss 5(2) – (6); *Long-Term Care Homes Act, 2007*, *supra* note 425, ss 96–97.

[1546] *Nursing Homes Act*, *supra* note 786, s 5(7); *Long-Term Care Homes Act, 2007*, *supra* note 425, s 98; O Reg 79/10, *supra* note 811, s 270.

[1547] Reg 832, *supra* note 831, s 3; *Long-Term Care Homes Act, 2007*, *supra* note 425, s 101.

[1548] Ministry of Health and Long Term Care, *McGuinty Government Continues to Improve Quality of Life For Residents in Long-Term Care Homes (January 16, 2007 News Release)* (Toronto: Ministry of Health an Long-Term Care, 2007).

[1549] *Nursing Homes Act*, *supra* note 786, s 5(8). See also Auditor General of Ontario, *supra* note 557 at 381. The Auditor General noted that homes did not have current licences.

[1550] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 102(1). When the LTCHA was introduced, the maximum term was 25 years. In 2014, the maximum term was extended to 30 years by Bill 14. *Building Opportunity and Securing Our Future Act (Budget Measures),* 2014, SO 2014, c 7. See also Ministry of Health and Long Term Care, *Enhanced Long-Term Care Home Renewal Strategy: Frequently Asked Questions* (Toronto: Ministry of Health and Long-Term Care, 2015) at 6.

[1551] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 180. A home with new beds (built since 1998 to current design standards) would have a 30-year term licence. A home with D-beds (do not meet the 1972 design standard) would get a 4-year licence. Upon expiration, these beds will not receive a new licence unless they are upgraded to meet current design standards. See Ministry of Health and Long-Term Care Act, *supra* note 1543 at 4.

[1552] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 157.

- More detailed guidance on the operation of the home once a revocation or suspension order is issued.[1553]
- Removal of certain rights to appeal refusal to issue licence decisions.[1554]
- More approval, disclosure, and reporting requirements on the home's part pertaining to the *de facto* control of the home.[1555]
- Longer notice period (changed from 16 weeks to five years before the intended closure date) and a closure plan and a closure agreement are required if a home wants to close.[1556]

Second, the licensing approval process has become more complex, in the sense that requirements are denser and more technical. One significant change was to ensure that the government's discretion to make policy and funding decisions about LTC homes remains as unfettered as possible. For example, although competitive procurement processes have always existed, the LTCHA states explicitly that a competitive process may be used, but is not required.[1557] Furthermore, the scope of matters that the Director of MOHLTC may consider in relation to eligibility and ineligibility for licensing is broader than under the previous Act[1558] and potentially more flexible for deeming an applicant ineligible. To retain the ability to manage the supply of beds in the short-term, the MOHLTC can issue temporary, emergency, or short-term licences and stipulate who may be admitted to beds offered under such licences.[1559]Procedural fairness also necessitates more transparency requirements. While the process has always involved public consultation and the Director was required to consider submissions received before making a decision,[1560] the LTCHA is slightly more certain in terms of articulating the requirements for consultation, including: who can chair a public meeting, details of notice requirements, and clarification that the home's failure to post notice does not invalidate the

---

[1553] *Ibid*, ss 157(4) – (7).

[1554] *Nursing Homes Act*, *supra* note 786, s 15; *Long-Term Care Homes Act, 2007*, *supra* note 425, s 116.

[1555] *Long-Term Care Homes Act, 2007*, *supra* note 425, ss 107–110.

[1556] O Reg 79/10, *supra* note 811, ss 308–311. The Director may agree to a shorter notice period or to a plan being submitted or an agreement entered into by a later date.

[1557] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 115.

[1558] *Nursing Homes Act*, *supra* note 786, s 5(7); *Long-Term Care Homes Act, 2007*, *supra* note 425, s 98; O Reg 79/10, *supra* note 811, s 270.

[1559] *Long-Term Care Homes Act, 2007*, *supra* note 425, ss 111–113; O Reg 79/10, *supra* note 811, ss 277–279.

[1560] *Nursing Homes Act*, *supra* note 786, s 12.

notice.[1561] Finally, more requirements have been introduced to improve transparency and certainty around fees and undertaking to issue licence.[1562]

Third, the changes are intended to control the capacity of the LTC system in light of the changing non-profit/for-profit mix in the sector. The preference for non-profit delivery is proffered by the government as follows: "The people of Ontario and their Government: . . . Are committed to the promotion of the delivery of long-term care home services by not-for-profit organizations."[1563] The LTCHA prescribes more detailed requirements in terms of amendments to a licence (increase or decrease in number of beds, change of location of the home, and increase in preferred accommodation),[1564] such as the consultation requirements and public interest considerations discussed above. Transfer of licence was not permitted under the previous Act,[1565] whereas transfer of licence or beds is now permitted with limitations,[1566] but a non-profit entity may not transfer a licence or beds to a for-profit entity except in limited circumstances (for example, if the non-profit entity is in default).[1567] However, at the same time, the Minister is no longer required to announce, annually, in the Legislature the desired balance between non-profit and profit-oriented nursing homes.[1568]

8.2.4 **Summary**

The table below is a summary of the key changes related to regulating the capacity of the LTC sector:

[1561] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 106; O Reg 79/10, *supra* note 811, s 273.
[1562] O Reg 79/10, *supra* note 811, s 314; *Long-Term Care Homes Act, 2007*, *supra* note 425, s 100.
[1563] *Long-Term Care Homes Act, 2007*, *supra* note 425 at Preamble.
[1564] *Ibid*, s 114; O Reg 79/10, *supra* note 811, s 280.
[1565] *Nursing Homes Act*, *supra* note 786, s 5(9).
[1566] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 105.
[1567] O Reg 79/10, *supra* note 811, s 271.
[1568] *Nursing Homes Act*, *supra* note 786, s 5(6).

Table 26: Key changes related to the capacity of the LTC sector under the *Nursing Homes Act* and the LTCHA

	Nursing Homes Act	LTCHA
Admission and prioritization of LTC applicants	• May be eligible based solely on potential harm to applicant or others	• Stricter eligibility requirements • Prioritization categories change
Co-payments and other fees	• Rate reduction available if spouse resided in the community • Bed-holding fees permissible	• Rate reduction available if spouse or dependents (e.g. children) reside in the community • No bed-holding fees
Licensing requirements	• Licences issued for one-year term • More rights of appeal regarding licensing decisions	• Licences issued for maximum fixed term of 30 years, depending on the type of beds • More types of licences • More government discretion over the licensing processes

As a public benefits scheme, the LTC program illustrates the relationship between state and citizens when the latter is dependent on the former to make available the necessities of life. The state's role is to redistribute some of the dependencies associated (though not exclusively) with aging and disability so that care is also a collective responsibility. Thus far, I have explained how the government has attempted to control the supply and demand of LTC beds in order to meet and prioritize the needs of older Ontarians while managing the tensions between affordability of beds and fiscal pressures. My reading of the changes related to admission is similar to conclusions reached by other scholars i.e., that eligibility for LTC admission has become more restricted, however at least the rules are fair and transparent (on paper). Some of the changes are positive because to a certain extent, they do recognize the circumstances of residents for example, poverty in older age. The changes concerning resident charges and rate reductions can potentially make access more equitable. That said, the problem is that even if an applicant is eligible for and can afford LTC (or is eligible for rate reductions), access is still difficult due to restrictions to the number of homes and beds being licenced. The changes to the licensing system are necessary if seen from the perspective of maximizing the discretion of the government over the supply of beds. If properly funded (capital and operating costs), more stringent licensing requirements could contribute to a LTC system that is more predictable and is run by suitable operators.

But LTC is also a regulatory regime – the government is also the regulator of LTC and citizens are part of the regulated. I will now turn to situations where the government uses coercive and non-coercive means to address current and anticipated problems in the sector.

8.3 How far does the state have to go to protect vulnerable citizens?

The responsibility of the state goes beyond creating and funding the capacity of the LTC system. Recent events in Ontario, notably the Public Inquiry into the Safety and Security of Residents in the Long-Term Care Homes System, clearly show that the public expects the state to protect those who are considered to be "vulnerable" by holding those in charge of providing care accountable for actual or perceived harm. The dark side of care has been examined by disability scholars. But how the state should intervene, for example by establishing a legal regime of protection for those who receive care,[1569] is far from settled. For some feminist political economy scholars, detailed regulations and documentation to demonstrate they are followed are often detrimental to care relationships and take time away from care.[1570] I now turn to the coercive and non-coercive means by which the government controls or influences the behaviour of participants in the sector. I will also briefly address the role of other bodies that are involved in regulating the behavior of LTC participants.

8.3.1 Compliance and enforcement: what are the coercive means?

As discussed in Chapter 4, responses to the tragedies and scandals during the period leading up to the implementation of the LTCHA involved strengthening the Ministry's ability to

---

[1569] Herring, *supra* note 112 at 260–318.

[1570] McGregor & Armstrong, *supra* note 719 at 84.

address poor care, such as setting up a toll-free number for complaints. But as I will explain later in this chapter, the Ministry also has other policy objectives in the sector, such as value for money, and the compliance and enforcement tools are used to pursue those other objectives also. In Chapters 5 and 6, I described how law is used to prescribe what homes can and cannot do when they deliver care. The LTCHA enables the establishment of a new inspection program, which continues to evolve legally and administratively. Bill 160 is the latest attempt to create new enforcement tools, including financial penalties, and new provincial offences to ensure that LTC home operators are addressing concerns promptly.[1571] However, there are other legal mechanisms through which the state can attempt to assert its oversight role, including mandatory reporting obligations, issuance of directives and performance and financial management. In the process of defining, negotiating and enforcing compliance, residents, families, and those who have contact with residents such as volunteers, are also involved in (and in some sense, conscripted into) detecting non-compliance with various regulatory requirements in homes. The main difficulty is that while these means may be effective in recognizing disabling relationships and relational wrongs (e.g. abuse), they very much understand relationships as being unidirectional where residents are passive recipients of care while workers are providers of care. A related difficulty is that the regulatory changes say very little about the responsibilities of residents, other than those related to their role as consumers (see section 8.4).

8.3.1.1 Long-Term Care Home Quality Inspection Program

While the Ministry has always undertaken activities to monitor homes' compliance with the applicable law, the Ministry's approaches have changed significantly over the years. It should be noted that under the LTCHA, not all of the legal requirements are new in the sense that they have never been implemented. Indeed, some legal requirements simply formalize existing Ministry policies or approaches. By way of example, prior to the LTCHA, the Ministry adopted the practice of unannounced visits to homes and performed annual inspections.[1572] The LTCHA includes provisions that mandate annual inspections of homes and that no prior notice should be given of such inspections.[1573] Another example is the notion of risk, which was frequently

---

[1571] Ministry of Health and Long Term Care, *Backgrounder "Strengthening Quality and Accountability for Patients Act, 2017" (September 27, 2017)* (Toronto: Ministry of Health and Long-Term Care, 2017).

[1572] Ministry of Health and Long Term Care, *supra* note 622 at 4.

[1573] *Long-Term Care Homes Act, 2007*, *supra* note 425, ss 143–144.

mentioned and referred to as something to be identified and managed in the Program Manual; under the LTCHA, a risk-based approach is now formalized.

A good starting point for comparing the previous and current regimes is to consider the respective legal authority to undertake compliance-related activities. The *Nursing Homes Act* and its Regulation provided little specific guidance with respect to compliance and enforcement, but guidance for homes was included in the Program Manual.[1574] In contrast, the LTCHA and its regulation contain more rules defining what the Ministry can or cannot do in order to enforce compliance. It should be noted that some of the details of the inspection program are expressed in the form of inspection guidelines (31 in total).[1575] These protocols explain how government inspectors intend to determine the meaning of compliance, such as what types of documents they have to check, who they have to talk to, and which questions they have to ask.

The first significant change is the Ministry's purported approach to monitoring compliance and detecting non-compliance. The Program Manual repeatedly emphasized the collaborative nature of the relationship between the Ministry and the home and expressed a desire to work with homes to address concerns. For example, activities to be undertaken by ministry staff included "providing feedback and addressing concerns and issues using a collaborative approach" and "offering interpretation and consultation to facility staff".[1576] Further, the review of resident care process was "completed in collaboration with the facility's management staff, to assist in identifying factors contributing to the presence of the indicator of risk or negative outcome, and to assist in development of a corrective action plan."[1577] The organization of the Ministry's LTC division was indicative of the collaborative orientation: 1) the compliance management unit ensured homes provide care and services according to ministry requirements and 2) the enforcement unit investigated very serious complaints and incidents, implemented sanctions and conducted pre-licence reviews and other inspections.[1578] The

---

[1574] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 11.

[1575] Ministry of Health and Long-Term Care, *Inspection Protocols Summary (31)* (Toronto: Ministry of Health and Long-Term Care, 2013). The 31 protocols are divided into the following categories: 1) Home-Related Mandatory; 2) Inspector-Initiated; 3) Home-Related Triggered; and 4) Resident-Related Triggered.

[1576] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 1101-01, page 2.

[1577] *Ibid* at Tab 1101-01, page 7.

[1578] *Ibid* at Tab 0402, page 1–2.

compliance advisors of the compliance management unit clarified ministry expectations to homes, using a consultative and collaborative approach.[1579]

In contrast, the new program under the LTCHA is based on more formal and standardized processes and procedures in order to induce homes to comply with legal rules. The LTCHA defines a more prescriptive compliance and enforcement system (Part IX of the LTCHA). The Preamble of the LTCHA states:

> The people of Ontario and their Government:
>
> ...
>
> Firmly believe in clear and consistent standards of care and services, supported by a strong compliance, inspection and enforcement system;
>
> Recognize the responsibility to take action where standards or requirements under this Act are not being met, or where the care, safety, security and rights of residents might be compromised.[1580]

Some requirements are new, in the sense that they are strengthened requirements or represent more clearly articulated expectations of the regulator. They are characterized by greater reliance on formal legal rules and the force of law. They are intended to create more certainty about expectations by taking some discretion away from the regulator, especially after non-compliance has been established. The LTCHA specifies a wider range of potential action(s) that an inspector must take if a home is non-compliant such as the types of orders that can be issued against the home (for example, order for a home to prepare, submit and implement a compliance plan), and cost recovery.[1581] A compliance plan under the LTCHA is similar to the corrective action plan under the previous regime. Furthermore, the criteria to be considered in determining what actions to take or orders to make for non-compliance are: severity, scope and history of non-compliance.[1582] But they essentially build on the guidance and examples regarding issuing notice of compliance and ordering suspension of admission described in the Program Manual.

[1579] *Ibid* at Tab 0402-02, page 1. It should be noted that the *Nursing Homes Act* did not have any reference to compliance advisors.

[1580] *Long-Term Care Homes Act, 2007*, *supra* note 425 at Preamble.

[1581] *Ibid*, ss 152–153.

[1582] O Reg 79/10, *supra* note 811, s 299.

There are also new requirements that represent a more deterrent-based or adversarial stance of the Ministry as the regulator. To detect non-compliance, the scope of an inspector's powers has been expanded to facilitate fact-gathering and potentially restrict the rights of persons being questioned.[1583] More sanctions are made available to the Ministry as the regulator, notably, higher fines on conviction, administrative penalty, re-inspection fees and suspension of licence (by director or Minister).[1584] The LTCHA also states specifically that failure to comply with an order is an offence and that due diligence and mistaken belief do not prevent orders or penalties i.e., absolute liability offence.[1585] At the same time, the severity of the sanctions also necessitates more elaborate review and appeal processes and procedures, such as timelines for hearings and evidentiary rules. More information about what the Ministry has done to enforce compliance also must be published.[1586] See Appendix D for a more comprehensive explanation of the key aspects of the previous and current regimes.

The Program created under this new legal regime is called the Long-Term Care Home Quality Inspection Program. The aim of the Inspection Program is to protect residents' quality of care and quality of life by safeguarding their rights, safety, and security, as well as by ensuring that homes comply with legislation and regulations.[1587] There are four types of inspections: comprehensive inspections (also known as Resident Quality Inspection), complaint inspections, critical-incident inspections and follow-up inspections.[1588] Even within this highly prescriptive regime, the Ministry still has to make decisions about the administration of the program, such as determining what "risk-based" means. For example, while all LTC homes are subject to an annual Resident Quality Inspection, a new risk-focused approach was introduced in August 2016, with the intensity of the Resident Quality Inspection informed by the home's compliance history and risk level. Approximately 80% of homes are considered to be substantially compliant

---

[1583] *Long-Term Care Homes Act, 2007*, *supra* note 425, ss 114, 147 and 151.

[1584] *Ibid*, ss 156.1, 158.1 and 182; O Reg 79/10, *supra* note 811, ss 299.1-299.2.

[1585] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 162.2; Ministry of Health and Long-Term Care, *supra* note 1100 at 21.

[1586] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 173.

[1587] Standing Committee on Public Account, *supra* note 1456 at 2.

[1588] Auditor General of Ontario, *2015 Annual Report of the Office of the Auditor General of Ontario (Section 3.09 Long-term-care Home Quality Inspection Program)* (Toronto: Auditor General of Ontario, 2015) at 364. The Program is administered by the Ministry's Performance Improvement and Compliance Branch, which falls under its Health System Accountability and Performance Division. The Program consists of a head office with a centralized intake unit and five regional offices.

in their overall operations and provision of care. Each year, one-third of substantially compliant homes will receive an intensive risk-focused Resident Quality Inspection.[1589] Homes that are substantially compliant and low risk may receive a risk-focused Resident Quality Inspection, which follows the same principles and algorithms but is shorter in duration and the inspection team is smaller.[1590] The point is that despite the Ministry's more adversarial stance, the regulator is still constrained by other considerations, such as availability of human and financial resources, and therefore may not necessary utilize the full extent of the law. I will return to this in Chapter 9.

The conduct and practices of inspectors are also governed by other soft law unrelated to LTC. For example, the Ontario government's 2011 *Regulator's Code of Practice: Integrity in Pursuit of Compliance*[1591] is also applicable to ministry inspectors. The *Code of Practice* is intended to ensure that businesses and the public are treated fairly and with respect when they are being licensed, inspected, investigated, audited or otherwise regulated.[1592] Most importantly, the *Code of Practice* promotes a compliance-focused approach, which "asks regulators to focus on the objectives of regulatory law and policy and then consider the most innovative, efficient and effective method of achieving compliance. This shift in focus can lead to proactive approaches to compliance based on prevention . . . rather than solely focusing on the investigation of compliance failures... The aim is to have greater effect with less burden."[1593] This compliance–focused approach is also combined with risk-based targeting: "Risk management is the process of identifying potential hazards and undesirable events, understanding the likelihood and consequences of the undesirable events, and taking steps to reduce their risk."[1594] As I will demonstrate in the next chapter, the assumptions and purported benefits of a risk-based approach to compliance need to be unpacked.

[1589] Standing Committee on Public Account, *supra* note 1456 at 7.

[1590] Ministry of Health and Long-Term Care, *Response from the Ministry of Health and Long Term Care to the Standing Committee on Public Account's report on Long-Term Care Home Quality Inspection Program (Section 3.09 of the 2015 Annual Report of the Office of the Auditor General of Ontario) (September 25, 2017)* (Toronto: Ministry of Health and Long-Term Care, 2017) at 4.

[1591] Government of Ontario, *Regulator's Code of Practice: Integrity in Pursuit of Compliance* (Toronto: Government of Ontario, 2011). The Code of Practice provides a set of Organizational Values, Elements of Professionalism, Service Principles and Best Practices to support compliance activities and to promote a consistent level of service.

[1592] *Ibid* at 7.

[1593] *Ibid* at 6.

[1594] *Ibid*.

8.3.1.2 Mandatory reporting and investigation of complaints

Despite the seemingly broad powers of the Ministry to monitor and inspect homes, the detection of non-compliance also relies on self-reporting by homes and complaints made by residents and anybody. Again, the concept of co-regulation[1595] is applicable here. Under both previous and current legal regimes, a system for making reports and complaints is established, together with whistle-blowing protections (see Chapter 6). Inspections and inquiries that must be made by inspectors in response to reports and complaints are also provided for. In the previous regime, many of the reporting requirements were contained in the Program Manual. These requirements are now formalized (with some modifications) in statute and regulation.

The following changes should be highlighted. First, the types of events that must be reported by the home and information about those events are similar but the LTCHA encompasses more events and the corresponding reporting obligation is intended to be more proportional to the potential consequences of the event.[1596] Second, under the LTCHA, the mandatory reporting requirements applicable to every person (other than residents), such as staff members, volunteers and family members, are more elaborate. For example, anyone other than a resident must report misuse or misappropriation of a resident's money as well as misuse or misappropriation of funding provided to a home.[1597] Third, a new provision is that incapable residents are exempt from the offence provision about making false statements to the Ministry.[1598] Fourth, the LTCHA provides more clarity about when an inspector must visit the home immediately and actions that the Ministry will take if an inspection is not warranted.[1599] Finally, under the LTCHA, the Home must promptly notify a resident's substitute decision-maker or anyone designated by the resident or his or her substitute decision-maker of any serious injury to or illness of the resident. Notice must be provided in accordance with instructions provided by the persons who are to be notified.[1600]

[1595] Windholz, *supra* note 50.

[1596] Reg 832, *supra* note 831, s 96; O Reg 79/10, *supra* note 811, s 107.

[1597] *Long-Term Care Homes Act, 2007*, *supra* note 425, ss 24(1)4–5.

[1598] *Ibid*, ss 24(2) – (3); Ministry of Health and Long-Term Care, *supra* note 782 at 2–74.

[1599] *Long-Term Care Homes Act, 2007*, *supra* note 425, ss 24–25.

[1600] O Reg 79/10, *supra* note 811, s 107(5); Ministry of Health and Long-Term Care, *supra* note 782 at 2–81.

The LTCHA is also more specific about the home's mechanisms for receiving, investigating, and responding to complaints from residents and family members. While the home has always been required to have policies and procedures about complaints in place, to respond to a complaint within 10 days and to forward to the Ministry all written complaints with follow-up actions,[1601] the LTCHA provides a few more clarifications such as: complaints may be verbal,[1602] information received by the Ministry may be shared with Residents' Council and Family Council,[1603] and the homes must conduct quarterly analysis of the complaints received.[1604] It also sets out the actions the home should take to deal with complaints.[1605]

8.3.1.3 **Operational or Policy Directives Issued by the Minister**

The Ministry has always used guidelines such as the Program Manual, memos, letters etc to guide homes in providing care. Thus far, I have referred to guidelines of various degrees of legal formality, issued by the government, agencies, professional associations and regulatory bodies. The issue is two-fold: first, whether a guideline is issued with any specific legal authority; second, the enforceability of a guideline. In 2017, the LTCHA was amended to provide authority for the Minister to make operational and policy directives (which are not regulations) in respect of LTC homes[1606] and to require every home to carry out a directive.[1607] The authority to issue directives is restricted to the sector and not to one particular home.[1608] Some of the public interest factors the Minister may consider when deciding to issue a directive include: the proper management and operation of homes in general; the availability of financial resources for the management and operation of the LTC home system and for the delivery of LTC home services; and the quality of care and treatment of residents generally.[1609] The directives must be available to the public.[1610]

[1601] *Nursing Homes Act*, *supra* note 786, s 26; Ministry of Health and Long-Term Care, *supra* note 545 at Tab 0902-01, page 9.

[1602] O Reg 79/10, *supra* note 811, s 101(1).

[1603] *Long-Term Care Homes Act, 2007*, *supra* note 425, ss 25(5) and (6).

[1604] O Reg 79/10, *supra* note 811, s 101(3).

[1605] *Ibid*, ss 103–105; Ministry of Health and Long-Term Care, *supra* note 782 at 2–74.

[1606] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 174.1 (1). See also Ministry of Health and Long-Term Care, *supra* note 1100 at 22.

[1607] *Long-Term Care Homes Act, 2007*, *supra* note 425 at s 174.1(3).

[1608] *Ibid*, s 174.1(4).

[1609] *Ibid*, s 174.1(2).

[1610] *Ibid*, s 174.1(6). At the time of writing, there is no directive posted on the MOHLTC website.

8.3.1.4 Other Oversight Mechanisms – Performance and Financial Management

In addition to statutory obligations and any policy directives, the home's operation is also constrained by contractual obligations. Previously the home negotiated a service agreement with the Ministry annually.[1611] Currently, the LHIN-Home accountability agreement can also be used to influence the behavior of homes. It is a funding agreement and contains typical contractual terms such as describing how the funding is to be used and financial reporting requirements, such as completion of the In-Year Revenue/Occupancy Report.[1612] Reporting is not new; the *Nursing Homes Act* and the Program Manual established requirements such as regular reports from homes,[1613] however the frequency and content of reporting have changed under the LTCHA. Obviously, the LHIN-home agreement provides the means through which the LHIN can compel performance on the home's part. For instance, the home is required to conduct quarterly and other assessments of residents using the RAI-MDS Tools, to ensure that the RAI-MDS Tools are used, to submit the RAI-MDS Data to the Canadian Institute for Health Information, and finally, to have systems in place to regularly monitor, evaluate and where necessary, correct the RAI-MDS Data.[1614] The agreement is also used to articulate the government's and the LHIN's expectations and priorities. For example, one of the schedules requires the home to support the LHIN's Ministry/LHIN Accountability Agreement Performance Indicators related to Alternative Level of Care and Emergency Department performance. As well, the home is required to participate in the LHIN's strategic priorities, such as supporting approaches to service planning and delivery that improve existing health disparities and actively seeking new opportunities to reduce health disparities.[1615]

8.3.2 Quality improvements (delegated to agency): what are the non-coercive means?

So far I have described means of ensuring regulatory compliance that are more like the "command-and-control" ideal type but as New Governance scholars point out, more flexible approaches can co-exist. One area that has been excluded from this research is the regulation of

---

[1611] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 0701-02, page 1–3.
[1612] Accountability agreement, *supra* note 593 at Article 4 and 5.
[1613] *Nursing Homes Act*, *supra* note 786, ss 112–113; Ministry of Health and Long-Term Care, *supra* note 545 at Tab 0602-01, page 2.
[1614] *Supra* note 911 at Article 8.1(c).
[1615] *Supra* note 593 at Schedule D.

executive compensation as a means to enforce compliance. Part III of the *Commitment to the Future of Medicare Act, 2004*[1616] created a framework for establishing accountability agreements and the issuance of compliance directives. One way of dealing with non-compliance was holding back, reducing or varying the compensation package of executives of health resource providers. In 2016, Part III was repealed by Bill 41, *Patients First Act*. Between 2004 and 2016, there were many initiatives that addressed executive compensation, such as the *Broader Public Sector Executive Compensation Act, 2014.*[1617] Some LTC homes would have been affected and some would not.[1618] Here I focus on the following initiatives undertaken by Health Quality Ontario: Quality Improvement Plans, publication of quality indicators and quality standards.

One new tool that is relatively more flexible (but is still connected to and overlaps with formal law and contractual requirements) is the annual Quality Improvement Plans, which must be submitted by health sector organizations, including LTC homes. The Quality Improvement Plan is a "public, documented set of quality commitments that a health care organization makes to its patients, clients, residents, staff, and community on an annual basis to improve quality through focused targets and actions."[1619] It consists of three components – the Progress Report, Narrative and Workplan.[1620] In previous chapters, I discussed the more recent focus on quality care from the perspective of inclusion and participation including the *Excellent Care for All Act, 2010* and homes' annual Quality Improvement Plans and satisfaction surveys. Here, I will address in more details how quality improvement plans[1621] are related to promoting compliance with the LTCHA.

The Quality Improvement Plan (QIP) is clearly linked to legislation and the accountability agreement. For example, according to Health Quality Ontario, the Health Quality Improvement Plan "provides a means to demonstrate that your organization is meeting the requirements of the legislation and/or accountability agreements."[1622] Further, "Where

---

[1616] *Commitment to the Future of Medicare Act, 2004,* SO 2004, c 5.

[1617] *Broader Public Sector Executive Compensation Act, 2014,* SO 2014, c 13, Sched. 1.

[1618] For example, the *Broader Public Sector Executive Compensation Act, 2014* applies to public hospitals. Some hospitals also operate LTC homes.

[1619] Health Quality Ontario, *supra* note 1476 at 5.

[1620] *Ibid* at 18.

[1621] It should be noted that the LHIN-home accountability agreement also requires a home to submit quality improvement plan to the Health Quality Ontario.

[1622] Health Quality Ontario, *supra* note 1476 at 7.

organizations are currently not meeting SAA [sector accountability agreement] expectations, the QIP can serve as a tool to identify how improvements will be made."[1623] The quality indicators are also related to compliance with legislation. For 2018-19, the indicators are: avoidable Emergency Department visits for ambulatory care sensitive conditions, pressure ulcers, resident experience, restraints, falls, prescribing antipsychotic medication, and percent complaints acknowledged.[1624] Other than the "avoidable ED visits" indicators, all other indicators can be traced back to specific obligations of the home defined in the LTCHA. Health Quality Ontario publishes data on these indicators and an annual report on its observations and one could argue that this provides an additional means of ascertaining compliance at the sectoral level.

Each year, Health Quality Ontario identifies as series of priority issues and corresponding indicators that are included in the Quality Improvement Plan. These quality priorities are selected through consultation with Health Quality Ontario's Patient, Family, and Public Advisors Council, key stakeholders, sector associations, the Ministry, the local health integration networks (LHINs), and other organizations.[1625] For example, one of the 2018-19 priorities is prevention of workplace violence. All health care organizations are asked to reflect on how workplace violence prevention is a strategic priority in their respective organizations.[1626] In other words, homes are asked to publicly explain how they address workplace violence issues (which do not constitute an entirely new legal obligation since violence and harassment issues are already addressed in the *Occupational Health and Safety Act*[1627]). This is supposed to be part of the efforts to address violence across the health care system without necessarily adding more law.

Last but not least, Health Quality Ontario also develops quality standards, which "address standards of care for clinically defined populations (for example, adults with schizophrenia), service areas (for example, preoperative-operative testing), and health system issues (for

---

[1623] *Ibid* at 14.

[1624] Health Quality Ontario, *Looking Back and Looking Forward: A sneak peek for the 2018/19 long-term care quality improvement plans (QIPs)* (Toronto: Health Quality Ontario, 2017) at 35.

[1625] Health Quality Ontario, *supra* note 1476 at 5.

[1626] Health Quality Ontario, *supra* note 1475; Health Quality Ontario, *Quality Improvement Plan Guidance: Workplace Violence Prevention* (Toronto: Health Quality Ontario, 2017) at 2. All organizations that submit QIPs will be asked to answer the following question in their QIP Narratives: "Please describe how workplace violence prevention is a strategic priority for your organization. For example, is it included in your strategic plan or do you report on it to your board?" Hospitals are required to complete an indicator that will measure the number of workplace violence incidents reported by hospital workers within a 12-month period.

[1627] *Occupational Health and Safety Act,* RSO 1990, c O.1, ss 32.01-32.08.

example, care transitions).”[1628] Each quality standard contains five to fifteen quality statements and each statement comprises a strong recommendation of high-quality practice for a specific aspect of care. In turn, each statement is accompanied by one or more process, structural, or outcome indicators to help health care professionals and organizations measure their achievement of the practice outlined in the statement. Quality standards also include a small set of outcome indicators.[1629] Interestingly, the standards are useful not only for care providers and patients, but from Health Quality Ontario’s perspective, they are useful to government also: “Government can use quality standards to identify provincial priority areas, inform new data collection and reporting initiatives, and design performance indicators and funding incentives.”[1630] An example of quality standards is the *Behavioural Symptoms of Dementia*,[1631] which was referenced in Chapter 6.

8.3.3 Reliance on other bodies for ensuring regulatory compliance: who else are responsible?

Thus far, this chapter focuses on what the government does in terms of enforcement and compliance with the LTCHA, as well as some of the more flexible means of influencing behaviours of health care providers used by Health Quality Ontario. Julia Black’s concept of de-centring directs our attention to how some of the non-state actors influence the behaviour of health care providers and homes. While the existence of self-regulation in parallel with command-and-control regulation is not new to the health care sector, how a hybrid approach is slowly evolving is new. The discussion below also illustrates how the government and the regulated entities work together on some of the regulatory tasks.

There are new ways that professional governance and formal command-and-control regulation work together in order to influence behaviours of health care providers. First, enhanced information-sharing is enabled to ensure the regulatory colleges can take action against their members. In Chapter 6, I explained the reporting requirements related to abuse and neglect of residents. In 2017, the regulation under the LTCHA was amended to allow the Ministry to

---

[1628] Health Quality Ontario, *Quality Standards: Process and Methods Guide* (Toronto: Health Quality Ontario, 2017) at 4.
[1629] *Ibid*.
[1630] *Ibid*.
[1631] Health Quality Ontario, *supra* note 1173.

disclose personal information about an individual to a regulatory College for the purpose of the administration or enforcement of certain statutes.[1632] Second, funding may be provided to professional organizations to develop guidelines that support legal compliance. For example, the Ministry provided funding to the Registered Nurses' Association of Ontario to implement the Long-Term Care Best Practices Program.[1633] I have referred to some of the guidelines in previous chapters.

Accreditation, as a form of self-regulation, is not new in the health sector. Indeed, homes have always received additional government funding to support their accreditation efforts.[1634] According to Accreditation Canada, to pursue accreditation, organizations conduct an extensive self-assessment to determine whether they are meeting the standards set by Accreditation Canada and where they need to make improvements. The standards encompass matters such as governance, risk management, infection prevention and control, and medication management. Every four years, trained surveyors (experienced health care professionals from accredited organizations), visit organizations to assess whether the standards are being met. Then Accreditation Canada assesses this information and provides the organization with a final report and an accreditation decision. [1635] With respect to the LTC sector, Accreditation Canada offers a two-year Accreditation Primer award as well as a four-year QuentumTM accreditation award.[1636]

Accreditation is linked to different parts of the regulatory regime in the following ways. Health Quality Ontario explains that when determining priorities to include in the Quality Improvement Plan, accreditation standards and processes are an important resource that help organizations identify priority areas for improvement and encourage organizations to review these standards (as applicable) as per ongoing accreditation processes relevant for the sector.[1637]

[1632] O Reg 79/10, *supra* note 811, s 304.1. They are the *Drug and Pharmacies Regulation Act*, the *Regulated Health Professions Act, 1991* or an Act named in Schedule 1 to that Act; and to the Ontario College of Social Workers and Social Service Workers for the purpose of the administration or enforcement of the *Social Work and Social Service Work Act, 1998.*

[1633] Registered Nurses' Association of Ontario, "Long-Term Care Best Practices Program", online: <http://rnao.ca/bpg/initiatives/longterm-care-best-practices-initiative>.

[1634] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 0603-03, page 2.

[1635] Accreditation Canada, *Accreditation Basics* (Ottawa: Accreditation Canada).

[1636] Accreditation Canada, *Helping you deliver quality residential care for seniors* (Ottawa: Accreditation Canada, 2015).

Indeed, Accreditation Canada's LTC services standards also emphasizes the fact that homes have to meet the requirements of the applicable legislation. Last but not least, the government also appears to give credibility to the accreditation process on the Ministry's website on LTC homes by indicating a home's accreditation status, along with information such as previous inspection reports and orders. According to the Ministry: "Accreditation is a voluntary process that LTC homes may use to assess their services and help them improve the quality, safety and efficiency of their performance for the benefit of their residents and the health system."[1638]

8.3.4 **Summary**

The table below summarizes the key changes regarding protection of residents discussed in this section:

Table 27: Key changes related to the state's obligations to protect residents under the *Nursing Homes Act* and the LTCHA and other means

	Nursing Homes Act	**LTCHA and other means**
Compliance and Enforcement	Statement of Unmet Standards or Criteria Fines and imprisonment	All non-compliance must be documented A wider range of sanctions Higher maximum fines and administration penalty Re-inspection fees Due diligence, honest and reasonable belief not a defence
Non-coercive means (other agencies)	N/A (but see Program Manual)	Health Quality Ontario's Quality Improvement Plans, publication of quality indicators and Quality Standards

---

[1638] Ministry of Health and Long-Term Care, "Reports on Long-Term Care Homes: Search Selections for Long-Term Care homes", online: <http://publicreporting.ltchomes.net/en-ca/default.aspx>.

	Nursing Homes Act	**LTCHA and other means**
Reliance on other bodies	Reporting about abuse and neglect Funding for homes for their accreditation efforts	Ministry is empowered to share personal information about an individual to a regulatory college Funding for the Registered Nurses' of Ontario to develop a LTC best practices program Accreditation standards more integrated with formal law and other parts of the regulatory standards

It is not surprising that in order to address real or perceived concerns about the quality of care provided in LTC homes, the formal compliance and enforcement system continues to evolve, with more regulatory and non-regulatory tools being made available to the Ministry. Concurrently, there are more informal and flexible means to influence the behavior of homes and health care providers. While these other means may not be mandatory in the sense that non-compliance does not carry formal sanctions such as fines, they nonetheless become interwoven into the formal law and reinforce the importance of certain objectives of regulation.

The question is whether multiple and overlapping layers of formal and informal rules coupled with enforcement tools can actually influence the behaviour of participants in order to promote caring relationships in homes. On the one hand, the more adversarial stance of the regulator can be justified theoretically with arguments made by Herring with respect to the danger of care becoming an exercise of power over a passive individual. One the other hand, feminist political economists also have proposed powerful critiques of regulation, especially of the detailed rules that are directed to individual carers and homes.[1639] My reading of the changes is that the compliance and enforcement regime is becoming more deterrent focused overall but the previous regime is no panacea. The question is whether state interventions in caring

---

[1639] Daly, *supra* note 514; Baines & Daly, *supra* note 514; Daly et al, *supra* note 672.

relationships, for example, rights afforded to those in caring relationships and legal recognition of responsibilities and obligations of the state (in this case, exemplified in the compliance and enforcement program), can actually promote the four markers of care advanced by Herring. A related question is how the state chooses particular tools when a whole range of various degrees of legal formality are available. In Chapter 9, I will also revisit the question about hybridity.

8.4 What does the state do to protect residents as consumers?

The state also plays the role of regulating the LTC market by imposing restrictions on transactions and exchanges between home and residents, among homes and within homes. In this final section, I will explore regulation of the home's corporate and business activities i.e., activities that are not directly related to hands-on care, including corporate governance of homes, and implementation of market-like mechanisms to promote efficiency and value for money. One could argue that the relationship between a home and its residents is akin to that of landlord and tenant, as residents contribute to their accommodation costs (in the form of co-payment). There is a contractual relationship between resident and home, and it is important to recognize the consumer protection objective as a secondary value (to use Windholz and Hodge's expression) here. Accordingly, the LTCHA also incorporates changes that are intended to protect residents as consumers or purchasers of goods and services from the home. Similarly, the home needs to engage in various transactions in order to deliver LTC services (such as raising of capital and related party transactions). Although these regulatory changes may not appear to be directly related to hands-on care, they contribute to the conditions of care. I call them conditions of care because they can foster or hinder relationships that are critical to the operations of the home. They represent another way the government attempts to create and maintain a LTC market since the government does not have a direct delivery role in the sector.

If interpreted from a feminist political economy perspective, extensive rules on governance and transactions become necessary because of for-profit ownership and other privatization techniques (such as contracting out of food services). This may very well be the case but even if there is no for-profit home anymore, there will always be a need to supervise governance and transactions within a home for a number of reasons. First, the effect of collective responsibility for care means the state now has an interest in how the homes are run and by whom. It follows that the state has to give itself the necessary authority to intervene in the operation of the home when necessary. Second, and more importantly, more rules are believed to be necessary in order to recognize that residents and their respective homes (even if they are municipal or non-profit) are not on an equal footing. How much liberty and agency the state should allow when residents enter into contracts with their respective homes depends on the nature of the relationship between the parties. Herring explains the image of a typical contractor in law:

> The typical contractor around which contract law is built is the man driven by rationality, who is intelligent, powerful, and able to stand up for himself. He is a man who likes to drive a hard bargain and get as much as he can from his contracting partner. His only real fear in terms of being taken advantage of in a contract is that another will use lies or threats against him.[1640]

Further, he provides a different vision:

> … a contract law built around vulnerable contractor: one who knows very little about what they are purchasing, who lacks the expertise to read complex legal documents, who is driven by emotional pressures as much as rational thought, and who enters contract without the time, energy, or ability to understand all the issues involved. . . Where contracts must be understood as part of the ongoing relationship between the parties and where they gain their meaning and value from those relationships.[1641]

There is a question whether the consumer protection measures in LTC are based on the image of the typical contractor advanced by Herring, or the vulnerable contractor. As I will show below, achieving a balance between protection and administrative burden on the home's part will not be easy.

8.4.1 **Corporate governance of homes**

There are a variety of means that the government can use to set expectations about the home's governance. Under the previous regime, although the *Nursing Homes Act* did not contain many requirements about governance, the Program Manual did include sections on governance, responsibilities and accountability.[1642] The government's expectation about governance is elevated to the LTCHA: "The people of Ontario and their Government: . . . Firmly believe in public accountability and transparency to demonstrate that long-term care homes are governed and operated in a way that reflects the interest of the public, and promotes effective and efficient

---

[1640] Herring, *supra* note 245 at 261.

[1641] *Ibid* at 262.

[1642] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 0701-02.

delivery of high-quality services to all residents."[1643] Under the LTCHA, there are more requirements pertaining to duties of officers and directors and ownership and control of the home. It should also be noted that the LHIN-home accountability agreement also contains a section on home governance in the representation, warranties and covenants article.[1644]

8.4.1.1 Duties of directors and officers

The *Nursing Homes Act* and its regulation did not have any reference to the duties of the home's board of directors and officers if the home is a corporation. However, the Program Manual contained references to activities that may be undertaken or approved by the governing body, board or owner of the home, for example, chair of the board's sign-off on the annual report of the home and approval of the home's mission statement.[1645] In contrast, when it was first introduced, the LTCHA adopted the duties of directors and officers of a home that is a corporation from the *Ontario Business Corporations Act*[1646] and the *Not-for-Profit Corporations Act* (not proclaimed yet).[1647] More recently, Bill 160 has brought the duties to a higher standard: "when a licensee is a corporation, every director and every officer of the corporation shall ensure that the corporation complies with all requirements under this Act."[1648] Further, a provision is added to clarify that corporate prosecution is not necessary for individuals to be prosecuted: "A person may be prosecuted and convicted under this section even if the corporation has not been prosecuted or convicted."[1649]

8.4.1.2 Ownership and control

The LTCHA focuses on who has *de facto* control in the home and attempts to mitigate the risk of poor governance by imposing restrictions on certain types of business transactions.

[1643] *Long-Term Care Homes Act, 2007*, *supra* note 425 at Preamble.

[1644] *Supra* note 593 at Article 10.

[1645] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 0605-01, page 1 and Tab 1011-02, 1.

[1646] *Business Corporations Act,* RSO 1990, c B.16, s 134. "Every director and officer of a corporation in exercising his or her powers and discharging his or her duties to the corporation shall, (a) act honestly and in good faith with a view to the best interests of the corporation; and (b) exercise the care, diligence and skill that a reasonably prudent person would exercise in comparable circumstances."

[1647] *Not-for-Profit Corporations Act, 2010,* SO 2010, c 15, s 43. "Every director and officer in exercising his or her powers and discharging his or her duties to the corporation shall, (a) act honestly and in good faith with a view to the best interests of the corporation; and (b) exercise the care, diligence and skill that a reasonably prudent person would exercise in comparable circumstances." As of September 27, 2019, the Act has not been proclaimed yet.

[1648] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 69(1).

[1649] *Ibid*, s 69(4). See also Ministry of Health and Long-Term Care, *supra* note 1100 at 17.

Consider the following matters: controlling interest,[1650] exercising security interest,[1651] and management contracts.[1652] In addition to reporting any changes to the home's directors and offices or in the persons who have a controlling interest in the home as required by *Nursing Homes Act*,[1653] the LTCHA also requires that if the home is managed by a corporation through a management contract, the home has the same obligations to report with respect to that corporation.[1654] Further, the *Nursing Homes Act* required that a person who has a security interest in a licence must not exercise that interest without the approval of the Director if exercise of the interest would change the ownership or controlling interest in the licence.[1655] In contrast, under the LTCHA, no person may acquire control over, or interfere with, the operation of a home by exercising a security interest except through a management contract. If that happens, the LTCHA applies to the person exercising the security interest as if the person were acting as the licensee subject to any regulation. No exercise of a security interest results in a transfer of a licence. This provision applies, with necessary modifications, to receivers and trustees in bankruptcy as though they were exercising a security interest.[1656] A home may not be managed under a management contract for more than one year (with possible extensions), unless the person exercising the security interest receives the same approval from the Director that would be required if the licence were being transferred to the person.[1657] While Ministry approval is always required before a home may allow anyone else to manage the home,[1658] the Ministry's ability to control management contracts also has been expanded: Ministry approval may be

---

[1650] The definition is in *Long-Term Care Homes Act, 2007*, *supra* note 425, s 2(2). "Without limiting the meaning of controlling interest, a person shall be deemed to have a controlling interest in a licensee if the person, either alone or with one or more associates, directly or indirectly,
(a) owns or controls, beneficially or otherwise, with respect to a licensee that is a corporation,
(i) 10 per cent or more of the issued and outstanding equity shares, and
(ii) voting rights sufficient, if exercised, to direct the management and policies of the licensee; or
(b) has the direct or indirect right or ability, beneficially or otherwise, to direct the management and policies of a licensee that is not a corporation."

[1651] *Ibid*, s 107(5). The definition is as follows: ""security interest" means an interest in or charge upon a licence or property of the licensee to secure a debt or the performance of some other obligation."

[1652] The LTCHA does not contain a definition of "management contract".

[1653] *Nursing Homes Act*, *supra* note 786, ss 9(1) – (2).

[1654] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 108.

[1655] *Nursing Homes Act*, *supra* note 786, ss 10(1) – (2).

[1656] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 107. See also Ministry of Health and Long-Term Care, *Compendium to Bill 140, Long-Term Care Homes Act, 2007* (Toronto: Ministry of Health and Long-Term Care, 2006) at 27.

[1657] O Reg 79/10, *supra* note 811, s 274(2).

[1658] *Nursing Homes Act*, *supra* note 786, s 11.

subject to restrictions imposed by the Minister and can be withdrawn by the Ministry, amendments to the management contract also have to be approved by the Ministry and requirements of the management contract are also specified (e.g. management of the home cannot be subcontracted or assigned).[1659]

8.4.2 **Market-like mechanisms to facilitate transactions**

Earlier in this chapter, I discussed how the government attempts to control the capacity of LTC while managing fiscal pressures. Optimizing the use of limited public financial resources also entails identifying strategies to modify relationships, practices and structures between providers and purchasers.[1660] This last area concerns strengthened or new measures that were intended to facilitate the efficient functioning of the LTC market. Of course, the relationship between resident and home is not completely market-based in the neoclassical economics sense: those who need LTC cannot freely enter into contracts with homes under any conditions they negotiate. The allocation of beds is not completely determined by the price of a bed (in the form of resident fees), and residents have preferences other than quantity and price. However, there are indications that market-like mechanisms are introduced to correct market failure in order to facilitate private ordering in a highly regulated context.[1661]

To allow residents, substitute decision-makers and/or their families to make rational decisions like consumers do, it is necessary for homes to disclose more information about their operations. While homes have always been required to post information publicly, such as residents' bills of rights, accountability agreements, and financial statements,[1662] under the LTCHA, more information must be posted, such as decisions of tribunals and divisional courts, mandatory reporting requirements, minimization of restraints policies, and zero tolerance of abuse policies.[1663] There are also more ad hoc information requirements once a resident is

---

[1659] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 110; O Reg 79/10, *supra* note 811, s 276; Ministry of Health and Long-Term Care, *supra* note 1656 at 28.

[1660] Joanna Marczak & Gerald Wistow, "Commission Long Term Care Services" in Cristiano Gori, Jose-Luis Fernández & Raphael Wittenberg, eds, *Long-Term Care Reforms in OECD Countries* (Bristol: Policy Press, 2016) 117.

[1661] For background on neoclassical economic assumptions see Gary Stanley Becker, *The Economic Approach to Human Behavior* (Chicago: University of Chicago Press, 1976). For an explanation of different types of market failures or imperfections, see Windholz, *supra* note 50 at 36–39.

[1662] Reg 832, *supra* note 831, s 121.

[1663] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 79; O Reg 79/10, *supra* note 811, s 225.

admitted. For example, homes are required to provide monthly statements about their charges to residents instead of quarterly statements, as mandated in the previous act.[1664] As well, Cabinet may make regulations requiring that certain documents meet certain requirements (called "regulated documents"). The home must ensure that these documents are not presented for signature to a resident or prospective resident, their substitute decision-maker or family member unless the documents comply with the requirements set out in the regulations and the compliance has been certified by a lawyer.[1665]

Furthermore, to create a more equal relationship between homes and residents (outside of medical and nursing care), more legal protections are included in terms of any agreements or contracts between a resident and a home. No person shall be told or led to believe that prospective residents can be discharged from the home for: not signing a document; voiding an agreement; or giving, not giving, withdrawing, or revoking a consent or directive with respect to treatment or care.[1666] As well, the content of an agreement relating to accommodation is now prescribed by regulation instead of the Program Manual.[1667] Some of the requirements about trust accounts have also been updated to prevent financial abuse: homes are prohibited from holding more than $5,000 in trust from any one resident at one time and can no longer charge any transactional fees for using the trust account.[1668] In addition to regulation of co-payments (see above), new requirements about fees include: any fee other than accommodation has to be reasonable, much more guidance about when residents do not have to pay for the maximum amount and the government has the ability to regulate non-accommodation costs, restrictions on interest charges, and more clarity about non-allowable charges.[1669]

Finally, while the LTCHA has shaped residents into consumers, it has also clarified the role of government as the ultimate purchaser of goods and services in addition to being the regulator of the sector. While the government has always possessed permissive monitoring

---

[1664] O Reg 79/10, *supra* note 811, s 261; *Nursing Homes Act*, *supra* note 786, s 21(3).
[1665] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 80; O Reg 79/10, *supra* note 811, s 227; Ministry of Health and Long-Term Care, *supra* note 1656 at 20.
[1666] *Long-Term Care Homes Act, 2007*, *supra* note 425, ss 81–83.
[1667] O Reg 79/10, *supra* note 811, s 227; Ministry of Health and Long-Term Care, *supra* note 545 at Tab 0902-01, page 9–11.
[1668] O Reg 79/10, *supra* note 811, s 241; Ministry of Health and Long-Term Care, *supra* note 545 at Tab 0609-01, page 4.
[1669] O Reg 79/10, *supra* note 811, ss 245, 246–254.

power such as auditing,[1670] the establishment of LHINs necessitated another layer of monitoring. As per the more recent amendments to the *Local Health System Integration Act*, new procedures and requirements are provided for the negotiation of service accountability agreements between LHINs and service providers. The additional provisions concern situations where a LHIN and a service provider fail to reach an accountability agreement: mandatory meetings between LHIN and service provider, notice requirements, and ability of a LHIN to impose an agreement on a provider.[1671] At the same time, the Ministry retains much financial oversight at both the system level and the home level to ensure value for money. For example, the LTCHA and regulation prohibit the home from entering into certain types of non-arms' length transactions, mostly related to suppliers, or without the prior consent of the Director where required. The home must submit reports to the Director on every non-arm's length transactions entered into by the licensee as provided for in the regulations.[1672] As well, the accountability agreement assigns the role of receipt of reconciliation reports (a type of financial report) to MOHLTC.[1673] As explained earlier in this chapter, provincial priorities such as quality of care are embedded and reinforced in agreements.[1674]

8.4.3 **Summary**

The table below summarizes the key changes to consumer protection measures:

Table 28: Key changes related to consumer protection under the *Nursing Homes Act* and the LTCHA

	Nursing Homes Act	**LTCHA**
Corporate Governance	No provision regarding duties of directors and officers	Ministry's ability to monitor and possibly control those who have a controlling interest, exercise of security interest and management contracts expanded

---

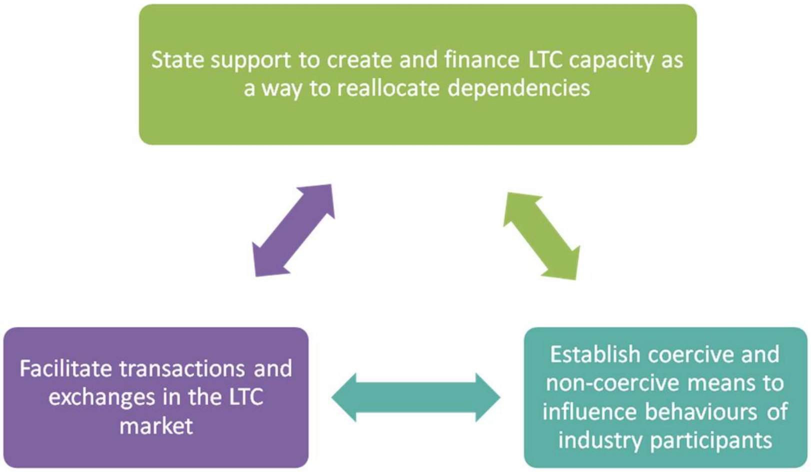
[1670] Ministry of Health and Long-Term Care, *supra* note 545 at Tab 0604-01.
[1671] *Local Health System Integration Act, 2006*, *supra* note 591, s 20.
[1672] *Long-Term Care Homes Act, 2007*, *supra* note 425, s 93; O Reg 79/10, *supra* note 811, s 265.
[1673] *Supra* note 593 at Article 3 and 5, and Schedule B.
[1674] *Ibid* at Article 8.0 and Schedule B.

	Nursing Homes Act	**LTCHA**
		Director and officers must ensure that the home complies with all requirements in the LTCHA
Market-like mechanisms	Information disclosure Requirements about accommodation agreements in the Program Manual	More information disclosure More requirements about trust accounts and contracts between homes and residents (accommodation agreements)

In the LTCHA, there is a recognition that unrestrained commercial relationships are probably not conducive to quality care. This will be an increasingly important topic as more complex forms of investment and ownership may emerge in the health sector, such as Real Estate Investment Trusts (REITs). The downside of this recognition is that more elaborate legal interventions need to be in place in order to mitigate the effects of an imperfect market. While many regulatory requirements are related to how care is delivered, by whom and when, another function of the regulatory regime is to prescribe limitations and restrictions that contribute to care conditions. To conclude this chapter, I have considered protection of residents as consumers. This last section shifts to the corporate and business activities of the home and focuses on the corporate governance of homes and the market-like mechanisms that facilitate transactions and exchanges between LTC homes and their residents. Together, the legal interventions discussed here represent the government's increased efforts to promote economic values such as consumer protection, efficiency and value-for-money in the LTC market. The tension here is that if residents (or their substitute decision makers) are treated as consumers who are expected to be responsible for their choices, it is necessary to recognize the fact that the relationship between home and residents is asymmetrical. The question is whether market-oriented legal interventions can actually support or undermine relationships between a home and its residents. More protections such as information disclosure to residents and/or their substitute decision-makers will be more onerous on the home's part.

8.5 Conclusion

Illustration 7: What the state has to do to support care?



This chapter has explored some of the structural issues inherent in the LTC sector in order to examine the relationship between state and citizens. At the core of this chapter is the question of how to reallocate dependencies from the private realm to the public domain and protect those in caring relationships. In the previous chapters, implicit in my findings is how caring relationships in homes are shaped by regulation, which is undertaken by the government as well as other bodies. In this chapter, I raised the question of what the state must do in order to protect its citizens, in this case LTC residents, beyond defining how care is supposed to be delivered at the home level. The first issue is the control of the supply and demand of beds, which has significant implications for those who are waiting for a bed and for their caregivers. The measures in place raise questions about who are considered more deserving of state support. The second issue pertains to about enforcement and compliance in LTC homes. I have explored both the formal and the more flexible ways by which the government (in conjunction with other bodies) attempts to influence the behaviour of homes and those who work in homes. The last issue is about shaping the corporate and business activities within the home, which contribute to care conditions. It concerns putting measures in place to protect residents as consumers, including corporate governance and market-like mechanisms to facilitate transactions and exchanges in the LTC market.

To conclude, one could identify a few tensions at the system level. First, there is a tension between meeting the needs of individuals and those of the health care system (and presumably other patients in the system). The result is the necessity of stricter admission requirements and prioritization, which means LTC admission is also used to support other priorities in the health care system, such as Alternative Level of Care pressure. The prioritization categories show the tension in defining and negotiating “assessed need”. Second, while the legal framework imposes more onerous requirements on homes so the government can intervene, or at least influence the behaviour of participants in the sector if necessary (the new compliance system being the latest example), the government also attempts to distance itself from some of the quality improvement initiatives (delegated to Health Quality Ontario) and some of the financial decisions such as those related to the negotiation of accountability agreements with homes. Third, while the government continues to assert that it controls LTC policy decision-making at the provincial level, including the supply of beds and eligibility for licensing, it also realizes that it must make LTC an attractive investment as it relies on the sector not just to operate beds on an ongoing basis, but also to make the necessary transformational changes for the future. Fourth, since the government is not operating the homes, it must create consumer protection measures that recognize the unequal relationship between a home and its residents (who could be considered as vulnerable as a result of their social locations) while still allowing homes to be financially viable in the long-term. These tensions will inform our analysis of the implications of the regulatory changes discussed so far, which will be presented in Chapter 9.

9 Discussion and Analysis

9.1 Introduction

The research question that this dissertation seeks to answer is: what are the potential implications of the changes made by the Government of Ontario between 2004 and 2018 to the legislation and governance of treatment, care and living circumstances within LTC homes for persons with disabilities? In Ontario, the implementation of the LTCHA in 2010, along with changes to other statutes relevant to the LTC sector, represented another regulatory milestone in the history of LTC in Ontario. What emerges from a comparison of the current and previous legal regimes is a clearer picture of the nuances of LTC regulation evolution that have not been fully explored in previous studies. This research is motivated by a desire to identify the consequences of these nuances for residents, who are most likely to be older women with multiple impairments and illnesses. Following feminist political economists[1675] and care researchers, this research also attends to caring relationships (as understood by Herring[1676]) in homes. The preoccupation here is gaining a better understanding of law and caring relationships. Recall the conceptualization of care offered in Chapter 2. In this research, care is understood in the following ways: First, care is grounded in caring relationships and is fundamentally important for human survival; that care embodies intermingled needs and interests of all involved in caring relationships but must also recognize the actual and potentials for harm in caring. Second, caring relationships are constructed by law in many different ways and the promotion of caring relationships is simultaneously limited by current legal tools such as "rights". Third, caring relationships are shaped by the administrative processes and legal structures of public benefit schemes and regulatory regimes, many of which are indicative of the role of the state in supporting or neglecting care regardless of the setting in which care occurs. This chapter seeks to synthesize the data collected from the comparison as well as the themes from the key informant interviews. I hope to tell some of the stories of "how is" regulation experienced in everyday life by those to whom regulation is directed as regulated entities or beneficiaries[1677] i.e., homes, residents, workers, families and friends.

[1675] Armstrong & Daly, *supra* note 163.
[1676] Herring, *supra* note 112.
[1677] Parker, *supra* note 68 at 9.

In this chapter, I begin with a summary of the findings from my review of changes to the regulation of LTC homes between 2004 and 2018. Then I present my examination of some of the implications of the regulatory changes, which are divided into the following themes: the implications of understanding care as rights and entitlements, searching for changes in governance, meaningful participation and finally, law's response to caring. This chapter concludes with this study's contributions to the following scholarly debates: dementia as a disability, protecting the interests of those in caring relationships, and conditions necessary for successful implementation of New Governance principles.

9.2 Summary of the findings from previous chapters

9.2.1 Changes in legal form

The current regulatory regime is more prescriptive than the previous regime in the sense that more activities in the home are brought under the reach of formal law and are subject to standardization in terms of program structure. Equally important, the regulatory regime is also more complex in the sense that it is denser and more technical. As Herring explains, the 'rule of law' requires the law to be sufficiently certain so that citizens can know in advance what the law requires of them.[1678] Many changes as introduced by the LTCHA (2010) were simply requirements elevated from the Program Manual to regulation or statute, with some modifications. Such changes in legal form provide greater legal certainty to homes, caregivers, residents, families and friends in terms of what care means and how care is delivered in a communal or congregate setting. This could be an indication of a greater reliance by the regulator (MOHLTC) on the force of law to influence the behaviour of homes and of those who work inside the homes. I contend that requirements that define care and specify care delivery mean that care is expressed legally in the language of rights and entitlements for services. It should be noted that "choices", respect for individual preferences and accommodation of disability are built into the legal framework. It should also be noted that the regulatory regime covers a variety of topics and is not uniformly prescriptive. The comparison shows that indeed, some requirements were dropped when the LTCHA was introduced. An area that is notably less

---

[1678] Jonathan Herring, "Older People and Deficiencies in the Formal Care System: Equality and Rights" in Sue Westwood, ed, *Ageing, Diversity and Equality: Social Justice Perspectives* (Abingdon, Oxon ; New York, NY : Routledge, 2019) 276 at 285.

prescriptive than other areas of regulation is the home's staffing, which still allows considerable discretion over how many staff members are hired and scheduled.

However, even with a highly prescriptive regulatory regime sustained by formal law, there are still regulatory gaps. The proliferation of soft law in the form of guidelines and standards issued by regulatory colleges, professional associations and accreditation bodies provide additional guidance to homes as well as regulated and unregulated health care providers on a variety of topics. These guidelines and standards reinforce the expectations articulated in formal law and at the same time, give more instructions as to how to meet those expectations, and therefore may lead to less interpretation being required at point of care.

9.2.2 More Procedural Protections for those in Caring Relationships

The majority of the new requirements concern processes and procedures that create and shape the caring relationships between residents and their formal and informal caregivers on the one hand, and among residents on the other. One category of changes is the provision of more procedural protections to residents when they receive care, encounter caregivers or deal with the home. These changes are built around the image of a resident who is vulnerable because of his / her age and impairment and therefore needs to be protected from the risks in the home. Paradoxically, another image of the resident also emerges: he / she may inflict serious harm on other residents and those around him/her because of his/her age-related impairments such as dementia. Changes to consent and capacity law, to admission and discharge of resident requirements, and to designation of specialized units fall into this category. Another category of changes is made to reflect the expectations in other statutes and the Constitution, including the AODA, the Human Rights Code of Ontario and the *Charter*. These changes ensure that other fundamental legal values, such as freedom from discrimination and non-arbitrariness, are embedded into the rules that govern the caring relationship. These changes are usually expressed in the language of rights and entitlements. The modifications to the Residents' Bill of Rights, to requirements about accommodation of certain types of disability and to additional information disclosure requirements fit into this category. The last category of changes allows more formal opportunities for residents, families and friends to be included in and to participate in the operation of the home. The legal recognition of Family Councils and Residents' Councils is the most significant change. The participation envisioned in law is mainly in the form of problem-solving, from giving feedback via satisfaction surveys and Quality Improvement Plans, to being conscripted into helping the ministry to detect non-compliance and to monitor enforcement in the home.

9.2.3 Few substantive changes for residents

The introduction of the LTCHA brings only a few new requirements that can be described as truly substantive for residents. The first category of changes deals with safety and security of residents and others in the home and possibly imposes restrictions on the autonomy of residents. This category includes the duty to create a safe and secure home, the minimization of restraining and confining residents, zero tolerance of abuse and neglect, and the management of responsive behaviour and altercations. These changes provide greater consistency in terms of what the home can or cannot do in order to manage the risks to safety and security, usually understood in relation to physical or bodily harm to residents and others in the home. The most common techniques employed include reliance on homes having the necessary policies in place, increased monitoring and documentation, mandatory reporting and evaluation, and training. The second category of changes allows the Ministry to intervene and maintain credible deterrents against homes and their employees contravening applicable law as necessary. In addition to strengthened compliance and enforcement mechanisms including a wider range of possible sanctions for non-compliance, it is evident that the Ministry also relies on more flexible and informal means backed by law to influence the behavior of homes. The final category of changes allows the government to further distance itself from the day-to-day home operations while maintaining discretion over policy issues and funding commitments. The changes to government control over supply and demand of beds, licensing of homes, regulation of co-payments and fees and funding arrangements belong to this category. The government also uses other tools such as contracts and directives to influence the operation of homes indirectly. These regulatory changes, along with the amount of funding provided to the sector, define the capacity of the sector to respond to the needs of residents and their informal caregivers.

9.2.4 Can legal regulation transform care and caring relationships in LTC?

To summarize, I contend that the majority of changes to regulation and governance to LTC between 2004 and 2018 created new or strengthened existing processes and procedures. The few substantive changes identified in my review can be described as fragmented efforts to reduce risks to the safety, physical survival and security of individual residents. In the remainder of this chapter, I will argue that these changes to regulation and governance – if properly understood and implemented - are significant for persons with disabilities. They afford more procedural protections to residents in caring relationships and allow residents to make claims for inclusion and participation in making care decisions and to influence conditions within the home.

It is apparent that the majority of the regulatory changes introduced between 2004 and 2018 created additional sources of legal complexity.[1679] In this LTC regulatory landscape, we now have multiple organizations (MOHLTC, Health Care Ontario, Local Health System Integration Networks, and regulatory colleges, just to name a few), each subject to different combination of statutes, contracts, soft law and processes. I agree that legal complexity has been increasing in the regulation of LTC and that this can be problematic for those who provide care, receive care and support caring relationships. The LTCHA probably has received more scrutiny than other statutes such as the *Excellent Care for All Act*. Many commentators and scholars have commented that the LTCHA is highly prescriptive,[1680] perhaps substantially more so than the previous *Nursing Homes Act*, *Charitable Institutions Act* and *Homes for the Aged and Rest Homes Act*. However, it is probably not controversial to suggest that the previous regime was no panacea: having a regime composed of three similar statutes and their associated regulations and a 800 page-long Program Manual was also onerous for homes, health care providers, administrators and so on. In Chapter 2, I referred to Peter Schuck's work on legal complexity. Schuck defines a legal system as complex "to the extent that its rules, processes, institutions, and supporting culture possess four features: density, technicality, differentiation, and indeterminacy or uncertainty."[1681] Recall that legal complexity can only be located on a continuum: extreme simplicity on one end and extreme complexity on the other.[1682] The LTCHA can be described as more complex on the continuum because of its density, technicality and differentiation. Many of the requirements are intended to reduce indeterminacy.

[1679] Schuck, *supra* note 497.
[1680] Armstrong & Daly, *supra* note 163.
[1681] Schuck, *supra* note 497 at 3.
[1682] *Ibid* at 6.

Legal complexity has consequences.[1683] The benefits and costs of complexity are not evenly distributed.[1684] In my opinion, the greatest danger of unrestrained increasing legal complexity in LTC are delegitimation costs, which occur when rules become so complex that their intelligibility and legitimacy decline.[1685] It is not hard to imagine that care providers will find ways to avoid meaningful compliance when the rules become too complex.[1686] For this reason, it is important to understand how homes, residents, workers, families and friends experience regulation. Are the benefits of a given level of complexity worth its costs?[1687] If the purported benefits of the LTCHA cannot even materialize, then it would be even more difficult to justify the costs of the complexity of the LTCHA (or other related statutes).

Here is how my argument proceeds. I will first establish that care conceived as rights and entitlements can change the conversation about the needs of residents. However, there is a clear gap between the promise of rights and their realization. This gap leads to questions about how policy, financial and operational decisions are made about LTC in Ontario. Next I will show how governance changes shape care and caring relationships re-orienting the process through which problems are to be solved in the sector. A significant part of problem-solving is meaningful participation. Participation mechanisms have the potential to reconcile dependence and autonomy in caring relationships in LTC. One of the strengths of Ontario's system is that participation rights and mechanisms are well established and some are even enforceable. I make the case that the key concern is whether the appropriate supports can be provided to residents so that disabilities and impairments are not barriers to meaningful participation for those who are willing to participate. I will return to the question of law's response to care and caring relationships as a means to examining an ongoing struggle to define the state and citizen relationship. Access to LTC is increasingly restricted in order to limit the state's financial responsibility. The rhetoric of choice is deployed by the government to justify the difficult situations of some residents. The choices made with respect to enforcement are illustrative of the responsibilities of the state towards those in caring relationships. The greatest weakness in

---

[1683] *Ibid*.
[1684] *Ibid* at 26.
[1685] *Ibid* at 20.
[1686] Braithwaite & Braithwaite, *supra* note 515.
[1687] Schuck, *supra* note 497 at 8.

Ontario's system is that the law creates an unwarranted appearance of legitimacy as far as the more 'macro' conditions of care are concerned.

9.3 From 'total institution' to caring relationships: the significance of rights and entitlements in the regulation of care

In this section, I bring the insights of the interviewees in order to illustrate some of the gaps left by the new legal framework. The debates about "care" in the disability literature (outlined in Chapter 2) as well as the tensions in LTC identified by feminist political economists such as Pat Armstrong (detailed in chapter 4) will be integrated into the analysis. In Chapter 5, I made the case for a close study of the ways in which the government attempted to use social regulation to control quality of care as a policy objective. Then in Chapter 6, I explained that the new legal framework emphasizes resident safety and security as integral to care. The objective here is to identify gaps in the new legal framework regarding care by analyzing the implications of understanding care as rights and entitlements. Here I start by examining the priority given to the safety and security of disabled residents. This topic is chosen because the government has always maintained that resident safety is paramount and the LTCHA is the policy response to resident safety. Disability is clearly implicated in the debate about safety, in particular, the risks around responsive behaviour. Then, I turn to the limitations of a rights-based approach to care.

9.3.1 Emphasis on safety and security of disabled residents

The emphasis on safety and security of disabled residents, including measures to address responsive behaviours, seeks to discourage certain potentially harmful practices, such as the inappropriate use of restraints and anti-psychotic medications. In previous chapters, I have explained why residents may need to be restrained, confined in some way, or put in a locked unit. I have also explained the legal protections in place to ensure these measures are not done in an arbitrary manner. Legal rules, as well as soft law, may be effective at communicating the normative aspects of the prevention of harm in care. However, the effects of legal rules are more indeterminate, and the question of how to recognize and evaluate safety in LTC is more difficult to answer. This section will examine the tension between the safety of all in a home and the liberty of residents. I will then shift to the safety of caregivers, a subject that has received less attention than resident safety but is slowly gaining more recognition. The section will end with a discussion on responsive behaviour.

9.3.1.1 How do we know if residents are safe?

It is not possible to talk about safety in LTC without making reference to the concept of risk. As discussed in Chapter 2, 'risk' has a range of different meanings, and risk and its management are becoming increasingly pervasive features of the contemporary world.[1688] Risk, as Moran puts it, "has increasingly come to occupy a central place in analyses of the regulatory state."[1689] More importantly for the purpose of this research, regulators use risk control as the language to explain and justify regulatory decisions.[1690] One view is that safety-related outcomes in LTC are generally those considered to be largely preventable through close monitoring of risk factors at critical points during care.[1691]

Since the implementation of the LTCHA, the manifestation of risk control and its deficiencies takes a number of forms in public policy debates. In Chapter 4, I mentioned deficiencies in care attracted intense media and public scrutiny. First, reporting on LTC performance, including resident safety, is based on seven indicators: wait times, antipsychotic medication use, falls, physical restraint use, pressure ulcers, pain and depression.[1692] The indicators, which are published by Health Quality Ontario, are supposed to tell us how the LTC system and individual homes are performing in terms of risk reduction in these areas. Second, safety is defined in relation to the presence or prevalence of adverse incidents or events that are deemed to be harmful or tragic, such as abuse and neglect, homicides and suicides. An example is the annual review of homicides in LTC by the Geriatric and Long-Term Care Review Committee.[1693] Third, safety is also described in relation to the government's actions (or inactions) of monitoring, evaluating and responding to risks in homes, including those related to the safety of residents. Examples include the Long-Term Care Task Force on Resident Care and

---

[1688] David Garland, "The Rise of Risk" in Richard V Ericson & Aaron Doyle, eds, *Risk and Morality* (Toronto: University of Toronto Press, 2003) 47 at 50.

[1689] Moran, *supra* note 37 at 407.

[1690] Windholz, *supra* note 50 at 39; Robert Baldwin, Martin Cave & Martin Lodge, *Understanding Regulation: Theory, Strategy, and Practice*, 2nd ed (Oxford: Oxford University Press, 2012) at 292–294.

[1691] Shawna M McDonald & Laura M Wagner and Andrea Gruneir, "Accreditation and Resident Safety in Ontario Long-Term Care Homes" (2015) 18:1 Healthcare Quarterly 54 at 55. Five areas of care considered to be amenable to such risk reduction in LTC are: (1) falls, (2) physical restraints, (3) urinary catheters, (4) pressure ulcers and (5) infections.

[1692] Health Quality Ontario, "Long-Term Care Sector Performance", online: <http://www.hqontario.ca/System-Performance/Long-Term-Care-Sector-Performance>.

[1693] Geriatric and Long term Care Review Committee, *2016 Annual Report of the Geriatric and Long term Care Review Committee* (Toronto: Office of the Chief Coroner for Ontario, 2017).

Safety[1694] and the 2015 Auditor General Report on the Long-Term Quality Inspection Program.[1695] Fourth, safety is also understood and articulated in terms of non-compliance with the LTCHA, such as summary statistics about critical incidents, number of non-compliances identified through annual comprehensive inspections and enforcement actions taken by the Ministry.[1696] These statistics are supposed to tell us which homes are considered "high-risk" and which ones are not. These sources of information were referred to by many of the interviewees and the interviewees' comments should be understood within this context.

Before outlining the themes that emerged from the interviews, I will add that collectively, these sources of information can tell us something important about how safety is understood: residents are safe (or not safe) not just because the intrinsic factors of the residents (e.g. dementia) or the resources available in the home (for example, adequately trained staff to deal with residents exhibiting aggression), but also because of the government's timely and appropriate intervention (for example, in the form of inspections) when there is information about identifiable risks (for example, complaints and critical incidents). The point of contention is how the government should intervene in the name of keeping residents safe. I will return to this point about the government's obligation to intervene later in the chapter.

9.3.1.2 Safety of all vs. Liberty of residents?

In the feminist political economy literature, one issue that is identified as problematic is that the safety and security of residents is prioritized over other needs or preferences of residents.[1697] If understood from a disability perspective, this is indicative of a "cared for" attitude of professionals. Here I will add one more nuance about this tension in the scholarly debate. As explained in Chapter 6, measures to keep residents safe may also restrict their liberty, which in turn contains an autonomy dimension. Implicit in the debate is how a resident's disability is implicated in the justification for restrictions on liberty. A recurring theme in the interviews is the question of where residents can be safe. To prevent serious bodily harm, the

---

[1694] Long Term Care Task Force on Resident Care and Safety, *supra* note 562.
[1695] Auditor General of Ontario, *supra* note 1588.
[1696] *Ibid*; Ontario, Legislative Assembly (Standing Committee on Public Accounts), Official Report of Debates (Hansard), 41st Parl, 2nd session, (26 October 2016); Legislative Assembly. Standing Committee on Public Accounts, *supra* note 599.
[1697] Baines & Armstrong, *supra* note 514; Armstrong & Daly, *supra* note 696.

government's first attempt at legally restricting the liberty of certain residents with the necessary safeguards was through the secure unit provisions included in the original LTCHA (Bill 140).[1698] Those provisions were never proclaimed and have since been repealed by Bill 160 in 2017. That means the home did not really have any statute-based authority to detain residents who attempted to leave the home or to detain residents in the dementia unit (locked unit) within the home for prolonged periods.

The issue of contention is not the existence of such locked units in the LTC system. One elder law lawyer reflected on the rationale for those unproclaimed provisions:

> We fought for those [secure unit] sections to get in because we wanted to protect the rights of people [who] object going in and to have a hearing. We weren't objecting to the fact there were locked units. But [since] you're being detained, you should have some rights to challenge that or ask for a review. But that was fair. That's in the mental health system, how come it's not in long-term care?[1699]

When I asked about the period when there was a gap in the appropriate detention authority (other than common law) to put residents on the dementia unit (or floor), the health law lawyer shared her thoughts on the difficulties facing the home, families and the incapable residents:

> What is the threshold to invoke the common law such that someone can be detained without the authority of the Mental Health Act? Are staff almost always at the threshold of common law authority for that person? (clearly that cannot be the case) . . . By invoking the common law very broadly, we are saying that this whole group of people belong in locked units, and in Ontario there is no real authority at this time to do this.. Right now, there is no authority, and there is no rights advice. There's no rights information.[1700]

Further, it is not clear if consent to live in a locked unit is always properly addressed:

> . . as far as I can tell, the home does not necessarily assess a resident for capacity to consent to live in a locked unit. Homes will say we just do it because the substitute decision-maker said it is okay - even though the substitute decision-maker does not specifically have the authority. To be frank, the adult children of an incapable resident would probably not want anyone from the home to advise the incapable resident that she could not leave and that she could challenge it.[1701]

[1698] *An Act respecting long-term care homes*, 2006 [*Long-Term Care Homes Act, 2007*], s 43.
[1699] Interviewee # 12, (2017).
[1700] Interviewee # 1, (2017).
[1701] *Ibid*.

But the health law lawyer also pointed out that the opposite can be true in some homes by offering the following example:

> a substitute decision-maker wants an incapable resident to roam free. Well, there's a construction site though between here and that corner store. Do you appreciate that your father can fall down the hole? No, he must be free ... Staff of the home ask me what should we do? Should we let him?[1702]

The point is that by not implementing the secure unit provisions in the LTCHA and the complementary provisions in the *Health Care Consent Act*, the implication is that the autonomy of some residents (specifically, those most likely to be living with advanced dementia) has been restricted without due process. That means some decisions about placing residents in locked units could have been made in an arbitrary manner, i.e., possibly inconsistent with sections 7 and 9 of the *Charter*. This also presented an untenable situation to the home, as administrators and health care providers do not have much guidance on the application of the common law duty in particular situations. It is not possible to ascertain how many residents or homes have been affected by the absence of appropriate authority. Regardless of the actual number, my objection relates to too little attention has been paid to protection of the fundamental rights of residents when they are the most vulnerable.

The latest unproclaimed provisions (2017) pertaining to the confinement of residents are unlikely to end the controversies around placing residents in a locked unit (or a confined area). A number of organizations commented on these provisions when Bill 160 was at the committee stage.[1703] The Advocacy Centre for the Elderly provided a legal analysis of these provisions. Some of its objections are worth repeating here. First, the legislation should allow only for the confining of incapable residents; capable residents should only be able to be confined in accordance with the common law.[1704] Second, the test for recommending confinement (where it is only to be recommended where there is a significant risk of serious bodily harm to self and others) conflicts with the principles in the *Health Care Consent Act*. As well, if the issue is

---

[1702] *Ibid*.

[1703] Legislative Library and Research Services, *Bill 160, the Strengthening Quality and Accountability for Patients Act, 2017: Summary of Recommendations* (Toronto: Legislative Assembly of Ontario, 2017) at 21–22.

[1704] Advocacy Centre for the Elderly, *Submission to the Standing Committee on General Government: Bill 160 Strengthening Quality and Accountability for Patients Act* (Toronto: Advocacy Centre for the Elderly, 2017) at 16–17.

potential serious bodily harm to self and others, the care is beyond the scope of a LTC home.[1705] Third, there is no ongoing review process or rights advice for the residents who are being confined.[1706]

My reading of the Advocacy Centre for the Elderly's critique is that there is an underlying tension between the rights of individual residents and the ability of the home to protect the safety of all residents and those who work in the home. Recall that in the civil mental health system, involuntary committal is *primarily* directed to the benefit of the individuals so that they will regain their health.[1707] In LTC, lawful confinement may be recommended if there is a significant risk that the resident *or* another person would suffer serious bodily harm. This begs the question of how much weight we should give to the rights of others when we interpret the rights of those who live with impairment effects and justify any potential restrictions of those rights. One way of understanding this tension is through the debate about "rights as trumps", as articulated by Jennifer Nedelsky.[1708] Recall that rights are understood as triggers for a dialogue of democratic accountability, which works best with a relational approach because it is an optimal way to describe conflicting interpretations of rights.[1709] Then the question is whether we are willing to explore rights that could structure caring relations differently. But first, I will explain how safety is understood if the caregiver experience is taken into account.

9.3.1.3 Are caregivers safe?

In a caring relationship, Herring argues, the interests and identities of the two people become intermingled. Thus, it becomes impossible to consider the welfare or rights of any one party in isolation.[1710] It follows that discussion about resident safety cannot be complete without consideration of the safety of formal and informal caregivers. The intertwined nature of caregiving was evident when the key informants discussed safety in LTC homes. One could

---

[1705] *Ibid* at 17–18.

[1706] *Ibid* at 21–22.

[1707] *McCorkell v. Director of Riverview Hospital 1993* CanLII 1200 (BC SC), *supra* note 1038 at 47. "… A protective statute and a penal statute operate in dramatically dissimilar contexts. Strict and narrow criteria for the detention of persons in a criminal law context reflect our society's notions of fundamental justice for an accused person and protection of the public is a foremost consideration. But in the field of mental health, the same criteria would defeat the purpose of the legislation which is to help seriously mentally ill people in need of protection."

[1708] Nedelsky, *supra* note 248 at 232.

[1709] *Ibid* at 234.

[1710] Herring, *supra* note 112 at 4.

argue that a clear gap in approaching safety in LTC homes is that resident safety and worker safety are addressed separately, often at different policy tables and then regulated by distinct statutes and regulators. As noted above, the Ministry of Labour led the workplace violence prevention activities but MOHLTC is responsible for resident safety and security issues. While the measures to protect resident safety are extensive (at least on paper, as described in Chapter 6), the right to a safe workplace is more circumscribed. One interviewee explained the matter succinctly: "If I'm safe working there, it's safe for you to be a resident there."[1711] There are indications that this separation may be slowly being dismantled.

Just how unsafe LTC homes are from the perspective of caregivers is hard to pin down. In Chapter 4, the feminist political economy literature research findings about workplace violence were outlined. The discussion here adds to that by providing updates on recent initiatives in Ontario. The major labour unions (CUPE, Unifor, ONA, OPSEU and SEIU)[1712] all have launched campaigns to increase awareness of violence experienced by workers in the health care sector. According to the Ministry of Labour, the health care sector represents 11.7 per cent of Ontario's labour market and is the largest sector impacted by violence in the workplace. Violence claims make up 11 per cent of the lost-time injuries in hospitals.[1713]

The union representatives I interviewed reiterated the long-standing problem of violence in the whole health care sector, in other words, not just LTC, although the problem has indeed received more government attention in recent years.[1714] One interviewee provided context for her union's workplace violence prevention campaign:

> … our members say loud and clear [that] they were, for lack of a better word, tired of being punching bags, that violence is not part of the job … They were done with being beaten at work, they were done with being verbally assaulted by

---

[1711] Interviewee # 11, (2017).

[1712] Canadian Union of Public Employees, "Stop the violence against us", (5 October 2017), online: <https://cupey.ca/stop-violence-against-us>; Unifor, *The Unifor Healthcare Council Action Plan 2016* (Unifor, 2016); Ontario Nurses' Association, "ONA – Workplace Violence | Recognize Violence. Report It.", online: <http://violence.ona.org/>; SEIU, "'Break the Silence': Workplace Violence Survey (Anonymous)", online: <https://www.surveymonkey.com/r/breakthesilenceonworkplaceviolence?sm=RiOpAicD7V0uDpGMjEzqDYZZiJm1d%2bdglkawhZtV4kE%3d>; OPSEU, *End Workplace Violence By making safety a priority in mental health* (OPSEU, 2016).

[1713] Ministry of Labour, *News release: Keeping Health Care Professionals Safe on the Job Ontario Moving Forward with Recommendations to Prevent Workplace Violence (May 15, 2017)* (Toronto: Ministry of Labour, 2017).

[1714] Interviewee # 11, *supra* note 1711; Interviewee # 15, (2017).

> patients, their families, and that was what triggered us to have a much more aggressive anti-violence campaign.[1715]

The interviewees expressed the view that violence should not be part of a caregiver's experience and explained factors that contribute to the violence problem. Part of the problem in LTC is that violence becomes normalized: "There's something different about violence in long-term care and it is about the fact that we've normalized it completely… by calling it a responsive behaviour."[1716] Another union interviewee also described their members getting assaulted verbally or physically as daily occurrences.[1717] The union representatives were careful to acknowledge that incidents involving residents should not be normalized neither. Further, they pointed out that the workplace safety solutions proposed by unions also support resident safety.[1718]

The issue of workplace violence has received more attention in recent years and some of the measures undertaken by the government are located outside of formal law. I examine these initiatives as government responses to the problems in the sector. Two initiatives are examined below: the Workplace Violence Prevention in Health Care Leadership Table and the workplace violence portion of the Quality Improvement Plans.

In May 2017, the Workplace Violence Prevention in Health Care Leadership Table released a report that includes 23 recommendations to address the issue of workplace violence in the hospital sector. The Ministry of Labour and the MOHLTC established the Leadership Table to improve workplace safety culture with respect to violence, to reduce violent incidents, and to make health care settings safer for both staff and patients. Initially, the Leadership Table focused on preventing workplace violence against nurses in hospitals; later it expanded its activities to preventing workplace violence against all workers in the broader health care sector. The second phase of the work of the Leadership Table included all workers in hospitals and LTC homes.[1719]

[1715] Interviewee # 11, *supra* note 1711.
[1716] *Ibid*.
[1717] Interviewee # 15, *supra* note 1714.
[1718] Interviewee # 11, *supra* note 1711; Interviewee # 15, *supra* note 1714.
[1719] Ministry of Labour, *supra* note 1713; Ministry of Labour, *Workplace Violence Prevention in Health Care Progress Report* (Ontario: Ministry of Labour, 2017). It does not appear that

As part of Phase 2, a number of resources such as checklists were developed for use in the LTC sector.[1720]

HQO has been using more flexible and non-coercive means to address workplace violence as a quality issue in the health care system. According to HQO, there is increasing recognition that worker safety must be included in the discussion about safety as one of the six dimensions of quality.[1721] As noted in Chapter 8, in the 2017/18 QIPs, the subject of workplace violence prevention was included, with the following instructions: "Describe what steps your organization is taking to monitor, reduce, and prevent workplace violence." The question was not mandatory, and organizations were not provided with specific instructions for answering it beyond the topic and question described above. Therefore, many organizations may not have described the full extent of their work to address workplace violence in their QIPs. Some organizations added specific indicators to track their performance on measures related to workplace violence prevention.[1722] 85 percent of LTC homes addressed workplace violence in their submitted QIPs.[1723] HQO conducted a qualitative analysis of all of the content related to workplace violence prevention in the 2017/18 QIPs.[1724] There was no separate analysis on sub-sectors such as LTC homes, but the HQO analysis did include examples from individual LTC homes.[1725] According to HQO, most organizations described prevention strategies, response strategies, and measurement and reporting strategies. Many organizations mentioned the importance of working in partnership with other sectors, as well as with police services. Further, many organizations described efforts that aligned with legislative requirements, and many described work that exceeded legislative requirements.[1726] HQO encourages "organizations to consider how they can continue moving toward leading practices as they focus on addressing workplace violence prevention through a quality improvement lens."[1727] For 2018-19, all sectors (hospital, primary care, long-term care, and home care) will address this question: "Please

---

[1720] Public Services Health & Safety Association, "Workplace Violence Prevention Resources – Hospital, Community Care and Long Term Care", online: <https://www.pshsa.ca/workplace-violence-leadership-table-4/>.
[1721] Health Quality Ontario, *Workplace violence prevention in the 2017/18 Quality Improvement Plans* (Toronto: Health Quality Ontario, 2017) at 4. See also Health Quality Ontario, *supra* note 1475.
[1722] Health Quality Ontario, *supra* note 1721 at 5.
[1723] *Ibid* at 6. Workplace violence was addressed in the narrative section of QIPs.
[1724] *Ibid* at 7.
[1725] *Ibid* at 12, 14, 16 and 17.
[1726] *Ibid* at 22.
[1727] *Ibid*.

describe how workplace violence prevention is a strategic priority for your organization. For example, is it included in your strategic plan or do you report on it to your board?"[1728] A mandatory indicator measuring workplace violence is included in the QIP for the hospital sector only.[1729]

While it is a positive sign that safety is acknowledged as a dimension of quality that can and should include both patient and workplace safety, the impacts of these initiatives on safety in the LTC sector remain to be seen. First of all, the hospital sector is the first sector to complete a mandatory quality indicator that measures the number of workplace violence incidents reported by hospital workers within a 12-month period.[1730] We will not have quantitative data about prevalence of violence (in terms of incidents) in the LTC sector in the near future. Second, while many resources are available to assist organizations in analyzing data and identifying opportunities for improvement,[1731] there is no reference to factors that may contribute to violence in the workplace, such as inadequate staffing resources and unresolved workplace issues related to racism and sexism (reported in the feminist political economy literature). Third, as HQO stated, the QIP indicator measures the number of reported violent incidents – and workplace violence is known to be underreported.[1732] While building a culture that supports reporting may help collection of baseline data, the reasons for under-reporting are complicated and will need to be addressed.

The interviewees representing unionized workers provided important insights into why critical incidents may be under-reported, including incidents where caregivers are harmed and require medical attention. Their comments help explain why mandatory reporting obligations alone (or reliance on self-reported complaints) may not be very effective in promoting safety of residents and caregivers. According to one union representative, even when the union has communicated to members about their rights (such as rights to refuse unsafe work and whistleblower protections), some frontline workers hesitate to report because they may have language barriers, or may be newcomers to Canada (especially in the GTA). They are afraid to

---

[1728] Health Quality Ontario, *supra* note 1626 at 2.

[1729] *Ibid* at 2 and 7. Each hospital is required to describe its change ideas and associated process measures in the QIP.

[1730] *Ibid* at 2.

[1731] Health Quality Ontario, *supra* note 1626.

[1732] *Ibid* at 3.

speak out because their jobs are everything to them. They may come from a cultural background that does not encourage speaking out and they may simply focus on just doing the job when they are in the LTC facility.[1733] Another union representative added:

> We do have nurses who struggle to question authority and some of it's generational, too. And it depends on how you were educated as a nurse, too . . . we have three distinct sets of nursing education out there. . . then you mix in our internationally educated nurses . . . we're a very diverse, multicultural group, but with a very different skill set, cultural background.[1734]

Two union representatives stated that their members are concerned about retaliation from their colleagues if they report any wrongdoing.[1735] Another union representative explained that while the union really promotes reporting, recording and follow-up, members sometimes hesitate to report because they would be pressed to defend their actions:

> When they report to the employer an aggressive behaviour, or an incident with a resident, the first question to them often is what did you do to provoke this, or how did you approach, the first questions are based on their actions, not on the incident itself.[1736]

The consequences of reporting can be far-reaching for regulated health professionals when they try to speak up to protect a resident and/or advocate for their colleagues:

> . . . the home terminates the nurse for cause. . . The union files a grievance but grievance process takes time. We could assist that nurse in doing a reprisal complaint under the Long-Term Care Home Act . . . the employer has to report that termination to College of Nurses. . . So, that nurse has three, at least, separate processes going on . . . If you know this is the risk, why would you do that unless it was something big and bad like sexual abuse, or big or bad like you had to transfer somebody to a hospital? The normal stuff, the stuff that they've normalized, I don't think gets reported hardly ever.[1737]

To conclude, despite being touted by the government as the solution to many problems in the LTC sector, the LTCHA has its limitations as far as worker safety is concerned. On the one hand, the actual results (based on medical and clinical data) are mixed: while a few safety-related quality indicators have improved, incidents involving residents have persisted.[1738] This may be indicative that existing hard law and soft law are having some influence over the behavior of

---

[1733] Interviewee # 9, (2017).
[1734] Interviewee # 11, *supra* note 1711.
[1735] Interviewee # 9, *supra* note 1733; Interviewee # 11, *supra* note 1711.
[1736] Interviewee # 15, *supra* note 1714.
[1737] Interviewee # 11, *supra* note 1711.
[1738] Geriatric and Long term Care Review Committee, *supra* note 1693.

caregivers as the strengthened regulatory requirements correspond to those indicators. On the other hand, the issue of safety, if understood as encompassing resident and caregiver safety, requires more work beyond the LTCHA. Next, I turn to how disability is used to structure the understanding and response to safety related issues.

9.3.2 **Responsive Behaviour – what's in a name?**

As explained in previous chapters, the new legal requirements in the LTCHA reflect in some limited way the idea that the environment can be disabling and the focus should be on the accommodation of differences including those related to disabilities.[1739] Changing the environment can mean others have to – though not always - adjust to the disabled person, not the other way round. The importance of having assistive devices available in the home, of consideration of communication barriers in care and of assistance with Activities of Daily Living should be self-evident. The LTCHA represents a small step towards tackling the barriers stemming from the interaction between multiple impairments (including cognitive impairment) and an institutional environment that was not originally designed for the types of residents we have today. This is particularly important for those living with advanced dementia because the stimuli in the environment (e.g. noise) can be triggers for their responsive behaviour. The danger is that disability is used as a justification for lawful interference with the body (person). At the root of the problem is that the health care system in Ontario is ill-equipped to respond to the cumulative effects of aging and age-related impairments.

A positive step in the new legal framework is the change in the legal language to talk about the needs of those who live with certain types of impairment (although the LTCHA does not actually say dementia) and exhibit behaviour issues. However, the expression "responsive behaviour" also comes with its own set of difficulties. My interviewees were all aware of the practical challenges while firmly rejecting stigmatization of those who exhibit behavior issues. According to one union representative,

> when you give the growing violence in LTC a nice name like a responsive behaviour, it makes it more normalized and more acceptable than calling it what it is, which is violence perpetrated against somebody else, it just is.[1740]

[1739] Lai, *supra* note 637.

[1740] Interviewee # 11, *supra* note 1711.

She then added an important insight about how violence affects everyone in a caring relationship,

> not every dementia patient has responsive behaviours as aggressive, not every mental health patient will be aggressive, it is a subset of them. My struggle with the word responsive behaviours is just that it minimizes the impact it has on everyone around them, and I don't think we should stigmatize these residents … There has to be a way for people to know who are those residents . . . the term responsive behaviour also takes away from how other people get to protect themselves and at least be alerted to risk."[1741]

As one elder law lawyer explained:

> the responsive behaviour language is really trying to get away from that blaming of the resident ... I don't think the term responsive behaviour diminishes the actual difficulties of dealing with that . . . it is to really bring attention to the fact that the staff have to watch out, that they have to manage the situation. And staffing should be sufficient to meet those needs, to also protect the staff, because it's extremely challenging to take care of some of these people.[1742]

My interviewees also had very different views about the actual impact of recent efforts to improve the LTC system's responses to residents' responsive behaviours. Medication management, use of physical restraints and responsive behaviours are closely related issues and recognized as such in hard law and soft law. One industry association representative explained that "Homes have been involved in antipsychotic reduction, long-term care physicians have been involved, so there's been a huge, huge push, so everybody is catching up on reducing antipsychotics."[1743] According to the representative from the Ontario Long-Term Care Clinicians (OLTCC),

> one item that's been big in the news over the last few years has been antipsychotic use without an indication in long-term care and there's been a successful effort to reduce the number of antipsychotics that are prescribed without an indication. There are four or five specific indications. It's not that all the prescriptions outside of those four or five indications are inappropriate, it's just that it is a measure.[1744]

One union representative cautioned that the picture may be more complex than it appears and expressed reservations about the sustainability of the recent efforts to reduce the use of antipsychotics:

[1741] *Ibid*.

[1742] Interviewee # 12, *supra* note 1699.

[1743] Interviewee #10, (2017).

[1744] Interviewee # 4, (2017).

> . . . our nurses will tell you, because of the push by government to get rid of the antipsychotic drugs, what happens is it’s a horrible, vicious cycle. The doctors will order antipsychotic drugs and get the behaviours controlled. Sadly, the resident will have not a lot of quality of life because of the horrible side effects of antipsychotic drugs, but the people around that resident are safe and the resident is safe from harming themselves. But then there's this push to take the antipsychotic drugs away, so then the doctors start weaning them off. And at first, the residents are okay … then something will trigger them and they’ll be back on the drugs and we’ll do the cycle again. But in the meantime, they could hurt someone, or themselves again.[1745]

Interviewees continue to be critical of or at least acknowledge the limitations of how our current health system responds to the complex needs of those experiencing severe cognitive and other impairments in LTC, despite the legal safeguards in place to protect residents and caregivers. One union representative explained how some LTC residents may be unwanted at different points of care:

> . . . what our homes are saying is they [cognitive impaired residents] do need acute care. They need acute care to bring these conditions back under control, at which point, then they should come back to long-term care. But what happens is they go over here [hospital], a psychiatrist sees them, gives them an antipsychotic med, puts them right back in an ambulance because they know if they keep them, they’ll never get them out of the building again. Our nurses tell us it’s futile to send them to hospital because they're only going to be back in three hours and pissed off because they got taken somewhere.[1746]

The elder law lawyer recounted examples of former LTC residents being “dumped” (or discharged) by their homes, and further explained that homes could still use various legal devices (such as Form 1 under the *Mental Health Act* and leave provisions in the LTCHA) and there are few remedies – legal and otherwise – for her and her clients: “There’s almost no remedy. That’s the problem.” [1747]But she was also careful to point out the importance of advocacy:

> This is the world of elder law. We try to find little hooks in something. . . Often when we were involved, because they [hospitals and LTC homes] knew we were lawyers, we also went to the mat for our clients, a lot of things worked out. But think of the people who don’t have the lawyers to find all those little nuanced arguments. They wouldn’t get anywhere. I think some places would concede to us, because they said, it’s only ACE [Advocacy Centre for the Elderly] and they only get a few clients . . . And they didn’t want us to go into courts . . . But they

---

[1745] Interviewee # 11, *supra* note 1711.
[1746] *Ibid*.
[1747] Interviewee # 12, *supra* note 1699.

> knew we were free. We would argue it, potentially argue it. They may have given up.[1748]

The final point is that interviewees also discussed the limited potential of and problems with the LTCHA in relation to responsive behaviours. They are similar to the criticisms about regulation expressed in the feminist political economy literature. One industry association representative remarked:

> The provisions are … not really designed to meet the needs of residents. . . the provisions are fine . . . they are just basic provisions. Have a program, make sure you've got goals. They do the PDSA [Plan-Do-Study-Act] cycle on all of their programs. You must have a program, you must implement it, you must evaluate it, you must fix it and you must do this on an annual basis. That's basic, there's nothing extraordinary in that.[1749]

One union representative commented on the prescriptive nature of the LTCHA in relation to the individual needs of residents:

> Some of the triggers in long-term care, we can't fix. . . If the trigger for me is it's too noisy and I'm in one of these 32 bed ward units, and when I go to have lunch there's 31 other people plus staff sitting in that area, what does that look like? . . . And some of this is really difficult because of how restrictive the Long-Term Care Homes Act is.[1750]

She further elaborated how difficult it is to provide individual care:

> . . . Where do you take me and another staff so the home still meets that requirement of feeding me within the prescribed hours and I'm supervised? . . . We hear this all the time that they [Ministry] wrote the Act as prescriptive as it is because people just weren't doing the right thing. But they've also now tied operators' hands and caregivers' hands so tightly, it's almost impossible to make the exception for one person.[1751]

9.3.3 **Limitations of a rights-based approach to receiving care**

To wrap up the analysis of the significance of rights and entitlements in the regulation of care, I will present some of the limitations of and tensions around residents' rights that emerged from the interviews. Disability scholars such as Tom Shakespeare and Marta Russell have raised objections to a focus on civil rights which implies a liberal solution to disability.[1752] Relational

---

[1748] *Ibid*.

[1749] Interviewee #10, *supra* note 1743.

[1750] Interviewee # 11, *supra* note 1711.

[1751] *Ibid*.

[1752] Shakespeare, *supra* note 130; Marta Russell, "What Disability Civil Rights Cannot Do: Employment and Political Economy" (2002) 17:2 Disability & Society 117.

theorists such as Jennifer Nedelsky and Johnathan Herring also pose constructive questions about rights and an individualistic understanding of the person.[1753] As explained in Chapter 5, the Residents' Bill of Rights reflects the fundamental rights that residents possess as citizens as well as service rights while they remain in the home. Equally important, the home has a duty to ensure that it is a safe environment. In addition, the LTCHA also provides for a number of participatory rights to residents and families as a collective by way of Family Councils, Residents' Councils and other mechanisms (which will be addressed later in this chapter). An obvious criticism of rights in LTC is that the LTCHA does not actually confer any resident rights to minimum care in the form of number of hours of direct care or staff-to-resident ratio standard, a frequently argued point in the feminist political economy literature.[1754] I will address some of these structural issues in the last part of this chapter. I do not question the importance of the existing rights but want to highlight some of the difficulties of interpreting and applying these rights in homes and to explore how some participants in the sector respond to those difficulties. I will revisit the issue of asserting rights in legal forums later in this chapter in the section on access to justice.

9.3.3.1 Implementation of rights

One critique of rights in LTC homes generally (not just in Ontario) is that these rights are too abstract and peripheral, and obscure to the everyday struggles that many people in LTC homes have to undergo.[1755] "Not all rights imputed to old people living in nursing homes can actually be exercised by them or, more importantly, are central to their day-to-day life. Some rights are simply too peripheral or require interests that nursing home residents seldom possess."[1756] Here I will attend to some of the "subtle concrete complexities"[1757] associated with living in LTC homes and its linkage to exercise of rights.

Despite the fact that the Bill of Rights has existed for a long time (with various amendments over the years), there are strong indications that its implementation is still a

---

[1753] Nedelsky, *supra* note 1492; Herring, *supra* note 245.

[1754] Choiniere et al, *supra* note 515 at 45; Braedley & Martel, *supra* note 678 at 65.

[1755] George J Agich, "Respecting the Autonomy of Old People Living in Nursing Homes" in *Health care ethics: critical issues for the 21st century* (Sudbury, Mass: Jones and Bartlett Publishers, 2009) 184 at 186–187.

[1756] *Ibid* at 187.

[1757] *Ibid*.

problem on the ground. The elder law lawyer offered her insights with respect to how homes may interpret the rights in the Bill of Rights by referring to the experience of her previous clients. She used the example of the right to have visitors and meet people in private to illustrate how a right may be interpreted independently of other rights and duties, rendering it devoid of connection to the actual circumstances of residents:

> A client whose husband was coming every Friday night to see his wife. He'd close the door. And then she'd scream. He was forcing himself on her. The home originally said she has a right to visitors. This woman was totally incapable and he was just using her as a sexual object. The home has a duty to protect her. But the home asserted that there was nothing in the Act that really said that.[1758]

The elder law lawyer then pointed out to the home the provisions on abuse prevention:

> They [the home] don't understand there's a whole body of law about duty to protect. And it's there. But it's not exactly in it. So, they interpreted this, she has a right to have visitors. Well, you also have the duty to protect. The provisions work together. No, they're not trained. They're not taught that stuff.[1759]

The existing rights may be premised on oversimplification of potential harms in a home. The Bill of Rights and other provisions such as altercations between and among residents are intended to create boundaries around residents so that they can be protected from their caregivers or other residents who experience cognitive impairments. Less attention has been given to situations where incapable residents are intentionally harmed by other, more capable residents. The elder law lawyer remembered an elderly woman client who ended up in a LTC home.

> She was extremely passive due to her dementia. She had never had sex with anybody other than her spouse. Six men were having sex with her on a regular basis. She did not know what was going on. The home thought this was fine because she was not screaming. When the daughter found out a couple of months into her mother's residency, she pulled her mother out of there immediately. The home wasn't protecting the resident from sexual assault . . . These men were capable ... they [the home] really have a duty to protect people who can't consent.[1760]

At the same time, it is useful to consider the possibility that homes may have real difficulties in applying several rights in particular situations. One lawyer representing homes provided important insights into how homes interpret the rights of residents when their capacity

---

[1758] Interviewee # 12, *supra* note 1699.

[1759] *Ibid*.

[1760] *Ibid*.

may be in question and there are competing rights. And then, Ministry inspectors may bring their own interpretations of the factual situations.

> I've come across situations where a resident may be forming an intimate relationship with another resident, one of whom has a mild to moderate cognitive impairment. In these instances, homes struggle with assessing whether the resident who has some level of cognitive impairment has the capacity to make their own decisions about their sexuality. Homes are required by their governing legislation to protect residents from sexual abuse, but they are also obliged to fully respect and promote friendships and relationships between residents. There have been contradictory findings amongst Ministry inspectors about what homes must be doing in such circumstances. One inspector might find that the residents had a right to pursue the relationship, and a different inspector may say there was an obligation to protect the residents from abuse and the home should not have allowed that relationship to develop. This is one example of the competing rights and obligations which homes may face. In two instances, I've had Ministry inspection orders rescinded at the Director level because it's a very grey area.[1761]

When asked about whether there are any particular rights that people have more difficulty understanding and implementing, the Ontario Association of Residents' Councils (OARC) representative felt that subjective rights can be tricky:

> We're treating people with dignity and respect, for example. What does that look like? What does that feel like? . . . An example is if a resident wishes to walk and they can walk, but if the staff members put their walker on the other side of the room, it can give the message to that resident that your independence and your ability to take personal risks is less important than our ability to protect you. So, there's a balancing of personal risk and personhood. It's recognizing the person as a whole, that they have the ability to make decisions for themselves.[1762]

The right to privacy is also tricky in a congregate setting:

> You have the right to privacy. If you're living amongst residents who are living with cognitive changes, you most likely will have people coming into your room, touching your things. That kind of thing is something that new residents are often horrified by.[1763]

But she pointed out a more fundamental challenge in terms of recognizing the rights of residents, especially those who experience more profound cognitive changes:

> It's difficult for staff members sometimes to view that person as a whole person, because they're meeting them in a state where dementia has led them down that journey where they have expressive behaviours, etcetera. To see that person as a whole human being — and again, that's around dignity and respect and valuing

---

[1761] Interviewee # 18, (2018).
[1762] Interviewee # 14, (2017).
[1763] *Ibid*.

> the person as a whole — is very tricky when you're working with people who have dementia and can't speak for themselves.[1764]

A lawyer representing homes provided more examples of practical difficulties with reconciliation of various rights in the Residents' Bill of Rights. The difficulty is not always about the home or caregivers refusing to acknowledge a particular right. One of the examples concerns the right to make lifestyle choices, which must be reconciled with the resident's right to share a room with a roommate in accordance with their mutual wishes:

> I had a situation in which two residents – one male and the other who was born of the male sex but identified as female – shared a room. The resident who identified as female began openly dressing as a woman and wished to be addressed as a woman. Their male co-resident had great difficulty understanding and respecting these choices – he felt he could not explain the situation to his visitors (including grandchildren) and requested a different roommate. As a long-term care home, it is difficult to respect one resident's gender identity and expression, and reconcile that with the right of another resident to share a room with another resident according to their mutual wishes. Who, if anyone, do you relocate in these circumstances? Respecting beliefs and lifestyle choices, and accommodating transgender residents, can be a challenge in long-term care homes.[1765]

Finally, it is not easy for residents and families to demand remedies for violation of rights *ex-poste*. As explained in Chapter 5, the LTCHA allows residents to enforce the Residents' Bill of Rights as if a contract has been entered into between the resident and the home. The elder law lawyer explained the rationale of such a private right of action. This idea of enforcing residents' rights like a contract came from American legislation. She was very practical about the utility of such a right:

> It's important to have that in the Act, because you never know where there's going to be a case where you'd want that. You don't want to be totally dependent on the inspection system. You want the private right of action, because something could happen. And I predict it might happen someday in the future, because now the tighter and tighter and tighter the resources you have, the more likelihood you've got some people looking at litigation.[1766]

The prospect of actually using litigation can be summarized as follows:

> Whether anybody has used that? I can tell you if we hadn't sued people on it, it's unlikely you're seeing any actions on that. And even if people do start an action, it will be settled very quickly, because the homes would be foolish to let

---

[1764] *Ibid*.
[1765] Interviewee # 18, *supra* note 1761.
[1766] Interviewee # 12, *supra* note 1699.

> somebody go through with the private right of action. It's cheaper just to settle it. It's typical civil litigation.[1767]

The elder law lawyer's view is similar to Herring's view about legal interventions. Herring suggests that although there are reasons to be wary of legal interventions, it would be wrong to dismiss their role entirely.[1768] The availability of credible threat is an important tool in the toolbox:

> I want it to be retained in there, but we never thought it would even be that useful. It's a good threat. As an advocate for those clients, we wanted to know that we had that ability if we had to pursue something.[1769]

9.3.3.2 Practical and concrete ways to respect rights

LTC participants, for example residents and advocates, are also taking their own initiatives to safeguard those rights on the ground and explore non-legal means to make those rights meaningful in their own local settings, considering the particular problems of their own constituencies. The description below resembles in some way Nedelsky's idea of rights understood as triggers for a dialogue of democratic accountability – but in a caring relationship setting. An example is the "Through Our Eyes: Bringing the Residents' Bill of Rights Alive", led by the OARC. This program is intended to guide LTC home teams of staff members and residents to co-develop and co-facilitate education sessions about the LTCHA's Residents' Bill of Rights. It is emphasized that residents living with cognitive changes can participate in the development and delivery of the education. Participants are challenged to re-examine how rights education is developed, who is involved in the process, and the program ties all efforts back to the lived experience of residents.[1770] I asked the OARC's executive director for background and context of this program and she pointed out that based on discussions from a focus group, it was evident that there was a disconnection between the lived experience of residents and the actual education about the Bill of Rights:

> There was so much education being poured into the annual mandatory core education for staff members, but behaviour, generally speaking, was not

---

[1767] *Ibid*.

[1768] Herring, *supra* note 1678 at 283.

[1769] Interviewee # 12, *supra* note 1699.

[1770] Ontario Association of Residents' Councils, "Through Our Eyes: Ontario Association of Residents' Councils", online: <http://www.ontarc.com/through-our-eyes.html>; Ontario Association of Residents' Councils, *Seasons (Spring)* (Toronto: Ontario Association of Residents' Councils, 2017). The program provides educators with a step-by-step guide, videos, exercises and resources to develop the education.

> changing. . . It's because the training was theoretical, there was no personal connect to the information. And part of that is, again, culture change, where well-meaning, professional caregivers do to a resident, as opposed to engaging with a resident. So, we had a brainstorming session, and we thought if residents are invited to be part of the solution, then what does that look like?[1771]

She elaborated:

> As soon as you can make that personal connection to a resident and their lived experience and how it feels to them to be treated in a certain way or to witness certain actions or behaviours or messages around them, that's when the light bulb went off.[1772]

The realization of rights of families and friends also present its own difficulties. Legal recognition of a particular type of participation mechanism or process does not always automatically produce meaningful collaboration and engagement. Legal recognition is best described as the beginning of an on-going dialogue to implement collaboration and engagement in response to the specific conditions in the home. The Family Councils Ontario (FCO) stated that the LTCHA is not a perfect piece of legislation but it provides an important framework and important powers to family caregivers through the Family Council.[1773] However, the practical reality of organizing a Family Council cannot be underestimated. According to the FCO, one of the challenges, is working with the administration of the home:

> Because Family Councils' membership changes a lot, the home needs to be able to help Family Council come together and often that's a difficult thing for the home, it's not in anybody's job description particularly. Often it's a matter of the home putting up a poster saying if you want to have a Family Council, go ahead or contact the activation coordinator.[1774] Often Family Councils will be talking about a particular care issue, or something within the home that they're concerned about and the home may or may not be able to respond to that concern, or fix it. The communication then breaks down and it can become a real point of contention for both the council and the staff.[1775]

The FCO also reflected on its mandate and role, and identified the need to work with the home in order support Family Councils properly. FCO explained that its mandate is to support Family Councils and family members. However, to better support family engagement in LTC homes, the organization has shifted its focus from solely engaging families to also supporting

---

[1771] Interviewee # 14, *supra* note 1762.
[1772] *Ibid*.
[1773] Interviewee # 2 and 3, (2017).
[1774] *Ibid*.
[1775] *Ibid*.

LTC home staff to understand the great value of Family Councils and to help Family Councils come together.[1776] Although the LTCHA is clear that the administration of the home must cooperate with the Family Council, it is evident that successful implementation of Family Councils requires more than just legal recognition. It is not a question of the administration of the home being unhelpful or obstructive (although that is possible too), families and friends can also have difficulties running a Family Council that accomplishes its legal mandate. I will return to the topic of Residents' Councils and Family Councils later in the chapter.

On its own, having strengthened mechanisms to promote a sense of inclusion and participation will not resolve the more pressing issues facing the sector today, such as extensive wait times, inadequate resources for those living with advanced dementia, and precarious care work. Far from it. More important, and perhaps even more difficult, is the task of teasing out the fundamental values that these processes are intended to nurture and examining what barriers exist to prevent them from functioning properly. I will return to the theme of meaningful participation later in this chapter.

9.3.4 **Summary**

Care conceived as rights and entitlements can change the conversation about the needs of residents: instead of being labeled as passive care recipients being managed by their caregivers, residents are considered to be bearers of rights. One could conclude that the changes to regulation and governance still reflect the assumptions of a medical model of disability, but have incorporated elements that are consistent with Shakespeare's interactional model of disability. The discussion here also draws on the work of Herring and Nedelsky in order to set out what care in LTC is like if we consider all of those who are in caring relationships. There is also clear skepticism towards formal law and government agencies as the protectors of residents' and formal caregivers' rights and needs. In short, there is a clear gap between the promise of rights and their realization. This gap is created by the ways in which policy, financial and operational decisions are made and by whom. This leads me, in the next section, to take a step back and add some remarks about the governance of the sector.

[1776] *Ibid.*

9.4 The Significance of New Governance approaches

While many regulatory requirements are indeed dedicated to describing how care is to be provided, another group of regulatory requirements is intended to create processes and procedures. While they may not have any immediate impact on the nursing care provided or activities of daily living of residents, these requirements can influence the "conditions of care" (as used by Armstrong and others) and caring relationships within the home. They go hand in hand with other changes to the governance of the sector, backed by various degrees of legal formality. The discussion below is also informed by the limits of protections offered by conventional law discussed in the previous section. While the precise issues addressed in the previous section may appear to be very different than the ones being addressed in this section, the common thread is how law is both a problem and solution at the same time. The law here sets parameters about governance in the form of processes and procedures. Here, I proceed from the assumption that it is prudent to examine whether participants in the sectors are actually using these strengthened or new procedures. It is important to understand the inherent limitations but it is equally important to avoid the mistake of thinking that these processes are completely irrelevant.

There are many changes to processes and procedures mandated by law that represent a re-orientation of how problems in the sector are to be solved. As noted in Chapter 2, to paraphrase various scholars in the regulation and governance literature such as Lobel, regulation is about problem-solving. I am not suggesting that there is a complete departure from state-centred approaches, because as Jason Solomon puts it, regulatory design rarely occurs on a blank slate.[1777] I now turn to the question of what these processes mean for the governance of the sector, in particular, the changing boundaries between the public, private and non-profit bodies that make up the sector. The analysis here is informed by a larger scholarly debate about shifting relations of power and shifting boundaries between public and private that make up the state itself.[1778]

[1777] Solomon, *supra* note 309 at 624.

[1778] Parker, *supra* note 68 at 6.

The governance-related changes will be analyzed with the arguments and counter-arguments in the New Governance literature. The objective here is to use the prescriptions of New Governance scholars to categorize these changes and examine their significance in terms of problem-solving. The discussion here is intended to contribute to the concept of problem-solving as a continuous activity[1779] by expanding on who are involved, how are they involved and why. I explore what types of problems are being addressed by these mechanisms. It should not be surprising that given the "quality of care" discourse (see Chapter 4), many of these mechanisms are linked to quality.

I have described examples of the manifestation of New Governance approaches in the LTC sector elsewhere. I argued that these approaches are not about de-regulation; in fact, they are created and sustained by law. They are about strengthening or creating additional processes and procedures for participants—homes, residents, families, advocacy groups, industry organizations and government—to problem-solve challenges in the sector.[1780] The government maintains and gives itself as much discretion as possible over structural issues in LTC, such as the capacity of the system, overall funding levels to the sector and working conditions. Here, I will expand on this point about problem-solving by adding more recent approaches that are consistent with New Governance principles. I will then point out what other developments in the sector deviate from New Governance principles.

Despite a generally more prescriptive legal regime, it is evident that additional processes and procedures of various degree of legal formality, are in place to facilitate problem solving. This period is also marked by the appearance of new (or transformed) actors in the health care system, some are permanent organizations created by statutes or other instruments, but some are short-term bodies created to carry out particular tasks. All are located outside of the provincial government, but still work closely with the provincial government. Some of these processes and procedures concern the workings of internal organizations, while others are intended to facilitate relationships between stakeholders. These developments are significant for residents, their families and friends. Together, with the additional non-state actors, the processes and procedures

---

[1779] Simon, *supra* note 321 at 179.

[1780] Lai, *supra* note 1425.

represent new ways of understanding and solving problems in the sector. The table below summarizes New Governance approaches and their corresponding examples in the sector:

Table 29: Manifestation of New Governance principles in the LTC sector

New Governance principle	**Examples in the LTC sector**
De-centralization	• Implementation of regional health authorities (LHINs) • Behavioural Supports Ontario • Health Quality Ontario
Participation of non-state actors	• Long-Term Care Task Force on Resident Care and Safety • Workplace Violence Prevention in Health Care Leadership Table • Ministry's obligations to post information
Flexibility and non-coerciveness (softness in law)	• HQO's quality standards • Guidelines issued by professional associations, some financially supported by public funding
Collaboration and collaborative process	• Residents' Councils and Family Councils • Home's obligation to consult residents, families etc on its mandate • Requirements to post draft regulations • Consultation requirements with respect to licensing
Fallibility, adaptability and dynamic learning	• Quality Improvement Plans (submitted to HQO) including involvement of Residents' Councils and Family Councils • Quality improvement and utilization review system • Quality indicators published by the HQO • Satisfaction surveys • Resident Quality Inspections
Enforced self-regulation	• Enhanced legal protections for whistleblowers • Immunity for Residents' Councils and Family Councils

New Governance principle	Examples in the LTC sector
	• Formalized evaluation requirements for various programs mandated by the LTCHA • Mandatory reporting obligations imposed on homes and staff, volunteers and family and friends

9.4.1 Who are the new (or transformed) problem-solvers?

For Lobel, "the new model [New Governance] is better positioned to accept uncertainty and diversity, advancing iteratively toward workable solutions. The role of law is to promote practices that allow revision and improvement."[1781] Problem-solving responsibilities are more diffuse and not always clear. It is evident that in the LTC sector there is a gradual transfer of problem-solving responsibilities to localities and to the private sector, including to private businesses and non-profit organizations. The provincial government continues to retain regulatory functions and to set strategic directions for the health care sector, however operational decisions, such as managing performance relationships with providers, are also made locally. In Chapters 5 through 8, I have made frequent references to the work of Health Quality Ontario (HQO); obviously it is one of the new problem-solvers. Next, I will highlight the work of the LHINs and Behavioural Supports Ontario (BSO).

9.4.1.1 LHINs

The establishment of the LHINs under the *Local Health System Integration Act*[1782] is the most obvious example of decentralization. Not only are the LHINs managing accountability relationships with the homes, and in some cases, assisting MOHLTC to deal with compliance issues, they also play an important role in the delivery of health services, in the form of planning and co-ordination. The LHINs are now responsible for negotiating and executing Long-Term Care Home Service Accountability Agreements (LSAAs) with individual homes as per the *Local Health System Integration Act*. This process can be hailed as an example of New Governance as the process is decentralized and involves ongoing participation of non-state actors. The LSAA

[1781] Lobel, *supra* note 319 at 396.

[1782] *Local Health System Integration Act, 2006, supra* note 591.

Advisory Committee provides advice to and supports the development of the LSAA template agreement, as well as schedules and tools to ensure alignment with provincial strategic directions and streamline processes. The Committee comprises representatives from homes, industry associations, Association of Municipalities of Ontario (AMO), MOHLTC, LHINs, and various municipalities.[1783] A Work Group has been established to support the Committee. This Work Group comprises representatives from the LTC sector, including leadership from various homes, industry associations, MOHLTC, LHINs, and various municipalities. Based on direction from the LHIN CEOs, the Work Group produces documents and recommendations.[1784]

The LHINs are also involved in managing the performance of homes in terms of compliance. In the 2015 Auditor General report, one finding was that while inspection results for homes with longstanding problems were provided to LHINs, such results were not used by LHINs to monitor the performance of homes through their service accountability agreements. Instead, LHINs rely on the Program Director of MOHLTC to take actions whenever the Director considers it necessary to do so. The Ministry agreed that it should review the roles and responsibilities of the LHINs with regard to the use of inspection results in monitoring the performance of long-term-care homes.[1785] At a standing committee meeting, the MOHLTC emphasized how a LHIN would be invited to the meeting with a home with significant non-compliance issues:

> . . . we have a protocol whereby we are engaging with the LHIN locally prior to meeting with the licensee to talk about the issues that we've identified in that home, and talk about anything that the LHIN may be seeing on their side—any concerns that they may have. What we do is set up a meeting with the licensee. The LHIN is invited to that so that they can be a part of that discussion and then part of that quality improvement journey going forward, because they obviously have a real commitment and interest in well-being and making sure that those homes succeed. So we involve them at that level.[1786]

9.4.1.2 Behavioural Supports Ontario (BSO)

The extent of de-centralization also intensified on the program delivery front. Consider the example of Behavioural Supports Ontario (BSO), which is not managed centrally at the Ministry.

[1783] LHINs, *LSAA Indicator and Schedules Education Session Fiscal 2018/19* (2017).

[1784] *Ibid* at 8. The group is called the LSAA Planning and Schedules Work Group.

[1785] See Section 3.8 "Long-term-care Home Quality Inspection Program" of the Auditor General Report. Auditor General of Ontario, *supra* note 1588 at 386.

[1786] Ontario, *Official Report Journal of Debates (Hansard) Wednesday 26 October 2016*, *supra* note 1696 at 27.

As discussed in Chapter 6, one of the changes incorporated into the LTCHA is the responsive behaviour provisions. These provisions obligate the home to take steps to understand the meanings behind residents' behaviours and to address the needs of residents. More intense monitoring and documentation are also provided for.[1787] However, the LTCHA does not spell out the particular entitlements, supports and services to be provided to residents with responsive behaviour or their formal and informal caregivers. The programming part (via fiscal transfer) comes in with the launch of the Behavioural Supports Ontario. In 2010, the Ministry announced $40 million in funding toward the development of an evidence and experience-based framework to enhance the availability of supports and services to persons living with responsive behaviours.[1788] In 2016, Ontario increased base funding to Behavioural Supports Ontario to $54 million.[1789] Behavioural Supports Ontario provides services to individuals living in LTC homes, independent living settings and acute care environments.[1790] According to the Ministry, the techniques and methods used as part of this initiative in LTC have helped contribute to lower rates of anti-psychotic drug use, of injury to staff and to lower use of restraints.[1791]

The governance of BSO reflects the principle of de-centralization. When BSO was launched, leadership was provided by a Northern LHIN, Health Quality Ontario, the Alzheimer Society of Ontario, the Alzheimer Knowledge Exchange (AKE) (now called the brainXchange) and MOHLTC. As of April 2015, a provincial coordinating body to support and facilitate the work of the initiative re-emerged. The Provincial Coordinating Office is currently located in Northern Ontario.[1792] One notable feature of the BSO committees and advisories is that while MOHLTC staff participate as members or make presentations at meetings, all the committees and advisories are chaired by staff from the LHINs, BSO, Health Quality Ontario or the health

---

[1787] Reg 79/10, *supra* note 811, ss 53 and 55.

[1788] Behavioural Supports Ontario, *supra* note 1150.

[1789] Ministry of Health and Long-Term Care, *News release: Ontario Investing Additional $10 Million to Enhance Behavioural Supports Program* (Toronto: Ministry of Health and Long-Term Care, 2016); Ministry of Health and Long Term Care, *supra* note 613.

[1790] Michelle Grouchy, Tommy Wong & Nancy Cooper, "Implementation of Behavioural Supports Ontario (BSO): An Evaluation of Three Models of Care" (2017) 19:4 Healthcare Quarterly, online: <http://www.longwoods.com/content/25013> at 69.

[1791] Ministry of Health and Long-Term Care, *supra* note 1789.

[1792] Behavioural Supports Ontario, *supra* note 1150; Behavioural Supports Ontario, *Behavioural Supports Ontario Annual Report 2016-17* (North Bay: Behavioural Supports Ontario, 2017) at 36–37.

sector.[1793] But at the same time, BSO has reporting or information sharing obligations to MOHLTC.[1794] At a standing committee meeting, a government official also claimed that "[t]he ministry maintains strong engagement with BSO stakeholders, including the BSO Provincial Coordinating Office and … the lead LHIN for BSO."[1795]

Further, according to the Ministry, as part of their mandate for local system integration and planning, LHINs are accountable for embedding and sustaining the BSO Framework and the management of the ongoing BSO allocation. Each LHIN has established "unique and locally appropriate service models."[1796] At a standing committee meeting, a government official insisted the BSO is flexible, local and constantly improving:

> We really left it to the LHIN[s] to design how this should be implemented on the ground in concert with their mandate… All of the LHINs have developed locally appropriate implementation plans, and I'll also go further to say they're constantly refining those. As the populations change or as the needs of their providers change, they're constantly tweaking it.[1797]

According to one study, there was wide variation in the allocation of funds, based on demographic and population health statistics related to the over 65 and "at risk" population in each LHIN. Each LHIN then determined its own implementation of the BSO program and rolled-out different models, training and support for BSO staff, and focused on different partnerships among health service providers and community agencies.[1798] By 2015, three distinct BSO models were operating within the LTC sector.[1799]

While funding still comes from the MOHLTC (as central authority), decisions are also made locally. The LHINs have a lot of flexibility to determine how the BSO is structured. Each LHIN makes decisions according to "local" conditions. But the pitfall is that there are variations

---

[1793] Behavioural Supports Ontario, *supra* note 1792. The governance structure of the Behavioural Supports Ontario includes: Triple LHIN Senior Advisory, Steering Committee, Operations Committee, Systems Performance & Evaluation Advisory, Knowledge Translation & Communications Advisory, and Lived Experience Advisory.

[1794] Behavioural Supports Ontario, *Behavioural Supports Ontario Annual Report 2015-16* (North Bay: Behavioural Supports Ontario, 2016); Behavioural Supports Ontario, *supra* note 1792 at 12–13. For example, throughout the fiscal year, all 14 LHINs submitted their quarterly activity tracker data to be collated by the Provincial Coordinating Office prior to submission to the MOHLTC. BSO Activity Tracker Data captures the work of BSO-aligned staff, such as number of referrals, number of residents supported and number of family members supported.

[1795] *Official Report Journal of Debates (Hansard) Wednesday 26 October 2016*, *supra* note 1696 at P-40.

[1796] Ministry of Health and Long Term Care, *supra* note 613.

[1797] *Official Report Journal of Debates (Hansard) Wednesday 26 October 2016*, *supra* note 1696 at P-40.

[1798] Grouchy, Wong & Cooper, *supra* note 1790 at 69.

[1799] Grouchy, Wong & Cooper, *supra* note 1790.

in program design across Ontario. These variations in turn have implications for the care that residents receive. I take no position as to which model is the most suitable. My point here is that decentralization, which is advocated by New Governance scholars, can also create inconsistencies.

The involvement in health care delivery of bodies located outside of central government is not new in the health care system. Historically, provincial governments have delegated a wide range of powers over and responsibilities for governance to self-regulating health professionals in Canada. Just like HQO, the LHINs and BSO are situated somewhere between self-regulation and command-and-control. These bodies are publicly funded, receive their mandates from the government, and have the authority to solve some of the most pressing problems in the health care system. They are created by law and have specific legal authorities with respect to participants in the sector, but at the same time also use more flexible means (such as guidelines) to influence behaviour of homes. It is within this context of more diffuse problem-solving responsibilities that we need to analyze third way approaches, and therefore, it is within this context that the approaches described below should be understood. These non-state actors have their own mechanisms for engaging health care professionals, health facilities and users of the health care system. This has implications for how problems are solved in the sector, which will be my focus next.

9.4.2 **Experimentalism in Practice**

Problem-solving relies on industry participants' own attempts at experimentalism from within a prescriptive legal framework. As explained in Chapter 2, experimentalism is a central premise of the New Governance literature. In a New Governance model, as Bach explains, "program improvements occur over time through the experimentalist, evaluative, and orchestration process, and baselines are continuously reset as experimentation and evaluation lead to better and better results."[1800] More importantly, the government's role is conceived as a facilitator of the experimentalist enterprise, rather than as a centralized rule-maker.[1801] It is obvious that government expects the participants in the sector to do more problem-solving on their own because it believes homes receive funding to provide care and the LTCHA, the

---

[1800] Bach, *supra* note 347 at 110.
[1801] *Ibid*.

Excellent Care of All Act and the accountability agreements provide the necessary directions for delivering quality care. As one industry representative remarked, "the ministry's interest is only in providing a legislative framework and then ensuring that there's compliance to that framework. Beyond that, they really don't care. It's all about here's the law, what you have to do and we're going to see whether you're complying, yes or no."[1802] This remark is similar to the idea that conventional regulations are binary i.e., they specify fixed conditions of compliance in which an actor is either in compliance or not.[1803] The government's reliance on the LTCHA as the government's answer to the problems in LTC sector is obvious.

Experimentalism is supposed to occur as homes continue to work towards compliance with the LTCHA. What we also have here is a variety of means – some more formal legally than others - that prompt the participants in the sector to detect and resolve problems in LTC homes on their own through common techniques under the guise of continuous quality improvement. For example, through submission of QIPs, homes are encouraged to find out and implement best practices, to set appropriate targets for a number of quality indicators based on provincial targets, and to conduct their own program evaluations of the required programs as mandated by the LTCHA. Improvements to quality of care are expected to materialize through the introduction and repeated use of the right techniques, as predicted by experimentalism.

The government's role as "facilitator of the experimentalist enterprise"[1804] is more residual in the case of LTC. Instead of telling homes directly which best practices should be adopted or assisting homes to meet legislative requirements, the government's role is more indirect. To advance the government's reform in the LTC sector, there are three main ways: development of quality standards by HQO, funding to professional organizations to disseminate best practices and the threat of more law being introduced in the event of non-compliance of existing legislation. As explained in Chapters 5 and 6, despite a highly prescriptive LTCHA, there are still areas where soft law overlaps and adds to formal law. The HQO is the latest provincial body created[1805] to issue quality standards and other guidelines (such as patient engagement) as part of a larger initiative to carry out the provincial agenda in quality care. The ministry can request

---

[1802] Interviewee #10, *supra* note 1743.
[1803] Simon, *supra* note 321.
[1804] Lobel, *supra* note 319 at 377; Solomon, *supra* note 309 at 595.
[1805] The HQO is the reincarnation Ontario Health Quality Council.

quality standards in topic areas that support government priorities and provincial policy direction.[1806] While not mandatory, these standards and guidelines also address problems facing the LTC sector, such as responses to individuals living with dementia. As well, each quality standard is accompanied by a plain-language patient reference guide for patients, caregivers, families, and the public.[1807]

The government also funds organizations to disseminate best practices by revising or developing guidelines, to conduct pilot projects or to provide more training. In other words, the government also supports professional associations to develop solutions for their own members while allowing maximum flexibility. Consider the example of the Registered Nurses' Association of Ontario (RNAO)'s Long-Term Care Best Practices Program. Funded by the MOHLTC,[1808] this non-mandatory initiative supports LTC homes in the adoption of evidence-based practices that support systematic and consistent approaches to providing quality care for residents.[1809] This is how the linkage to formal law is described: "The LTC Best Practices Toolkit contains a variety of evidence-based resources and materials for implementing commonly used BPGs [Best Practices Guides] to assist homes in the work they are doing to meet the Ministry of Health and Long-Term Care regulations."[1810] There are indications that the resources made available through this initiative are used by participating homes to experiment as well as to meet legal requirements. In 2015, the RNAO conducted a survey of Ontario LTC homes.[1811] Respondents reported that the benefits of using RNAO resources included preparation for LTCHA quality inspections (41.5 per cent) and support in responding to LTCHA quality inspection findings (37.9 per cent).[1812] Of the top three clinical concerns identified by

---

[1806] Health Quality Ontario, *supra* note 1628 at 6.

[1807] *Ibid* at 4.

[1808] The RNAO receives funding from the Ministry of Health and Long-Term Care for special projects. Funding ($11.4M in 2017) is provided for a variety of projects, including Long-Term Care Best Practice Co-ordinators RNs and administration. Registered Nurses' Association of Ontario, *Financial Statements for the year ending October 2017* (Toronto: Registered Nurses' Association of Ontario, 2017) at 14–15.

[1809] Registered Nurses' Association of Ontario, *supra* note 1633.

[1810] Registered Nurses' Association of Ontario, *Long Term Care Best Practices Initiative: working together towards excellence in Long Term Care* (Registered Nurses' Association of Ontario).

[1811] Registered Nurses' Association of Ontario, *Long-Term Care Best Practices Program Newsletter (Summer 2015)* (Toronto: Registered Nurses Association of Ontario, 2015) at 7. The survey was largely completed by the LTCHs' directors of care, followed by administrators and leaders in other clinical and management roles. The response rate was 31 per cent.

[1812] *Ibid*.

respondents, two were related to required programs: falls prevention and management (67.3 per cent) and pain management (26.1 per cent).[1813] More recently, the RNAO has also positioned its guidelines as a means to achieve compliance. In its submission on Bill 160, the RNAO recommends:

> Fines should only be imposed as a last measure because the sector is already under-resourced. Instead, at the written notice stage, the inspector should recommend that non-compliant homes use the Registered Nurses' Association of Ontario's Long-Term Care Best Practices Guidelines Program to help them achieve compliance. At a compliance order stage, or for repeated violations, the use of these guidelines should be mandatory.[1814]

One could argue that initiatives led by non-state actors such as this are consistent with New Governance organizing principles.

That said, the government is well aware that it might also need to be more than a "background institution"[1815] and step in too. Therefore, the latest amendments to the LTCHA (2017) allow the Minister to issue policy or operational directives. The pre-emptive threat of more formal legal rules that can be introduced quickly is always in the background. As the LHINs begin to possess more powers as per the latest legislative amendments and are more involved in regulatory processes, it remains to be seen how quickly the government would resort to formal rules in the future. The availability of voluntary guidance with the threat of more formal law in the background is not necessarily a counter-argument to experimentalism. It remains true that these guidelines can duplicate formal law and may not even be implemented. As explained in previous chapters, the guidelines can fill in gaps and address matters that are not easily addressed in formal law or at least not currently addressed adequately.

The need for experimentalism, for example in the form of industry-oriented guidance, also relates to how the government sees its role as the source of information. The lawyer representing homes explained that under the previous legislation, homes had compliance advisors, as opposed to inspectors. When compliance issues arose, the homes had a compliance advisor to guide them. When the LTCHA came into force, compliance advisors were replaced with inspectors who no longer provide any advice to homes. She speculated that the Ministry would not want an

---

[1813] *Ibid* at 8.
[1814] Legislative Library and Research Services, *supra* note 1703 at 22.
[1815] Simon, *supra* note 321 at 183.

inspector to make a finding that was contrary to advice provided by another Ministry inspector, so advice is not given. A preferable approach is to have a representative within the Ministry who is not an inspector who could still act as a compliance advisor, so that homes could raise issues and ask questions of the Ministry – before and after issues of non-compliance arise.[1816]

Matters that are clinical or medical in nature are obvious examples of the necessity of soft law. As the representative from OLTCC explained, LTC is an evidence-free zone:

> . . . we do practice in an evidence free environment. . . the guidelines that apply to so many of the medical conditions that we deal with are not based on the frail elderlies that account for four-fifths or more of the people we look after in long-term care … the physicians and other care providers in long-term care really do need to become the experts in giving good medical care, and well-referenced resources, such as Choosing Wisely, are good supports to us as the experts in long-term care.[1817]

However, other topics that require more contextual and purposive analysis also lend themselves to soft law. I have identified three areas where soft law is potentially helpful. First, issues that require careful consideration of gender and disability and other social locations may be addressed in soft law. Compared to statutes, the RNAO guidelines surveyed include more discussion about how impairment and disability should be taken into consideration when nurses provide care. An obvious reason for this is the increasing emphasis on how dementia affects patient care. It is a positive development to direct health care providers to consider how impairments may become barriers to receiving care. Second, the guidelines do recognize the social and economic context in which patients / family members are located (e.g. reference to social determinants of health). But these guidelines only address the more structural issues indirectly, through organization and policy recommendations. The downside is that, LTC residents, or those with disabilities more generally, are described as vulnerable and may reinforce the image of residents as helpless and needing to be protected. The objective of protection in turn leads to more interferences and interventions that may not be consistent with resident autonomy. Third, these guidelines include more references to how families might be involved in care. In the LTCHA, and HCCA, capable residents make health care decisions and substitute decision-makers make decisions for the incapable residents in accordance with the

---

[1816] Interviewee # 18, *supra* note 1761.
[1817] Interviewee # 4, *supra* note 1744.

principles of the HCCA. In reality, even for residents who can make autonomous decisions, there may be family members involved. Family members do not always agree and health care providers need to navigate the family dynamics and related legal issues, such as power of attorney. It is more useful to address the role of families in a principled way.

9.4.3 Transforming into what – New Governance Processes and "Command-and-Control Regulation" in a Highly Regulated Sector

In parallel with the more flexible and informal approaches, elements of the "old" command-and-control regime (as an ideal type positioned as the opposite of New Governance) remain in LTC. Below, Table 30 summarizes the elements of the "old" regime and their corresponding examples in LTC. The details of these examples are included in Chapters 5 to 8. It should be noted that some of these examples may belong to more than one category. The most obvious areas where "command-and-control" regulation continues to dominate are enforcement of and compliance with applicable law and mandatory reporting. These elements clearly reflect the old regime's reliance on adversarial enforcement and public litigation but they could also be described as "top down" rules.

Table 30: "Command-and-control" elements and examples in LTC

Elements	**Examples**
Top-down rules	• Provision of care • Admission eligibility and prioritization requirements • Discharge rules
Rights focused	• Residents' Bill of Rights • Consent to treatments and LTC admission • Zero tolerance of abuse and neglect
Inflexible rules	• Safety of residents, including use of restraints and confinement • Regulation of co-payments and other fees paid by residents
Centralized system	• Licensing of homes (including transfer and revocation of licences)

Elements	Examples
	- Funding of the system (including development of financial policies)
Adversarial enforcement / public litigation	- Long-term Care Quality Inspection Program - Mandatory reporting - Review and appeal processes - Agreements with homes

Three observations can be made about this hybrid model. The key observation that can be made from the co-existence is that the boundaries between the old and the new approaches are blurry. Solomon explains how the idea of blurring boundaries pervades New Governance regulation and thought.[1818] One could argue that the blurring of boundaries occurs as the old relies on the new to be implemented fully. All of the elements in the old, no matter how prescriptive, they are and even with the full force of law, still require other aspects of the new in order to achieve their regulatory objectives. By way of example, the provision of care requirements in the LTCHA are highly prescriptive but more specific guidance is also available in the form of guidelines produced by regulatory colleges, professional associations and institutes. The move towards greater transparency in the form of more disclosure of performance of the LTC system and homes against provincial benchmarks also augments the formal legal requirements. At the same time, the new also relies on the old to be in the background in order to have any meaningful effects or have similar normative justifications. Consider the example of quality improvement. While homes are not legally mandated to engage Residents' Councils and Family Councils on the completion of the Quality Improvement Plans, the Residents' Bill of Rights sets the tone for participation. In other words, it is not clear where old ends and the new begins.

The second observation is that the regulatory changes that conform more closely to the 'old' regime are those that require greater legal certainty because they deal with or engage some fundamental legal values that require careful interpretation at the system level, rather than being

---

[1818] Solomon, *supra* note 309 at 594.

left to individual decision-makers at the home level. These legal values include, but are not limited to equality, non-arbitrariness, fairness and fundamental justice. In any program delivery context, providers need discretion in order to make operational decisions. By the same token, the regulator also needs discretion in order to make decisions about carrying out its regulatory tasks effectively and efficiently. However, without sufficient guidance, decision-makers (whether they are providers or the regulator) may make arbitrary decisions that can be detrimental to the legal rights and entitlements of others. Sometimes clear rules and bright-line tests are especially needed in order to avoid inappropriate use of discretion in contexts involving significant power imbalances or vulnerable stakeholder groups. Under the LTCHA and *the Health Care Consent Act*, the rules about safety and security of residents may be considered highly prescriptive, however they also take away some possibility of misinterpreting or misusing discretion on the home's part. Similarly, homes can also be subject to the wrath of inspectors. Very detailed rules about what inspectors must do in the event of non-compliance can help ensure fairness of the process and outcome of the inspection or enforcement decision. In other words, some issues are not suitable for a 'command-and-control'-free approach.

The last observation is that the changes that fit the command-and-control ideal type are in areas where the government has always regulated one way or the other – either directly through statutes or the Program Manual or contracts, or indirectly, by delegation to regulatory colleges. In other words, these areas are not new risks that the government has no experience in regulating. They are less amenable to new approaches since regulation is never ahistorical. That said, the interpretation of risk tends to change over time and it is possible to move from the old to the new and vice versa. In Chapter 5, I have demonstrated how the regulation of provision of care is highly prescriptive, but not uniformly so. Evidently the "how to regulate better" question[1819] is always in the background. When the substantive ends of regulation do not change significantly but the risks to those ends appear to be clearer in the decision-maker's mind, there is a tendency to tackle those known risks with the implementation of the most inflexible rules. The implication is that well-known risks are over-regulated even when the available evidence shows that the

---

[1819] Parker, *supra* note 68. Parker observes that much of the scholarly literature on regulation is focused on "how to" regulate markets, capitalism, and individuals better.

performance continues to improve. I will return to the question of using the idea of risk later in this chapter.

In sum, the hybridity model in LTC looks like this: (1) the government continues to use command-and-control regulation to (a) manage risks that have always existed and appear to be well understood (such as the administration of drugs, the use of physical restraints and nutritional care), albeit the likelihood of the risks and the consequences of the risks are different now because the acuity levels of residents have increased over time, (b) maintain policy discretion over structural issues, and (c) preemptively give itself rule-making ability to go back and forth among various instruments; (2) the command-and-control elements take away discretion from decision-makers in order to protect certain fundamental legal values; and (3) New Governance approaches are added whenever there are inherent uncertainties about how best to solve problems. It is this last step where one could find more experimentation as envisioned by new governance scholars. The traditional regulation and new governance approaches are not necessarily merged into one integrated system where each element is necessary for the successful operation of the other. Rather, it is more apt to talk about several smaller, overlapping integrated systems in which law plays a slightly different role in each. The most integrated system governs provision of care requirements. There are extensive new governance practices – from soft law to benchmarking - to give content and meaning to formal law standards and public law norms. The least integrated system governs licensing and funding of homes. It is very much dominated by formal law, with guidelines adopted by reference in contracts.

For LTC residents, and to a lesser extent, their families and friends, the hybrid model offers limitations and promises. The main limitation is that the substantive ends of the LTC systems are rarely questioned in any meaningful manner. Problem-solving tends to focus on how to find solutions to a pre-defined problem. Two examples will suffice. First, an aspect of the problem of residents' safety is perceived to be contributed by the presence of residents with responsive behaviours. And the solution is to separate them. However, no one really questions what safety really means in this particular context. Second, the admission eligibility requirements are necessary because admission has to be fair and perhaps more importantly, the average resident stay should be as short as possible to reduce demands on the public purse. The solution is the development of rules that are very detailed and clear about which needs are prioritized. Transforming LTC into a last resort for those who are close to death (as opposed to a viable living option on the continuum of housing) is rarely debated or challenged in a meaningful way. In this hybrid model where there are more choices with respect to instruments, it is not immediately apparent who is responsible for the implementation of these choices.

The second limitation concerns the New Governance organizing principle of softness in law.[1820] Some scholars suggest creating a more flexible and fluid policy environment that promotes "softer" processes that either replace or complement the traditional command-and-control regulatory model.[1821] The question is whether these guidelines, which almost inevitably cover clinical matters that are regulated in multiple ways, are actually consistent with and can keep up with evolving legal expectations. The guidelines are prepared by a large number of organizations; the development process may or may not include meaningful review and input from a legal perspective. The elder law lawyer shared her extensive experience in various working groups and committees about a variety of guidelines in the health care sector. She noted that sometimes, guidelines are based on research in the form of literature review, which may include findings that are incorrect from a legal perspective. Alternatively, a guideline may derive from research conducted in a few select jurisdictions but any common tool developed could end up being incompatible with the law in a particular jurisdiction because the jurisdictional differences have not been taken into consideration.[1822] The problem for any promotion of the greater use of soft law is that without careful consideration of its compatibility with Ontario law, there is a strong possibility that guidelines can actually disseminate the wrong information in the sense that it is not legally correct in a particular jurisdiction, which in turn may affect people's understanding of their rights and obligations.

A related concern is whether these guidelines can actually be implemented fully across the sector without additional funding. According to the OECD, monitoring of compliance is expensive for regulators, while adherence to norms and protocols can be costly for LTC providers.[1823] It makes sense for both the Ministry and homes for exploring voluntary means to improve quality of care while meeting the expectations of the LTCHA and other statutes. One industry association representative confirmed that association members use the RNAO

[1820] Lobel, *supra* note 319 at 388.
[1821] *Ibid*.
[1822] Interviewee # 12, *supra* note 1699.
[1823] OECD / EU, *supra* note 478.

guidelines to implement the core programs of the LTCHA, as well as guidelines from accreditation agencies, policies from the Ministry and any education materials developed by the association.[1824] One union representative expressed reservations about the utility of best practices advanced in these professional association guidelines. When I asked about the RNAO guidelines, the union representative explained:

> A lot of nurses know what the best practice standards are from the RNAO, many of them will have read them. . . The reality is, when acuity in long-term care goes up . . . The patient demands are higher but we don't have the resources to provide and meet their demands. . . the government does not fund what it takes to implement them, because at the end of the day, what it truly takes to implement them is more people.[1825]

Here, the question is identifying the conditions necessary for successful implementation of experimentalism, including the necessary funding of such initiatives.

The third limitation concerns the problem of how to preserve the more traditional legal tools such as rights in order to hold decision-makers accountable. Problem-solving does not necessarily mean less talk about rights. In fact, problem-solving requires protection of the following rights for individual residents and residents as a group: to receive and distribute information, to request accommodation and to be included in meaningful participation, which may require legal and non-legal representation in order to be effective. For Simon, one of the predispositions of Legal Liberalism is the priority of rights and he illustrates how problem-solving is distinguished from claiming rights.[1826] But I believe that claiming rights is also a part of problem-solving. This is because residents, family and friends would not be able to participate in problem-solving unless they also have the means to participate. I agree that many of the rights in the LTCHA are individualistic in nature and ignore the relational aspects of the reality of living in LTC. However, another set of rights in the LTCHA actually augments "interest in and capacity for active participation in decision making".[1827] Enforcing rights pertaining to participation is important for problem-solving because this contributes to defining problems correctly in the first place. "Part of the idea of problem solving is to focus attention on matters that are of practical importance to the participants and thus divert attention from merely abstract,

---

[1824] Interviewee # 16, *supra* note 620.
[1825] Interviewee # 11, *supra* note 1711.
[1826] Simon, *supra* note 321 at 136.
[1827] *Ibid* at 173.

moot, or academic disagreement. Defining issues in practical terms, however, is not the same as defining them narrowly."[1828] Having residents and families and friends (or their representatives) participate in the operations of the home can increase the chances of identifying matters that are meaningful to them. This does not imply residents and families and friends have exclusive right to define a problem.

In the LTC sector, many accountability mechanisms exist to define relationships among homes, the Ministry, the LHINs and to a lesser extent, Health Quality Ontario. However, there is little discussion about how residents, families and friends can hold the homes, the Ministry, the LHINs and Health Quality Ontario accountable for problem-solving. I do not question that given the public interest involved in providing quality LTC, the Ministry and other bodies need to hold homes accountable for solving problems in their own homes. However, LTC residents and their families and friends also need to have the right to participate in problem-solving as a way to hold homes, as well as decision-makers, accountable. While not all problems that occur in homes are conducive to inputs from residents and families and friends, they need the right to receive and distribute information, to request accommodation of disabilities and to be included in meaningful participation so that they can decide how they want to be engaged in problem-solving. I will return to the issue of participation later in this chapter.

9.4.4 **Summary**

This section began with my reflections on the application of New Governance approaches in LTC, which remains a highly regulated sector. The variety of legal and non-legal instruments requires close study. Disability scholars have not paid enough attention to the nuances of the different types of legal and non-legal instruments, each of which brings different limitations and promises. Ignoring the nuances of the different types of legal and non-legal instruments will affect our ability to explicate and evaluate future law reform initiatives. I contend that the New Governance approaches in LTC are created and sustained by law. They are about strengthening or creating additional processes and procedures for participants—homes, residents, families, advocacy groups, industry organizations and government—to problem-solve challenges in the sector. Further, I made the following claims about problem-solving in LTC. Problem-solving

---

[1828] *Ibid* at 184.

responsibilities are also more diffuse and are not always clear. Problem-solving relies on industry participants' own attempts at experimentalism from within a prescriptive legal framework. Despite the limitations of hybridity, the main promise is that this hybrid model offers more opportunities to be vigilant about the operations of their homes. There are simply more points to access information, and be consulted either formally (as required by law) or informally by the home or by other third parties. Problem-solving requires the following rights individually and collectively: to receive and distribute information, to request accommodation of disabilities and to be included in meaningful participation, which may require legal and non-legal representation in order to be effective. The next section will concentrate on unpacking what participation looks like at the individual and collective levels.

9.5 Meaningful participation of residents and families: law and reality

Chapter 2 makes the case for an empirical study of the processes and procedures – many of them mandated by law - that purport to promote inclusion and participation of disabled people and their families and friends. The normative justification for more emphasis on participation can be grounded in the notion of "nothing about us without us". As Michael Prince argues persuasively, "social inclusion is a flagship concept in disability politics, associated with the active participation of persons with disabilities in all life domains."[1829] I propose that participation can be analyzed at the individual as well as at the collective levels. Further, a gap in the literature surveyed is that it is short on prescriptions for participation techniques.

In LTC, participation at the individual level usually means making decisions about health care and personal care activities such as eating and bathing. This decision-making ability is reserved for those who are deemed capable. Here, the focus is interrogating how those participation rights are exercised in practice and the barriers experienced by those who are deemed incapable. As for collective participation, many of the new or enhanced legally-enabled processes are intended to give a voice to residents and their families and friends (but rarely to workers and volunteers) by permitting them to access certain kinds of information (such as inspection reports), to be consulted on certain issues (such as quality improvement) or to provide input into the process of a certain activity (such as development and implementation of

---

[1829] Prince, *supra* note 116 at 91.

satisfaction surveys). These mechanisms can be interpreted as ways to achieve social inclusion in LTC. To be certain, these rights are more about having a voice in the operations of the home rather than about having meaningful influence over regional or provincial policy-making.

9.5.1 **Allowing autonomous decisions where possible**

In Chapter 5, I explained how LTC residents may be able to make decisions about activities of daily living such as choice of clothing and dining as well as health care decisions. The notion of "choice" figures prominently in the LTCHA, from the admission process to matters of everyday living. Some scholars have called into question whether residents of LTC homes can actually make meaningful choices and assert their rights to exercise autonomy. As explained in Chapter 2, the debate about care challenges the "caring for" attitudes of professionals and other carers. As Morris explains, "[p]eople who are said to need caring for are assumed to be unable to exert choice and control."[1830] In theory, the incorporation of choice into the LTCHA reflects the criticisms of disability scholars. However, as explained in Chapter 4, care practices that have been reported to undermine the autonomy of LTC residents include the use of restraints,[1831] involuntary confinement,[1832] inappropriate uses of surveillance cameras,[1833] barriers to sexual expression,[1834] rigid work routines within homes[1835] and over-emphasis on avoidance of safety risks and standardization of care.[1836]

In this section, I will focus on health care consent as a way to explain the notion of participation at the individual level. As discussed in Chapters 6 and 7, autonomy is an important value in our legal system. The ability to carry out the process of decision-making, as Hall explains, is essential to both autonomy and individual identity according to the modern guardianship paradigm.[1837] The concept of autonomy figures prominently in landmark Supreme

---

[1830] Morris, *supra* note 197 at 54.

[1831] Fiona McDonald, "'To Become Old is to Become Institutionalized and Imprisoned': Comparing Regulatory Frameworks for the Use of Restraints in Long-Term Care Facilities" (2003) 12:1 Health L Rev 22.

[1832] Cathrael Kazin, ""Nowhere to Go and Chose to Stay": Using the Tort of False Imprisonment to Redress Involuntary Confinement of the Elderly in Nursing Homes and Hospitals" (1989) 137 Univ Pa Law Rev 903.

[1833] Lisa Minuk, "Why Privacy Still Matters: The Case against Prophylactic Video Surveillance in For-Profit Long-Term Care Homes" (2006) 32 Queen's LJ 224.

[1834] Emily Hayter, "Sexual Expression in Long-Term Care Homes: Capacity & Consent Special Topic: Aging" (2014) 35 Windsor Rev Legal & Soc Issues 54.

[1835] Armstrong & Daly, *supra* note 696; Armstrong & Daly, *supra* note 163.

[1836] Armstrong & Daly, *supra* note 771; Armstrong, *supra* note 1003.

[1837] Hall, *supra* note 1288 at 295.

Court of Canada decisions such as *Carter,* which guide lower courts and tribunals on a variety of health care-related decisions.

A clear theme that emerged from my interviews with key informants is that while informed consent is a fundamental principle in health care decisions, this does not always work to the satisfaction of the resident (or patient), their families or health care providers. There is a concern that capacity, consent and substitute decision-making issues are not well understood in the health care sector generally. There may be a few contributing factors. First, there are different tests for legal capacity; some tests are in the *Health Care Consent Act* while others fall under the *Substitute Decisions Act*. Second, the law around capacity is very black and white: a person is either capable or incapable. As the disability rights lawyer I interviewed remarked:

> The legal structures … do not support people to engage in a variety of decision making relationships that could really enable them to exercise their legal capacity to a much greater extent than people do now.[1838]

When a person is deemed incapable, then the substitute decision-maker makes decisions for the incapable person. The problem is that substitute decision-making and the law are not well understood outside of lawyers who practice in this area. For example, substitute decision-makers may not understand that they have an obligation to involve the incapable person in the decisions.[1839] Third, incorrect assumptions may be made about the patient / resident's capacity for making health care decisions. According to the representative from the OLTCC:

> What I observe sometimes happens is that in the admission process there is maybe a spouse, a child, or another family member, or designated substitute decision maker who goes through the admission process and that person may rightly have current power of attorney for finance and property, but it's assumed that person is then the substitute decision making for healthcare decisions. The resident's own ability to make those decisions is overlooked. I think that all providers, but I think especially physicians, have become more and more aware in recent years that consent needs to be given at the time and it is situational, and the resident's capacity needs to be judged and re-judged on an ongoing basis.[1840]

Others have also pointed to the issue of capacity and consent in relation to the circumstances of older adults. For example, determination of capacity and consent for treatment/Do Not Resuscitate order is always one of the themes in Geriatric Long-Term Care

---

[1838] Interviewee # 13, (2017).

[1839] *Ibid*.

[1840] Interviewee # 4, *supra* note 1744.

Review Committee reports, but its prominence varies year over year. In the 2016 report, the Geriatric Long-Term Care Review Committee observes that:

> It is clear that organizational practices often do not reflect the law in regard to the use of advance directives, do not resuscitate orders and powers of attorney for personal care. The committee has identified a need for broad industry education in order to ensure the rights of elderly individuals and residents of long term care facilities. Healthcare providers in particular must be aware of their responsibilities and authorities and of the resources available to them when questions and conflict relating to consent and capacity arise.[1841]

To be fair, health facilities are in a difficult situation in terms of providing the medical care to a patient who appears to languish and they often proceed from a point of view that the patient is not safe to remain in the community. According to the health law lawyer I interviewed, one possible scenario is that an older person living in their own home in the community requires multiple visits to the emergency room, for example, due to dehydration. The hospital staff provide the necessary acute care to the older person, but eventually, they may question whether the older person is able to live at home. Sometimes the hospital discharge planners will do a site visit to determine if any help will be required from an occupational health and safety perspective. But the point is that "people are allowed to assume risk . . . people generally have a lot of autonomy to make poor choices if they are capable."[1842] The health law lawyer explained that there are very few ways to deal with such situations:

> What are the options? Can they go home with family? Do they go to a retirement home which is a paid option? Long-term care is covered under OHIP. … You can get relief from the co-payment. But if I'm capable, I can say no . . . what's going to become of this person? I get this question all the time.[1843]

She further commented that the law does not provide many options if an incapable person refuses to enter a LTC home or decides to leave, even after consent is properly provided by the substitute decision-maker:

> . . . We would invoke other authorities ... most people when they think of the *Mental Health Act* . . . think as a result of my mental disorder, I am either going to harm myself, or that I'm going to harm a third party. But the one that they don't usually focus on … is serious physical impairment. … Pearl [a pseudonym to represent an older woman] is wandering around in her night clothes in the winter at night, her house isn't maintained, there's no food in the fridge, the newspapers

---

[1841] Geriatric and Long term Care Review Committee, *supra* note 1693 at 13.
[1842] Interviewee # 1, *supra* note 1700.
[1843] *Ibid*.

> are piling up and there's a fire hazard. You might be able to rely on the *Mental Health Act* and make a pitch that Pearl's situation meets the serious physical impairment category. . . There's consent for admission, but there's no opportunity to detain her. So that will be challenging.[1844]

In sum, the law on consent and capacity is very complex. At the same time, application of the law does not always respond well to real life situations of individuals who experience the effects of aging and disability. I now turn to some of the ideas that emerged about access to justice from the lawyer interviewees.

9.5.2 **Access to justice**

This section examines of how potential rights violations may be pursued by LTC residents or their litigation guardians if they are incapable. In the disability literature, the pursuit of equality rights is a common theme. I build on this theme by attending to how difficult it is to assert rights. As I will demonstrate below, any difficulties associated with LTC residents asserting their rights should be understood as part of a larger problem with disabled people's encounters with health and legal systems that do not adequately take into account the complexity of circumstances, needs and experiences of disabled people. A problem or issue may originate in the health care system, but then it migrates to the legal system. At the micro level, residents experience power dynamics when they are in caring relationships. In turn, these relationships are shaped by a multitude of institutional or systemic barriers, which have differential impacts on disabled people. The discussion here is intended to complement existing studies about access to justice.[1845] While law is the solution to many potential harms associated with care (especially institutional care), law turns out also to be a problem for many residents because for those who require support to make decisions, the legal interventions available to them are usually blunt instruments.

In this section, I focus on health care consent decisions. The small number of human rights cases concerning LTC residents does not allow us to make any definitive conclusions about using the tribunal as a way to redress discrimination claims. All cases engaged the enumerated ground of disability and none were initiated by the residents. Without a family

---

[1844] *Ibid.*

[1845] Lisa Ramano & Jane Meadus, *Congregate Living and the Law as It Affects Older Adults* (Toronto: Law Commission of Ontario, 2009).

member or advocate, it is very difficult for a LTC resident to initiate an application. The circumstances of a LTC resident or applicant also matter, as I will explain below.

9.5.2.1 Lack of rights information and advice

To recap, currently the following legal forums are available to LTC applicants and residents to adjudicate on a variety of matters related to LTC: Health Services Appeal and Review Board, Consent and Capacity Board (CCB), Human Rights Tribunal of Ontario and the Superior Court. These matters may be bought forward pursuant to the *Long-Term Care Homes Act, 2007, Substitute Decisions Act*, the *Health Care Consent Act* and the *Human Rights Code*. These matters include eligibility for LTC admission, incapacity finding, power of attorney, guardianship, and services received while in LTC. The review and appeal procedures are clearly spelled out in statutes, supplemented by the rules of procedures issued by each tribunal.

A clear concern expressed by the lawyer interviewees is the lack of awareness of rights and lack of (or limited) availability of legally correct rights information and support being provided to individuals (or their representatives) who may choose to pursue remedies in the legal system. As explained in Chapter 7, the *Health Care Consent Act* provides for a mechanism to protect those who may be found to be incapable of making decisions in one or more domains. One indication of whether people are utilizing this review right is the number of applications to CCB. In 2016-2017, the CCB received a total of 7,770 applications. Three types made up the majority of the applications: 46% related to a review of involuntary status under the *Mental Health Act*, 26% related to a review of a finding of incapacity with respect to treatment, LTC admission or personal assistance, and 21% related to a review of a Community Treatment Order under the *Mental Health Act*.[1846] Table 31 shows the number of annual applications to the CCB concerning findings of incapacity, divided into three categories i.e., treatment (T), LTC admission (A) and personal assistance (PA).[1847] I have included both Form A applications (application to the Board to Review a Finding of Incapacity under Subsection 32(1), 50(1) or 65(1) of the *Health Care Consent Act*) and Deemed Form A applications (some applications trigger a deemed application, such as Form C - Application to the Board to Appoint a

---

[1846] Consent and Capacity Board, *Annual Report 2016-2017* (Toronto: Consent and Capacity Board, 2017) at 16.
[1847] The statistics is provided by the Consent and Capacity Board. The interpretation of the statistics does not represent the view of the Consent and Capacity Board.

Representative under Subsection 33(2), 51(2) or 66(2) of the *Health Care Consent Act*).[1848] Both types of applications are included because they represent how often the CCB is asked to adjudicate on capacity matters. It should be noted that the CCB also adjudicates other *Health Care Consent Act* matters, such as application for permission to depart from wishes under subsection 36(1), 53(1) or 68(1) of the *Health Care Consent Act*. They are omitted from the table below for presentation reasons.

Table 31: Annual applications to the Consent and Capacity Board (capacity-related)

Application type	2006/2007	2007/2008	2008/2009	2009/2010	2010/2011	2011/2012	2012/2013	2013/2014	2014/15	2015/16	2016/17
A (T)	833	860	833	990	1024	1231	1252	1467	1584	1674	1858
A (A)	71	71	78	47	52	51	54	45	46	42	31
A (PA)	2	2	2	3	10	9	4	5	2	3	1
Deemed A (T)	82	56	80	73	89	78	78	73	65	80	103
Deemed A (A)	70	50	42	49	48	34	35	56	26	36	33
Deemed A (PA)	29	7	18	18	18	19	13	13	6	1	6
Total (T)	915	916	913	1063	1113	1309	1330	1540	1649	1754	1961
Total (A)	141	121	120	96	100	85	89	101	72	78	64
Total (PA)	31	9	20	21	28	28	17	18	8	4	7
Total (T, A and PA)	1087	1046	1053	1180	1241	1422	1436	1659	1729	1836	2032

A few preliminary observations can be made. The total number of applications regarding findings of incapacity has increased steadily: from 1,087 in 2006-2007 to 2,032 in 2016-17. This increase can be attributed to the increase in applications regarding treatment. This is consistent with the CCB's overall caseload trend. In the past five years, applications have increased, on average, 6% annually and hearings have increased, on average, 10.2% annually.[1849] Despite the overall increase in case load, the annual number of applications regarding LTC admission is actually on a downward trend, from 141 in 2006-2007 to 64 in 2016-2017, with small fluctuations in some years. The number of Form A applications may be a better indication of how people are aware of the right to challenge a finding of incapacity, as Form A applications are initiated by the persons deemed by the evaluators to be incapable. The number is even lower: from 71 in 2006-07 to 31 in 2016-17. This is surprising given the number of LTC admissions

---

[1848] Some applications trigger a mandatory review of capacity to make one's own decisions about treatment, admission to a care facility, and personal assistance services under sections 37.1, 54.1 and 69.1 of the HCCA (the "Deemed Form A applications"). The Consent and Capacity Board has to be satisfied that the person is incapable first before a representative is appointed.

[1849] Consent and Capacity Board, *supra* note 1846 at 15.

each year (37,639 in 2016-17).[1850] One possible explanation is that very few LTC admissions are consented to by substitute decision-makers because almost all LTC applicants are capable of consenting to their own admissions. This seems to be implausible since we know people are being admitted older and sicker (including significant cognitive decline). Another explanation may be that almost all capacity assessments are done correctly in a legal sense and therefore very few people decide to challenge findings of incapacity. This does not seem to be plausible either because if this is the case, the applications regarding incapacity for treatment decisions should not be increasing. A more plausible explanation is that people simply do not know they can challenge such findings.

It is true that access to the CCB is free and a hearing can occur in seven days anywhere (including in hospitals and in LTC homes) so that access to justice should not be a problem. But the picture is more complex. The availability of legal advice was a concern that came up in the interviews. The Consent and Capacity Board can appoint counsel for an unrepresented applicant, and in fact, one of the changes to the *Health Care Consent Act* was to allow the Consent and Capacity Board to direct Legal Aid Ontario - instead of the Public Guardian and Trustee Office – to arrange for representation. The applicant may qualify for Legal Aid, but this is unlikely because the financial cutoff is set so low.[1851] There are other factors. As the elder law lawyer explained, "a lot of seniors, even poor seniors, may have a little bit of savings and they're not going to use it to retain a lawyer for the purpose of challenging an incapacity finding."[1852]

The trigger for launching an application to the Consent and Capacity Board is an awareness of review and appeal rights. Such rights are not meaningful if there is no clear communication with the individual about the significance of a finding of incapacity and how to challenge such finding. The new requirement in the *Health Care Consent Act* about providing information about the consequences of findings of incapacity for LTC admission is a necessary step in the process to ensure the assessment process is not abused or misused. This means that the relationship between the health care provider (assessor) and the patient is critical. Both the

---

[1850] The CIHI publishes sources of admission for residents admitted into continuing care facilities. The admission number includes transfers from other LTC homes i.e., not just new admissions. Canadian Institute for Health Information, *supra* note 558, ch Table 4.

[1851] Legal Aid Ontario, "Will legal aid pay for my lawyer?", (2019), online: *Getting legal help* <https://www.legalaid.on.ca/en/getting/eligibility.asp>.

[1852] Interviewee # 12, *supra* note 1699.

health law lawyer and elder law lawyer raised questions about how rights information is communicated to patients (if at all) and both compared LTC admission decisions with the mental health system.[1853] For the elder law lawyer, in reality, nothing really works the way it is supposed to under the law. She emphasized that there is a deeper, long-standing problem with the process of requesting consent from patients and evaluating capacity. Health care providers may not have received training on the legal test for capacity nor understand the definition of capacity. There is also the question of whether regulatory colleges are willing to pursue complaints about a regulated professional's alleged misconduct in requesting consent, given the more grievous complaints received by regulatory colleges. She was also careful to point out that the evaluator of capacity may be subject to other pressures too, for example, the need for vacating a hospital bed and family members' problems with coping with the care needs of an older disabled adult living in the community. In sum, she explained that only a small number of cases reach the Consent and Capacity Board because:

> you've got to have somebody who is pretty savvy to figure out what's going on or something that's so blatant . . . With the assistance of counsel, the blatant cases may be diverted from the formal review process and resolved.[1854]

This is not limited to older, disabled adults. The disability rights lawyer I interviewed explained the experience of her clients in health care settings. Her clients were not told in any meaningful way from their perspective that a capacity assessment was being done. They were not provided with documentation related to the assessment or to the finding of incapacity. They were not informed of the implications of the finding of incapacity and the process for challenging such a finding.[1855]

It is suggested that family dynamics may also play a role in the background. The health law lawyer explained that there is an inherent tension here. The actual circumstances of an older disabled adult makes her access to justice more complicated. This is because the person most likely to help the older disabled person with all kinds of things such as driving them to appointments and making sure their fridge is full and their living environment is clean, may also be the person who is going to consent to LTC admission. She may try to persuade the older

---

[1853] Interviewee # 1, *supra* note 1700; Interviewee # 12, *supra* note 1699 at 12.
[1854] Interviewee # 12, *supra* note 1699.
[1855] Interviewee # 13, *supra* note 1838.

disabled person not to challenge that finding because she is worried that the older disabled person will remain in her home and it is creating a safety risk.[1856]

> I've seen some tense situations where inherent conflicts are over the norm. And I'm not saying that people are not earnest and may not want her there for the right reasons. And guess what? Maybe she should be there and maybe the finding is going to be, no, she is eligible to be admitted to long-term care and there is valid consent and she is incapable.[1857]

Family members may not have an accurate understanding of consent and the substitute decision maker's role. As explained in Chapter 7, the substitute decision-maker may give consent to LTC admission on behalf of the incapable person. This authority to consent does not include the authority to detain the incapable person in the LTC home. As an example, the meaning of giving consent to LTC admission may not be well understood.

> I am certain the adult kids think or the spouse thinks by virtue of having the power to make the legal decision to give the consent, that that means that the individual must go to long-term care, and must stay. . . I don't even think if you asked 100 people who consented to the admission of their person to long-term care, that they would appreciate that the incapable person could then walk out the door, whether there are other measures available to then act to keep them safe such as the *Mental Health Act*.[1858]

Therefore, the unproclaimed amendment to the *Health Care Consent Act* that would require the placement co-ordinator (i.e., the employees of LHINs) to ensure the substitute decision-maker provides consent in accordance with the HCCA[1859] could make a difference in terms of safeguarding the rights of incapable LTC applicants.

Another concern is the barriers faced by older disabled adults. According to the health law lawyer, there are other barriers in place. The actual circumstances of an older disabled adult make her access to justice more complicated. Adjudication under the *Substitute Decisions Act* is even more complicated. As noted in Chapter 7, the *Substitute Decisions Act* governs power of attorney and guardianship. Unlike health care decisions, disputes about powers of attorney will have to be heard in the Superior Court – possibly a barrier to access to justice, especially given

---

[1856] Interviewee # 1, *supra* note 1700.
[1857] *Ibid*.
[1858] *Ibid*.
[1859] A number of provisions in the HCCA have not been proclaimed yet. The unproclaimed Section 40(1)(b) states: "the person responsible for authorizing admissions to the care facility shall take reasonable steps to ensure that the person's admission is not authorized unless the person responsible for authorizing admissions is of the opinion that the substitute decision-maker has given consent on the person's behalf in accordance with this Act."

the contrasting framework under the *Health Care Consent Act* that establishes the Consent and Capacity Board:

> The issue here is who decides under a power of attorney for personal care if a person is incapable for shelter and nutrition decisions? … Adult son says, well, you're incapable to make that decision. I'm now invoking. I'm now your attorney for such a decision. And there is no real review. . . What does she do? Go look up the *Substitute Decisions Act* and find her way? Going to court costs a lot of money and takes a lot of time. . . There is no mandatory rights advice, rights information, or assistance of any kind.[1860]

Another way that family relations may affect a resident or applicant occurs when there are multiple powers of attorney:

> . . . if you have dueling adult children swapping out powers of attorney (the documents), which unfortunately we do see. Let's say we're siblings and our mother gave you authority for decision-making. I go and visit her and slip her the piece of paper to sign, naming me instead. Or maybe she says, I'm really tired of your sibling acting for me, and I'm going to move it over to you. She signs it. My clients in the homes and the hospitals sometimes get stuck between dueling adult children or other substitute decision-makers.[1861]

The health law lawyer explained that occasionally, one or both parties with competing powers of attorney may threaten to sue the home or hospital if their version is not followed.[1862] The problem is if the mother is incapable, the parties will have to go to court to resolve the dispute, and that's costly.[1863] The point is that if the older adult has any relations, her rights need to be understood within the context of all the influences she may be subject to. Some of her relationships are enabling; some maybe not. The law offers the means to protect incapable individuals from disabling relationships but is silent on the promotion of enabling relationships. This helps explain caring relationships and some of the pitfalls that can occur in real life.

9.5.2.2 Other disabled people's experience with access to justice

Because there are so few cases of LTC residents using formal legal mechanisms to assert their rights, I borrow insights about other disabled people's experience. The disability rights lawyer provides the context in which people with disability have to assert their capacity to make decisions, including challenging findings of incapacity in legal, quasi-legal and non-legal

---

[1860] Interviewee # 1, *supra* note 1700.
[1861] *Ibid.*
[1862] *Ibid.*
[1863] *Ibid.*

forums. This context is important for this project because the experience shows that it is a more far-reaching problem. People with disabilities encounter barriers in a variety of situations. Some of those reasons are related to very direct discrimination, or assumptions being made about people's capacity to make their own decisions. In particular, many assumptions are made that if someone has an intellectual or mental health disability, or any kind of disability related to their cognitive functioning, then they cannot make their own decisions and others need to step in. Barriers may also exist simply because the right accommodations are not put in place. Others may assume those with communication disabilities cannot make their own decisions. However, if proper accommodations around communication were in place, they would be able to communicate their decisions readily and their decision-making capacity would not even be an issue. Another example of a communication accommodation barrier is failure to incorporate clear language, or plain language accommodation. To initiate a legal process at a tribunal or court, one may have to fill in forms or receive notices that are written in very complex legal language. A person with an intellectual disability may not understand the content of the forms or notices simply because of the inaccessible language. If the form or notice is written in plain language, the person with a disability may be able to understand the actions required of him or her.[1864]

The lesson learned here is that the common techniques used to enhance procedural protections, such as review mechanisms and notice requirements, are not always going to be useful for people with disabilities unless accommodations are in place so that the information is meaningful to those who experience cognitive and other types of disability. In Chapter 7, I explained how the processes under the HCCA and SDA have changed. Some processes are indeed consistent with the objectives of the AODA, for example, the SDA refers to an "accessible copy" of the notice of resignation of the resigning attorney. From the perspective of autonomous decision-making, these processes are indeed necessary to protect the autonomy of the person. In fact, the LTCHA is also filled with notice requirements and disclosure of information obligations, either to individual residents or to residents as a collective. It is reasonable to assume that without proper accommodation, some residents will not be able to understand the information that is legally mandated to be provided and to take necessary actions.

[1864] Interviewee # 13, *supra* note 1838.

When asked whether the AODA could be a means to removing some the communication barriers faced by people with disabilities since information and communication standards are in place, the disability rights lawyer expressed reservations. She explained that the AODA establishes a minimum standard around accessibility in certain areas of life and that it places requirements on certain organizations to implement those minimum standards. If anyone checks whether an organization is complying with the information communication standard, or any one of the standards under the AODA and the organization is not complying, there is no legal recourse for the individual. It is entirely the responsibility of the Ontario Government to implement and enforce the minimum standards that are set out in the accessibility standards. In her opinion, the Ontario Government can do that with a great degree of political will, or a very small degree of political will and there's really not a lot of accountability in that process.[1865] This remark is consistent with my interpretation of the Licence Appeal Tribunal decisions, which also confirm the self-reporting regime of the AODA. In the four decisions regarding appeals of fines imposed by the Director, the Licence Appeal Tribunal noted that the Act and its standards rely on self-reporting for compliance. In other words, the Accessibility Directorate of Ontario can only monitor compliance with the obligations set out in the Act when an organization files its accessibility report. Reporting is a key mechanism by which the Accessibility Directorate of Ontario measures compliance.[1866] The nature of enforcement of the AODA illustrates the limitations of AODA as a tool on its own to bring about specific changes for people with disability. On the other hand, the fact that there are piecemeal efforts to introduce information requirements more aligned with the intent of the AODA in other statutes probably means that the norms around accessibility are becoming more entrenched in the sense that they are more difficult to remove (at least from a "law on the books" perspective).

9.5.2.3 Intervention in the form of support for autonomous decision-making

It should be emphasized that some issues will have no clear legal solutions and we need to resist the temptation to turn to law immediately. As Herring explains, our society has built up

---

[1865] *Ibid*.

[1866] *8677 v. Director under the Accessibility for Ontarians with Disabilities*, *supra* note 975; *8635 v Director under the Accessibility for Ontarians with Disabilities Act*, 2014 (available on http://canlii.ca/t/g90w7); *8647 v Director under the Accessibility for Ontarians with Disabilities*, 2014 (available on http://canlii.ca/t/g8kh1); *8750 v Director under the Accessibility for Ontarians with Disabilities Act, 2005*, 2014 CanLII 46587 ON LAT (available on http://canlii.ca/t/g8kj0).

a wide range of structures and forms of assistance to accommodate the needs of adult working people.[1867] The question here is a lack of appreciation of similar accommodations for disabled people so that they, too, can make claims for autonomy and decision-making capacity. While rights have always been conceived as a means to keep a person free from unwanted intrusion or interference, the safeguarding of individual autonomy requires interventions in some cases. As explained in Chapter 7, the Office of Public Guardian and Trustee (OPGT) may be appointed by the court as the guardian of an incapable person, and about 51% of OPGT's property guardianship clients (or 5,600) are 60 years old and over.[1868] The appointment of the OPGT as guardian is not simply the inevitable result of an impairment or a lack of family members. Therefore, examining OPGT guardianship is a useful way to explore how lack of support can be an environmental barrier to autonomy for disabled people.

The disability rights lawyer referred to clients under OPGT guardianship and explained the circumstances that contributed to them remaining under OPGT guardianship:

> we have encountered a number of situations where clients are under OPGT guardianship and so there's already been a finding of incapacity against them and they are desperately struggling to get out of OPGT guardianship and it's very, very challenging for them to do so. There's many, many barriers in place. . . the most readily understood barrier is that most of the clients, at least who we interact with, that are under OPGT guardianship, are on ODSP [Ontario Disability Support Program], so they don't have a lot of money. Capacity assessments are very expensive, generally. The OPGT does provide a subsidy, they have discretion about whether to provide that subsidy or not. You can apply for it and our clients do, but, first of all, it's not always given, secondly, it's not usually enough to cover the full cost of the capacity assessment. If our clients do not have the funds to cover the assessment they basically have to wait until they save up enough money to do that.[1869]

The other issue is that while there are some assessors who understand disability accommodation from a disability rights point of view, there are not many:

> . . . there must be disability accommodations in place to enable that person to really demonstrate their level of capacity and decision making, … we've had to

---

[1867] Herring, *supra* note 190 at 11–12.

[1868] The Ministry of the Attorney General stated that there are nine datasets contain statistics covering the OPGT's clients and their operations. They are all related to public guardianship. The percentage here comes from "Property guardianship client by age and gender||CSV" dataset. "Property guardianship for incapable adults | Ontario.ca", online: <https://www.ontario.ca/data/property-guardianship-incapable-adults>. No public information about the personal guardianship was available.

[1869] Interviewee # 13, *supra* note 1838.

> find very creative ways of explaining that to assessors, getting them to agree to have those accommodations in place and demonstrating to them how the person can make decisions with the supports and services that they need in place … And the OPGT itself is a barrier … it's very difficult for our clients to get any kind of meaningful communication with their OPGT representatives.[1870]

The OPGT represents the state's responsibility towards its citizens in a concrete way. The problem is that we may be willing to intervene in the name of protection in the form of taking over decision-making for the person deemed incapable, but less willing to intervene to provide support that allows for autonomous decision-making. The disability rights lawyer pointed to the importance of having the necessary supports in place, such as stable housing, access to health care, and disability services and supports, so that her clients under OPGT guardianship can be stable enough to demonstrate to the OPGT that they can be independent decision-makers again. There is a systemic problem with the way that the OPGT approaches its role as guardian of property. OPGT representatives have very high caseloads and tend to crisis manage clients. It is very difficult for clients to have meaningful conversations with their OPGT representatives. OPGT representatives are not well trained in working with people with disabilities to connect them with the right community supports to enable them to develop their decision-making capacity and enable them to create situations in their lives that can support their capacity.[1871] One could argue that for some disabled people, there is a need for extra protection and support so that they can lead lives of an equal quality to other disabled and non-disabled people.[1872]

It is not my intention to argue that any legal reform will be straightforward.[1873] Some of the legal constructs such as capacity and consent are so ingrained in our health care system, legal system and our everyday language that wholesale legal reform will have significant implications well beyond LTC and the health care system. I do not suggest that the state no longer has any obligation to protect us when we become incapable or where we otherwise pose a danger to ourselves and others. I also do not suggest that current legal safeguards such as notice requirements are completely irrelevant or simply too abstract for LTC residents and similarly situated persons. The small number of successful challenges of findings of incapacity with

---

[1870] *Ibid*.

[1871] *Ibid*.

[1872] Shakespeare, *supra* note 106 at 21.

[1873] Law Commission of Ontario, *Legal Capacity, Decision-making and Guardianship Final Report* (Toronto: Law Commission of Ontario).

respect to LTC admission illustrate that the checks and balances are still being used. But I do suggest that it is easy to overlook the legal rights of LTC residents, and by extension, individuals who experience disadvantages in relation to disability, age and gender. There is no shortage of policy prescriptions and commentary on this subject.[1874] If one accepts the proposition that caring for another can amount to an exercise of power,[1875] it is necessary to attend to the realization of legal rights (even in their current individualistic form). Unfettered exercise of power can easily lead to the harms that disability scholars have pointed out in the context of institutional care. The existing rights are justifiable if understood as the result of an ongoing struggle for striking an uneasy balance between the state's protective function and individual autonomy.

9.5.3 Co-regulation: What does participation look like in LTC?

In this section, I concentrate on describing the collective dimension of participation in LTC, rather than individual participation at point of care, such as those described in the previous section. In particular, I will focus on two related issues: enforcement and compliance and continuous quality improvement. I concentrate on these issues because they have not been dealt with in recent research on participation,[1876] and information about participation and engagement is available. As well, the current policy work on patient engagement[1877] serves as an interesting backdrop to the existing mechanisms in LTC.

In LTC, and possibly true for other parts of the health care system, there are only a few organizations that represent service users or clients: Ontario Association of Residents' Councils (OARC), Family Council of Ontario (FCO), Concerned Friends of Ontario Citizens in Care Facilities (Concerned Friends) and regional organizations such as regional networks of Family

---

[1874] *Ibid*; Law Commission of Ontario, *A Framework for the Law as It Affects Older Adults: Advancing Substantive Equality* (Toronto: Law Commission of Ontario, 2012).

[1875] Herring, *supra* note 190 at 6.

[1876] Barken & Lowndes, *supra* note 705.

[1877] Mandate letters are issued to provide direction and highlight priorities for government agencies. Health Quality Ontario received a mandate letter on May 1, 2015 that helped clarify its role in key areas of the health system. In his mandate letter to Health Quality Ontario, the former Minister of Health and Long-Term Care Dr. Eric Hoskin stated that "I am deeply committed to creating a health care system with patients and not just for patients. My goal is to have Ontario recognized globally for its commitment to patient engagement." Ministry of Health and Long-Term Care, *Mandate Letter from the Minister of Health and Long-Term Care to the Health Quality Ontario* (Toronto: Ministry of Health and Long-Term Care, 2015).

Councils.[1878] They participate in different ways, partly because their memberships have different legal rights to participation. As explained in Chapter 7, Residents' Councils are mandatory and empowered by the LTCHA to perform certain functions and exercise rights within the home. Family Councils are optional, but where they exist, the LTCHA confers certain powers and assign functions to them. Families and friends may have certain rights to participate if they are substitute decision-makers or have power of attorney.

One theme that emerged from the interviews is that the concept of co-regulation is a useful way to describe the involvement of residents, families and friends. The concept of co-regulation connects well to the regulatory techniques as well as the relationships of those involved in regulating. In Chapter 8, I discussed the formal legal reporting requirements, such as reporting obligation of abuse of residents for everyone except residents, that are part of monitoring of compliance in homes. These reporting requirements help the Ministry to identify potential incidents of non-compliance and possible quality problems in homes. The respective roles of residents, families and friends in co-regulating are described below. As discussed in Chapter 4, the Ministry's enforcement and compliance activities have always been subject to intense scrutiny and to criticisms from all sides. Compliance is intended to be one of the solutions to the problem of quality care. It is interesting to see how compliance is a problem of itself. If problem-solving is a discursive process, how do participants provide feedback to each other? "Each stakeholder brings a different type of local information and feedback to the process of creating interim regulatory goals and to the assessment of the feasibility of the goals."[1879] I will first explain how different participants provide feedback to the regulator, then how some participants use their own expertise to provide feedback to consumers, and finally, how participants provide feedback to the homes (the regulated).

9.5.3.1 Providing Feedback to the Regulator to Reformulate the Regulatory Goals

In previous chapters, I have compared how the current compliance and enforcement regime becomes even more prescriptive over time as the LTCHA becomes more precise in terms of the

---

[1878] Family Councils Ontario, "Education and Networking", online: <https://fco.ngo/education-and-networking/family-council-networking>. An example is the Champlain Region Family Council Network. Champlain Region Family Council Network, "About the CRFCN", online: <https://www.champlainfamilycouncils.ca/about>.

[1879] Alexander, *supra* note 339 at 128.

range of powers and objectives of the regime. The legal requirements are given operational meaning by administrative decisions made by the Ministry, such as training, human resources and communication. From a problem-solving perspective, I will explain how the two user organizations provide feedback to the Ministry.

Compliance and enforcement can be described as the "human face" of regulation.[1880] One such human dimension of enforcement is the training of inspectors. Both the FCO and the OARC have reported on the work they have done to support the on-going transformation of the Long-Term Care Quality Inspection Program (LQIP). Their involvement in the LQIP is just one of the many Ministry, or Ministry-related, advisory groups and consultation tables that they are involved in. For the FCO, they worked with the Ministry on the Inspector Protocol on Family Councils and addressed concerns about inspectors' interviews with Family Council members. The FCO agreed that the inspectors have responded really well to some of the issues that they brought forward, such as families' difficulties with talking about suspected abuse and neglect issues or families being shy. The inspectors have really tried to learn how to speak with families better and have also been able to offer various ways of having a Family Council involved in the inspection process, for example through having an online survey.[1881]

Similarly, the OARC also referred to its on-going relationship with the compliance and enforcement branch of the Ministry and provided examples of OARC's involvement in inspector training. The OARC emphasized to inspectors the importance of the Residents' Council interview and "digging deeply" through their questions and observations to protect residents' dignity and respect.[1882] The Executive Director elaborated on how residents may experience inspection of their home:

> It was identified through their [MOHLTC's] own metrics and evaluations, that there needed to be a little bit more sensitivity to residents, more positive relational … words used, phrases used, etcetera. Because sometimes, when inspectors go into the homes, there's a sense of intimidation. And sometimes residents themselves and staff members are unsure of what to say and what not to say.[1883]

[1880] Morgan & Yeung, *supra* note 75 at 10.

[1881] Interviewee # 2 and 3, *supra* note 1773.

[1882] Ontario Association of Residents' Councils, *OARC in Action (June)* (Toronto: Ontario Association of Residents' Councils, 2015).

[1883] Interviewee # 14, *supra* note 1762.

She reported that at a recent inspector training, there were inspectors who were fully recommitted to looking at the inspections from a resident's perspective.[1884]

9.5.3.2 Providing Feedback to Consumers about Regulatory Outcomes

The process of providing feedback is not always unidirectional i.e., from third party associations to the regulator. One of the regulatory tasks is to communicate performance of the system. According to Windholz, monitoring regulatory regime performance and adjusting accordingly is one of the regulatory tasks.[1885] This task is shared with the third-party associations also. The key here is a third-party association providing feedback to consumers, in addition to providing feedback to the regulator. In some ways, this may represent a solution for the scarce resources issues on the regulator's end.[1886] However, there are no clear and transparent ways for third party associations to be accountable to consumers.

The Concerned Friends of Ontario Citizens in Care Facilities represents another way of being involved in the co-regulation of the sector. As a non-profit organization run by volunteers, Concerned Friends is involved in both individual and systemic advocacy work.[1887] The presence of advocacy groups in the health care system is not new. Some of its work can be described as filling in knowledge gaps of the current compliance and enforcement system. Concerned Friends receives electronic copies of every inspection report. Its volunteers review each report and maintain a database with the results of the inspections for each home. In the case of the RQIs, they do a more detailed analysis which allows them to track and compare over time the most frequent areas of non-compliances.[1888] On its website, the Concerned Friends provides information about the number of Written Notifications, Voluntary Plans of Correction and

---

[1884] *Ibid.*

[1885] Windholz, *supra* note 50 at 227.

[1886] Julia Black & Robert Baldwin, "Really Responsive Risk-Based Regulation" (2010) 32:2 Law & Policy 181. Black explains that regulating according to a risk-based framework exposes the reality that there will be a limit to the resources that can be spent on controlling certain types of risk creators (e.g., low-impact firms) or on firms in certain cases (e.g., medium/high impact but low risk).

[1887] Concerned Friends of Ontario Citizens in Care Facilities, "The Work We Do", online: <http://www.concernedfriends.ca/our-work>.

[1888] Concerned Friends of Ontario Citizens in Care Facilities, "How the Inspection Process Works", online: <http://www.concernedfriends.ca/look-long-term-care-homes/how-inspection-process-works>. See also Long Term Care Task Force on Resident Care and Safety, *supra* note 562.

Compliance Orders issued as a result of RQIs.[1889] In addition, in its newsletters, the Concerned Friends publishes a list of high-risk homes regularly. The Board of Directors of Concerned Friends provided the rationale for doing the work that they have been doing and explained what type of information and assistance that families and friends of LTC applicants or residents require. It is apparent from the interview that greater transparency and accountability in LTC is an important driving force in the work of Concerned Friends.

> . . . the way we summarize it is we're looking for trends, so year on year, are certain areas of the province getting better or worse? Are certain areas, in terms of the types of issues that arise, like safety or resident rights, whatever it may be, are they improving or getting worse?[1890]

Further:

> what we did was out of everything we picked the top homes that had the most director's referrals that were unresolved in that year. It's just based purely on fact. We didn't want to publish anything inflammatory, but we just wanted for people to know and to hold the homes a little bit accountable, and the Ministry accountable.[1891]

They were careful to point out that they also publish the names of homes that have no compliance orders and have done well in the RQIs so that a more balanced picture is presented.[1892] But they also commented that the Ministry should be disseminating information: "In some ways we feel kind of like we've been doing this work that the Ministry should be doing."[1893]

One could argue that the Concerned Friends uses its knowledge of what friends and families need to (or wish to) know about LTC to disseminate information about the sector in the form of advice about individual homes or interpretation of trends and emerging issues in the sector. Recall that regulation is about behaviour change or modification.[1894] And the concept of co-regulation is used to capture a variety of regulatory models that sit between the extremes of government regulation and self-regulation. In co-regulation, government and private parties

---

[1889] Concerned Friends of Ontario Citizens in Care Facilities, "Inspection Results", online: <http://www.concernedfriends.ca/look-long-term-care-homes/inspection-results>.

[1890] Interviewee # 5 and 6, (2017).

[1891] *Ibid.*

[1892] *Ibid.*

[1893] *Ibid.*

[1894] Windholz, *supra* note 50 at 8; Black, *supra* note 6.

share responsibility for the development and implementation for the regulatory regime.[1895] The Concerned Friends is co-regulating the sector in the sense of assuming some regulatory tasks (in this case, making information about enforcement and compliance more transparent) and of holding the regulator accountable. I am not suggesting that the Concerned Friends has the same power and responsibilities as the Ministry as the regulator. But one of the regulatory tasks is to inform and educate.[1896] While the Concerned Friends does not have any legal recognition of its status (unlike Family Councils and Residents' Councils),[1897] it operates in a more flexible and informal way to attempt to influence the behaviour of homes. The problem is that we do not know how to evaluate the impact of this type of feedback on the operation of homes over the longer term.

9.5.3.3 Providing Feedback to the "Regulated" to Influence Behaviour

One of the claims of New Governance scholars is that participating individuals, organizations and institutions can hold each other accountable to achieve interim regulatory goals because they are armed with better information.[1898] In Chapter 7, I explained how the LTCHA created or strengthened procedures and processes for inclusion of residents and friends. Together, they allow users to provide feedback directly to the home. On the one hand, these procedures and processes to some extent empower residents and friends to hold homes accountable for certain aspects of the operation. Additional space for problem-solving is made possible. One could even go as far as arguing that residents, families and friends now have a responsibility to monitor the operations of the home. On the other hand, these new or strengthened procedures and processes do not guarantee that their advice and recommendations will be accepted by the home. One implication is that once these mechanisms are in place, they may be used for other purposes that go beyond the scope of the LTCHA. Quality improvement is

---

[1895] Windholz, *supra* note 50 at 162–164; Dennis D Hirsch, "The Law and Policy of Online Privacy: Regulation, Self-Regulation, or Co-Regulation" (2010) 34 Seattle U L Rev 439 at 465.
[1896] Windholz, *supra* note 50 at 227.
[1897] But its work is acknowledged in a formal way too. For example, the Task Force on Resident Safety noted that the Concerned Friends continues to analyze every MOHLTC inspection report, and post information about trends and areas of non-compliance. This work provides helpful information to families of residents in LTC homes. Long Term Care Task Force on Resident Care and Safety, *Third Progress Report on An Action Plan to Address Abuse and Neglect in Long-Term Care Homes (October 2013 – October 2014)* (Toronto: Long Term Care Task Force on Resident Care and Safety, 2014) at 8.
[1898] Alexander, *supra* note 339 at 131.

an example of how mechanisms can be used for a different purpose than the one for which they were originally designed.

Quality improvement is an area where we have some indication as to how Family Councils and Residents' Councils are included. The percentage of homes that described involving their Residents' Councils and Family Councils in the development of their 2016/17 QIPs increased to 92%, compared with 72% of homes in the 2015/16 QIPs.[1899] According to HQO, "This is an important way for residents and their families to be involved, and will facilitate the movement toward patient/resident-centred care in Ontario."[1900]

However, the percentages provided by Health Quality Ontario tell us very little about the experiences of homes, residents, and families in the development of these Quality Improvement Plans, aside from whether homes are involving the Councils. One industry association representative had not heard any positive or negative comments from association members about their experience with engaging Residents' Councils and Family Councils in the completion of Quality Improvement Plans.[1901] When I asked the interviewees from OARC and FCO about their members' respective experiences with Quality Improvement Plans and quality improvement in general, they both suggested that the picture is more complex. The OARC interviewee suggested that it is an "ongoing conversation to convince administrators and leadership teams that it is valuable to invest in the Residents' Council for the purposes of implementing quality improvement."[1902] The interviewees from FCO reported that it has not done any survey with Family Councils but remarked:

> it's really different from home to home. Some homes really involve the Family Council formally, and it works out really well. Those families are invited to the strategic planning retreats where they look at everything. They look at quality improvement and their vision and it's wonderful. And then there are other homes where they stood in the hallway and asked families and then indicated that they had Family Council involvement in their Quality Improvement Plans.[1903]

[1899] Health Quality Ontario, *supra* note 1470 at 6.
[1900] *Ibid* at 24.
[1901] Interviewee #10, *supra* note 1743.
[1902] Interviewee # 14, *supra* note 1762.
[1903] Interviewee # 2 and 3, *supra* note 1773.

The OARC has attempted to communicate to homes the importance of engaging Residents' Councils in quality improvement.[1904] The OARC interviewee elaborated on homes' responses to those efforts:

> It really is a mixed reception . . . Residents' Councils have often been viewed within the homes as almost frivolous activities that are plugged into the activity calendar, like tea socials, a nice opportunity for residents to get together and chat. But the dynamic nature of the Residents' Council in terms of influencing the operation of the home, to build quality, that is sometimes a difficult message for some administrators to grasp. We have seen a shift over the years. Absolutely, we are seeing more and more homes embrace the idea of utilizing the Residents' Council.[1905]

Again, she linked this back to the requirements in the LTCHA:

> The Long-Term Care Homes Act specifically says that the licensee is to consult with, take the advice of, report results back to the Residents' Council. The home is to have a program in place that analyzes the quality improvement in the care, services, accommodation, everything that affects a resident. And all of those results are to be communicated back to the Residents' Council on an ongoing basis.[1906]

But this process is more than just meeting legislative requirements:

> Quality needs to be driven from a resident's perspective. . . They [residents] see things, hear things, experience things that management and team members, staff members, just don't have the ability to tap into. So, encouraging homes to work very, very closely with the resident population through the Residents' Council is paramount in having Quality Improvement Plans that are meaningful. Again, there's a lot of activity going on, but if it doesn't change the residents' lived experience in a positive way, then it's futile.[1907]

This leads us to a more general question of whether these procedures and processes have any benefits. In the next section, I will consider the limitations of the new or strengthened participatory mechanisms. In particular, since these mechanisms are now firmly in place (at least legally), what factors may limit their usefulness?

[1904] Ontario Association of Residents' Councils, *2014-15 Annual Report* (Toronto: Ontario Association of Residents' Councils, 2015) at 10.

[1905] Interviewee # 14, *supra* note 1762.

[1906] *Ibid*.

[1907] *Ibid.*

9.5.4 Flourishing Participation Rights but Dwindling Benefits? Limitations of (New) Participatory Mechanisms

In the pages above, I have described how interviewees interpreted their organizations' participation and provided justifications for their activities. Together, they provide another layer for understanding participation and inclusion in areas where the disability literature has devoted less attention. Some may question whether these mechanisms actually have any influence over how problem-solving occurs. Some may discount the symbolic value of these mechanisms. It is more accurate to conclude that non-state actors have very different experiences in influencing problem-solving in LTC homes and at the provincial level. To conclude the analysis on changes to governance, I will explore the limitations of applying and developing New Governance approaches.

The techniques of participation require a closer look. New Governance approaches utilize local and informal networks of private and public stakeholders who are involved in complex, but collaborative, institutional relationships. Further, the "relational" nature of the collaborative networks is assumed to result in mutual trust and cooperation.[1908] To recap, one of the challenges is developing outsider groups' capacity to engage effectively and thus participate as equals in the deliberative process.[1909] As well, a process that purports to include marginalized stakeholders and work towards win-win solutions might instead re-inscribe existing power dynamics to the detriment of the client group.[1910] The research conducted here shows how these concerns documented in the literature are exemplified in my case study. In the remaining section, I will explain what participation looks like in LTC.

9.5.4.1 Responding to information generated by users

The utility of some mechanisms of participation (as currently conceived), specifically in terms of improvement to quality of care, is a matter of contention. From a New Governance perspective, participation is not an end in itself. New governance privileges continued and sustained collaboration, which is expected to produce key information, unique insights, and key

---

[1908] Alexander, *supra* note 339 at 126–127.
[1909] Sturm, *supra* note 351 at 269.
[1910] NeJaime, *supra* note 352 at 356–357.

innovations.[1911] In LTC, many of the participatory processes intended to generate information for quality improvement are generally consistent with the idea of problem-solving as a discursive process. The challenge is to ascertain whether the information collected or generated is useful, and for whom.

One criticism is that while LTC homes collect a great deal of information—to meet legislative requirements and as part of their accountability to government— homes have typically focused their efforts on data collection, not on using the data to identify issues and improve performance.[1912] Consider the annual satisfaction survey. According to the Canadian Institute for Health Information, LTC facilities across Canada use many different types of survey tools to capture feedback on quality of care. A standardized, common survey tool is key to improving performance through comparative reporting.[1913] According to one industry association representative, there are many variants of non-professional satisfaction surveys used across Ontario. Therefore, it is not possible to obtain reliable, sector-wide comparative data. The association has urged the government to implement one questionnaire, or one methodology, for resident satisfaction data and to have that data collected by an independent third party, as opposed to by individual homes doing the data collection.[1914] Another industry association representative expressed a similar concern. In a nutshell, the system as a whole does not benefit from any of the information that it has collected:

> You have everything from large organizations that use external processes, pay hundreds of thousands of dollars to do their satisfaction surveys and then you have homes that just build and administer a survey. The sector as a whole is not able to do anything with the outcomes of these surveys to respond to common resident and family issues because the data is not comparable from one organization to the other.[1915]

However, the need for standardization of satisfaction surveys may conflict with the intent of the LTCHA's requirements about surveys. The results of the survey, as well as the process of conducting the survey, are intended as a means of fostering inclusion and participation of residents and families independently. As the interviewee from the OARC explained:

[1911] Alexander, *supra* note 339 at 131.

[1912] Long Term Care Task Force on Resident Care and Safety, *supra* note 562 at 46.

[1913] Canadian Institute for Health Information, *Patient-Reported Experience Measures: Long-Term Care* (Ottawa: Canadian Institute for Health Information).

[1914] Interviewee # 16, *supra* note 179.

[1915] Interviewee # 10, *supra* note 1743.

> When homes are found non-compliant with regards to the annual satisfaction survey, it's because they have not understood or not articulated or not engaged in the three separate components of working with the Residents' Council. . . In some corporations . . . they have a survey . . . that is exactly the same across the entire organization. But the LTCHA is specific in terms of each home needs to provide the opportunity for residents to create questions that are very specific to them. . . . So, the Residents' Council needs to have the opportunity to review the existing survey and create questions or add to it, or take away from it, so that it reflects the current wishes of the residents who are living there.[1916]

That said, the interviewee also acknowledged the rationale for standardized questions:

> Our encouragement to homes is yes, you can have a standard kind of corporate survey, but as long as there is an opportunity for a few questions to be uniquely written per site, then they would be legislatively compliant, right?[1917]

Furthermore, residents are entitled to participate in the whole process, from providing feedback and input about the dissemination of the survey to working with the home to come up with plans to address any areas identified for improvement based on the information collected.[1918] The issue here is that while the law is clear that residents (through the Residents' Councils) have the right to influence the content and process of the surveys, it would take some creative negotiation between each home and each Residents' Council to come up with a solution that satisfies the system's need to have reliable and comparable data while at the same time allows residents to have a voice locally so that the survey is meaningful to them.

A more fundamental tension is that these formalized participation mechanisms are now tasked to do things that were not generally done by health care users until recently. According to one industry association representative, many Family and Residents' Councils are involved in fundraising, event planning and peer support. She offered possible explanations as to why Family Councils may not be involved in quality improvement:

> A lot of them operate still on that peer support basis. They're not interested in clinical quality outcomes, measuring the number of bed sores or the number of falls. They're interested in improving quality of life and improving the experience of living in a long-term care home. In addition, both Family and Residents' Councils are often in flux as membership turnover reflects the frailty of the population in long term care homes.[1919]

[1916] Interviewee #14, *supra* note 1762.
[1917] *Ibid.*
[1918] *Ibid.*
[1919] Interviewee #10, *supra* note 1743.

The FCO representatives expressed a similar view about why some family members may not participate:

> Quality improvement can be very, very boring. And it's hard to figure out how a family would be involved in some of it. Some of it's very detailed and very practical, that I'm not sure what involvement a family would have around that, other than to learn about it.[1920]

Further, the FCO representatives explained, "Family Council members are changing all the time. They may not understand the difference between an inspection and accreditation. There's still that knowledge gap with families."[1921]

9.5.4.2 Collaboration and enabling relationships

While this research has adopted the position that the interests of the parties involved in caring relationships are interdependent, I do not suggest that all caring relationships are enabling. Conflicts are not uncommon in LTC and some of the interviewees have shared their experiences of conflicts. The conflicts may be between health care providers and home, between health care providers and families, between residents, or between families and home. For example, one union representative explained that:

> . . . there have been some circumstances where there's limitations put on a family member visiting and the circumstances that they do. Because sometimes family members have their own issues and so it's tough, it's a difficult area . . . it's got to be a safe workplace and even family members need to be held accountable for their actions, right?[1922]

Complex power dynamics may be in place. Conflicts are also present in policy-making forums. The question is whether changes by way of New Governance mechanisms can actually foster collaboration.

One limitation of these legally-enabled participation mechanisms is that they do not always produce enabling relationships and collaboration within the home. Consider the example of Family Councils. The interviewees representing Family Councils provided an account of some of the challenges associated with supporting Family Councils and gave examples of when formal mechanisms are not enough. When asked whether a Family Council can help de-escalate a

---

[1920] Interviewee # 2 and 3, *supra* note 1773.
[1921] *Ibid*.
[1922] Interviewee # 15, *supra* note 1714.

situation or try to problem solve a little bit, the interviewees pointed out that the picture is more complex:

> That can happen. Sometimes it just makes it worse, because it can just become a spiral of complaints. And it really depends on the capacities of the Family Council members, whether they have the ability, the skill set, the knowledge and the willingness to undertake that conflict resolution approach, or whether they just let it spiral into something that's not productive.[1923]

It should be noted that while FCO has a variety of tools about how to run a Family Council,[1924] the interviewees noted that they would like to offer more support, such as community mediation. They also highlighted the potential negative impact on staff when a Family Council gets into a vortex of complaints:

> Staff feel targeted by the Family Council. And they try to avoid Family Councils. It gives the Family Council a bad name so that the staff who feel really scarred by whatever was said will be very hesitant to step up and help another Family Council. Even if those Family Council members that were originally there all step back from the council and another one is established, they're very hesitant, because they've already been scarred . . . it's hard to get beyond that.[1925]

But the interviewees rejected the idea that the LTCHA should be amended to prohibit family members of former residents from participating in Family Councils. Rather, they argued that each Family Council should be able to decide on membership, otherwise many Family Councils would lose some of their long-time members.[1926]

9.5.4.3 How to Augment Participation?

To conclude the analysis, I will provide my final thoughts on the conditions necessary for New Governance. In the literature, scholars have debated why New Governance experiments succeed or not and how these experiments can be perfected to achieve normative goals, including distributive justice. Here, my focus is on exploring how some of the intrinsic factors of participants and their circumstances may be implicated in their participation. I then add to the discussion about conditions necessary for meaningful participation and why existing "patient engagement" activities are not enough to accommodate the needs of those in caring relationships.

[1923] Interviewee # 2 and 3, *supra* note 1773.

[1924] Family Councils Ontario, "Resources", online: <https://www.fco.ngo/resources>.

[1925] Interviewee # 2 and 3, *supra* note 1773.

[1926] *Ibid*.

The demographics of residents and their family and friends also present challenges that the law cannot necessarily solve. It becomes a question of whether we should maintain the status quo (the law as it stands) while exploring which resources and supports are required to allow these legally mandated mechanisms to continue to function for as long as possible. For example, residents are increasingly entering LTC homes when they are older and have more impairments, including cognitive impairments. One industry association representative explained:

> People are being kept home longer and longer and longer . . . the length of stay in LTC is shortening to such an extent that homes are increasingly becoming a hospice for frail, elderly individuals with dementia.[1927]

Some associations in the sector have begun to re-think the viability of Residents' Councils, considering the range of engagement activities currently available in different parts of the health care system. For example, one of the industry associations, AdvantAGE Ontario, proposed to the government that instead of mandating that each home must ensure a Residents' Council is established, every home will make reasonable efforts to ensure a Residents' Council is established. The rationale is that homes are not capable of ensuring they have a Residents' Council; they can only encourage the establishment of one. Nor are homes able to guarantee how active a Residents' Council will be.[1928]

The Change Foundation's report, *Enhancing Care, Enhancing Life: Spotlight on Residents' Councils and Family Councils in Five Long-Term Care Homes in Ontario*, is a recent example of empirical research that has been undertaken on the councils. One of the report's findings was that many residents struggled with cognitive impairment, and these residents were not sure about how residents' councils functioned, were unclear about how the councils engaged with other residents, administration and family members, and had difficulty participating in face-to-face meetings.[1929] The report also noted that administrators and family members observed the difficulties of engaging these residents.[1930] "In the end, the home can report they have a Residents' Council, as the legislation requires, but the capacity of the Residents' Council to carry

---

[1927] Interviewee #10, *supra* note 1743.

[1928] AdvantAGE, *Advancing Senior Care Recommendations to Change the LTCHA and Its Regulation (February 2017)* (Toronto: AdvantAGE, 2017) at 16.

[1929] Change Foundation, *Enhancing Care, Enhancing Life: Spotlight on Residents' Councils and Family Councils in Five Long-Term Care Homes in Ontario* (Toronto: Change Foundation, 2017) at 36.

[1930] *Ibid*.

out its mandate may be limited."[1931] The report argued that mandating one specific model—a Residents' Council—may not be the best practice for engagement. Instead, it may make more sense to provide a range of engagement options for residents, families and home administrators to consider.[1932]

The OARC provided a counter argument to this recommendation. When asked about its reaction to the Change Foundation's report, the OARC interviewee emphasized the importance of having a protected space for residents:

> We are very pleased with the legislation that protects the sanctity of a private meeting for residents and only residents. . . . But the idea that Residents' Councils may not be the best way or the only way to get a resident's voice is something that . . . our organization strives to protect that notion.[1933]

The OARC actually encourages Residents' and Family Councils to work together, but also insists that having a "residents only" meeting is essential.[1934] The interviewee explained the rationale:

> Residents have told us, time and time again, that having other people in their meeting changes the dynamic. It often creates an environment where there is less sharing amongst each other. . . . there needs to be that sanctity about private meeting for residents only, and they get to invite whoever they wish to have come into their meeting.[1935]

She also explained that the solution is not opening up the legislation, but "equipping that Residents' Council, that core group of people, with what they need to make decisions."[1936]

The challenge of empowering a Residents' Council so it remains representative of all residents in the home does not appear to be insurmountable if different meeting formats, Council governance structures, and appropriate supports can be put into place. When asked about the priority of including the voices of residents who are living with cognitive changes,[1937] the interviewee reiterated the importance of having the necessary supports in place to allow

---

[1931] *Ibid*.

[1932] *Ibid* at 37.

[1933] Interviewee # 14, *supra* note 1762.

[1934] *Ibid.*

[1935] *Ibid*

[1936] *Ibid.*

[1937] The Ontario Association of Residents' Councils' 2015-17 strategic plan included four priorities, the other priorities were: respected community partners and strong community awareness, dynamic and sustainable growth and pursuit of excellence in governance. Ontario Association of Residents' Councils, *2015-16 Annual Report* (Toronto: Ontario Association of Residents' Councils, 2016) at 12.

Residents' Councils to be the voice of all residents, and working with other organizations to bring education to residents:

> The core group of residents who are actively involved in their Council need to be equipped with tools and knowledge so that they can build relationships with people who have dementia. It's not automatic, they need to have that education . . . so that the Council can be confident and the administrator can be confident that the decisions made in that Council represent, to the best of their ability, everyone who lives in the home.[1938]

In addition to residents learning how to build relationships with those residents living with cognitive changes, others in the home also need to learn how to support Residents' Councils:

> The assistants to Residents' Councils . . . received little to no education on how to facilitate a very complex group. One of our education modules is on facilitation techniques where we talk about exactly that, group dynamics and how to help navigate through conflict resolutions and difficult personalities. And very practical information around sound systems, speakers, microphones and various ways and techniques that you can implement, so that people who have issues with hearing comprehension, vision, et cetera, that their needs are met and participate to the best of their ability.[1939]

The point is that now that the legal rights are firmly in place, the next hurdle is to identify the variety of forms of participation that are not predicated on assumptions about independence and capacity. Shakespeare reminds us that disability should be understood in terms of a continuum.[1940] This is a respectful way of describing the diversity of residents living in LTC today in terms of how impairments affect them. We could argue strongly that the Residents' Councils can perform functions just like other patient advisory groups in other parts of the system. Yet it must be acknowledged that for residents with significant cognitive and other types of impairments, their participation may not look like anything familiar to us: rational individuals deliberating freely in an organized fashion without any assistance. These residents may communicate very differently and most likely require supports. It is possible that in some smaller homes, it is not even possible to have a sufficient number of cognitively well residents to be the core group that forms the Residents' Council. Some Residents' Councils may not perform all the functions that they are legally permitted to do. To put it differently, in reality there will always be Residents' Councils that do not conform to the legal image of a Residents' Council. This does

---

[1938] Interviewee # 14, *supra* note 1762.

[1939] *Ibid*.

[1940] Shakespeare, *supra* note 106 at 5.

not negate the fact that the ongoing existence of such mechanisms helps to change the language we use to describe the legitimate role of residents in the operations of their homes. The range of powers and functions of the Residents' Council is broad enough to accommodate residents at both ends of the disability continuum. Some Residents Councils will be very active and organized at some point, but later, may switch to a less active mode. The home is put in a difficult position when the Residents' Council is on hiatus because it could be found in non-compliance with the LTCHA. Rather than making the Residents' Council non-mandatory or merging it with the Family Council, the solution may be to clarify when a home has met its obligation in ensuring that a Residents' Council is established. Without the legal mandate, it is easy to reduce Residents' Councils to optional social activities offered at the discretion of the home.

Engagement with residents' families and friends comes with its own set of difficulties and the need for support in this area is also pressing. As mentioned earlier, patient engagement is a longer-term trend in the health care system and patient engagement activities occur across a spectrum of approaches.[1941] Health Quality Ontario has released the Ontario Patient Engagement Framework[1942] and published a variety for tools for health care providers and "patients" (which include patients, residents and families).[1943] The justification for patient engagement is instrumental in nature and grounded in the promotion of continuous quality improvement:

> Ontario's Patient Engagement Framework is designed to inspire action towards the ultimate goal—a strong culture of engagement that drives continuously towards better care and better health for Ontarians. With patients and caregivers as partners, there is no limit to the quality of care that Ontario can achieve.[1944]

Health Quality Ontario's tools address barriers to participation to various degrees. By way of example, a guide about patient and family advisory councils makes a case for diversity on councils:

> As publicly funded agencies, health care organizations also have an obligation and responsibility to reduce barriers so that all Ontarians can access high quality care that is appropriate to their needs. For the people who may face the highest challenges in navigating the health system (e.g., vulnerable or marginalized

---

[1941] Health Quality Ontario, *Ontario's Patient Engagement Framework: Creating a Strong Culture of Patient Engagement to Support High Quality Health Care* (Toronto: Health Quality Ontario, 2017).

[1942] *Ibid*.

[1943] Health Quality Ontario, *supra* note 1477.

[1944] Health Quality Ontario, *supra* note 1941 at 6.

> populations), this means making clear efforts to involve those with these lived experiences in decisions that affect their care.[1945]

The guide also suggests that health care organizations ask themselves questions about any barriers that might prevent people from participating, such as child care or elderly care, meeting times, accessible meeting places for people with disabilities, spoken or sign language interpretation, transportation costs, and culturally and religiously appropriate food.[1946]

While tips and tools for reaching out to those who face barriers to participation are helpful, the reality of being in a caring relationship[1947] makes participation impossible for some. This needs to be part of a larger policy conversation about supporting those who are in caring relationships. The interviewees from FCO explained the problem eloquently:

> I think there is this feeling, or there is this myth that family caregivers should be involved in all this stuff without really understanding that often family caregivers are a sandwich generation. They may have young kids, as well as being a caregiver to their mom or dad, or whoever. And they have limited time and focus and their hearts are broken, because they have to deal with whatever level of care there is for the person they are caring for. So I think it is all well to say family engagement, but without looking at the reality of that and figuring out how do you have that engagement really? So there needs to be all different creative ways.[1948]

To this observation, I would add that families and friends of residents are not always "young" in terms of chronological age, active, and independent (in the sense of not requiring any assistance).[1949] The point here is that if meaningful participation of those in caring relationships is considered an integral part of problem-solving, we must be mindful that the system's ability to harness their knowledge and expertise is curtailed by the reality of caring and other care and work responsibilities.

This speaks to a more general point about supporting families and friends of LTC residents. In the disability studies literature, some scholars object to or hesitate to engage in

---

[1945] Health Quality Ontario, *Creating and Sustaining Patient and Family Advisory Councils – Recruiting for Diversity* (Toronto: Health Quality Ontario, 2017) at 7.

[1946] *Ibid* at 8.

[1947] Herring, *supra* note 190 at 10.

[1948] Interviewee # 2 and 3, *supra* note 1773.

[1949] In one Canadian study of individuals between 45 to 85 years of age, 38.2% of participants report only providing care, 8.1 report only receiving care, and 6.2% are both caregivers/receivers. This study does not include individuals who live in LTC homes. See Debra Sheets et al, "Chapter 6: Caregiving and Care Receiving" in *The Canadian Longitudinal Study on Aging (CLSA) Report on Health and Aging in Canada: Findings from Baseline Data Collection 2010-2015* (Hamilton: Canadian Longitudinal Study on Aging, 2018) 74.

discussion about carers' rights or promotion of the interests of carers. Their objections reflect a deep resentment of the disability community being perceived as a 'burden' on society.[1950] The tension here is to recognize the inter-dependencies of both parties in a caring relationship without reducing one party to mere burden of care. The feminist political economy literature proposes a range of promising practices in LTC, including conditions that allow families and friends the option of participating or not in care.[1951] FCO is also doing research to examine the role and scope of available support services in LTC. The goal of this research is to understand how families are being supported and to explore ways that FCO can improve these services.[1952] One finding is that families that received regular care from a Social Work/Social Service Worker found that it had positive impacts on both their residents and themselves. These families accessed counselling services, support groups, workshops and other formal and informal supports. These services in turn helped family members to manage caregiver burnout and to better support their residents.[1953]

Currently, the LTCHA is silent on providing support to informal caregivers other than the provisions about powers and rights of Family Council and detailing the obligations of substitute decision-makers. Devoid of their socio-legal context and the reality of caregiving in our case, participation mechanisms are unlikely to significantly advance the interests of residents and families and friends. The challenge is to identify the ways in which law can support the implementation of promising practices identified in the literature or community-based research. As well, it is important to identify situations where the law should not intervene.

While the legally mandated mechanisms have definitely given a voice to residents and their family and friends, the limitations of law are also apparent. On the one hand, it is important to acknowledge that not all residents or their families and friends can participate simply because they have the legal right to participate and be included in different decisions. On the other hand, we need to re-think the purpose of different types of engagement. The key concern is whether the appropriate supports can be provided so that disabilities and impairments are not barriers to

---

[1950] Herring, *supra* note 190 at 5–6; Soldatic & Meekosha, *supra* note 116 at 204–205.

[1951] Armstrong & Daly, *supra* note 696 at 125–126.

[1952] Family Councils Ontario, "Supporting Families Research", (2018), online: *Updates and Events* <https://www.fco.ngo/updates-and-events/updates/supporting-families-research-project>.

[1953] Family Councils Ontario, *Supporting Families in Long Term Care Results from a Research Project* (Toronto: Family Councils Ontario, 2018) at 8.

meaningful participation. This discussion also invites disability studies scholars to continue to theorize the involvement of families and friends of disabled people in a respectful way while being vigilant against resurfacing the concept of of disabled people as mere “passive recipients of care”.

9.5.5 **Summary**

If we accept that relationality is one of the markers of care, as argued by Herring,[1954] then it is obvious why it is imperative to examine mechanisms that purport to enable and empower parties in caring relationships. Meaningful participation entails seeking out the needs and wishes of those in caring relationships, in particular residents. Participation – if properly understood and supported - can be a crucial concept in refurbishing institutional care. One of the strengths of Ontario’s system is that participation in health care and activities of daily living decisions are a matter of right for residents. In particular, residents (or LTC applicants) do enjoy a range of procedural rights to ensure autonomy is respected in health care consent and guardianship matters. However, the insights offered by the key informants and through data collected by the Consent and Capacity Board raise questions as to how those procedural rights are exercised in practice.

Since participation is a central organizing concept in New Governance, I have examined how participation is regulated in LTC. I concentrated on participation in regulatory tasks because this area has received less attention in the literature and remains under-theorized. I conclude this section with my thoughts on how to augment participation of residents and families and friends. New Governance approaches, including participation of non-state actors, are not panaceas. One of the debates in the literature is the conditions that are most likely to influence the realization of New Governance approaches. The key concern is whether the appropriate supports can be provided so that disabilities and impairments are not barriers to meaningful participation for those who are willing to participate. Since this dissertation is based on the assumption that the interests of those in caring relationships cannot be considered in isolation, it follows that participation of families and friends is worth exploring. The reality of being in a caring relationship serves as a concrete example of how the larger social context constrains

---

[1954] Herring, *supra* note 112 at 20.

participation of family and friends. This brings us to the last category of implications – the law's role in creating solutions for the broader structural issues. Since law is a tool that is at the disposal of the state, we can understand the relationship between state and citizens by looking at tools used (and those rarely used).

9.6 Law's response to caring: An on-going struggle to define state / citizen relationships

In the previous sections, I have explained the law is used to construct care within the home. The state's responsibility is to define what care means, to specify how to provide it, by whom and to reduce any potential of harm. One could also find expression of state responsibility in how the law creates or strengthens mechanisms to give residents and their families a role to play in problem- solving at the home level. I have also explained how problem-solving occurs in the area of quality improvement as understood by the government. In this last part of the dissertation, I will explain how the government deploys legal rules to delineate its responsibilities in LTC. The provincial government never really played the role of the provider state in LTC and its role is evolving. This section will present my observations and analysis regarding how these regulatory changes shape the balance of responsibilities among users of LTC (residents and families), homes and the state. I draw on the work of feminist political economy as well as on Herring's work on the markers of care. The discussion here focuses on the following aspects: access to LTC, choice in LTC and a risk-based approach to regulation and enforcement.

9.6.1 Few substantive changes to regulation in terms of entitlement, delivery and conditions of care

My main argument here is that while LTC (an institution created by law) can potentially play an important role in creating a safety net for a specific group of older adults (mostly older women with disabilities and illnesses), there are also obvious institutional gaps that from a gender perspective, have implications for those who require care. Filling in the gaps is a collective problem from an equality perspective. In the previous section, I explained how problem-solving occurs in the area of quality improvement as understood by the government. Now I turn to the government's role in problem-solving some of the structural issues in the sector. I look at how the government problem-solves the reallocation of dependency.

9.6.1.1 Access to LTC

In some ways, LTC is fulfilling its role as an institution, in terms of managing some of the common vulnerabilities generally associated with aging, in particular those vulnerabilities that emerge closer to the end of life. As Herring puts it, a central role for the state must be to ensure that the dependency needs of individuals are met. Thus, care cannot be dismissed as a private activity of no interest to the state.[1955] Although more older Ontarians, including those who depend on care as well as those who provide care, express their preference for aging at home and for receiving home and community care over institutional care,[1956] some will not be able to reside safely in the community. One of my interviewees provided a more balanced view about transitioning out of or remaining in LTC. He pointed out that for those who want to return home to live with a spouse or a family member, often there can be a smooth transition through the LHIN Homecare Services. Since over 90% of the doctors who give care in long-term care are family physicians themselves, often they can provide continuity of care or work with colleagues to give care. He cautioned that:

> Sometimes it can be an inappropriate discharge, but the patient or the resident is expressing their own autonomy with this decision, that it can be a relatively unsafe world for some people out there. At least in long-term care, they have their Residents' Bill of Rights and they have the assurance of medical care and care standards. Whereas in a community setting they don't have that same sort of established protection.[1957]

LTC is meeting the housing, health care, and personal care needs (but not always adequately, judging by the intense scholarly and media attention to the sector) of a very specific group of older women who are disabled and/or diagnosed with illnesses such as dementia. However, the interpretation of their needs is probably best described, to use Nancy Fraser's term, as subject to a thinner and narrower definition of need. As such, LTC reallocates, to some extent, the responsibility for dependency from individuals and the family to homes created and regulated under public authority. This reallocation is important not just for this particular group of older women, but also for their informal and formal caregivers (if any). The issues of wait times and projections of LTC needs have been written about extensively in scholarly and public policy

---

[1955] *Ibid* at 3.
[1956] Ministry of Health and Long-Term Care, *supra* note 562 at 174.
[1957] Interviewee # 4, *supra* note 1744.

documents, but the focus here is an exploration of how different individuals may be affected by wait times differently, although there is a common set of admission criteria and prioritization scheme applicable to everyone. Formal equality is not the problem here.

From the perspective of equality of access to LTC, the government has come closer to recognizing the relevance of age to economic insecurity and deprivation that older Ontarians may experience, but the necessary attention to the complex intersection of age, disability, and other grounds — and the resulting disadvantages and privileges — is still lacking. Indeed, there are piecemeal efforts to address the affordability of the LTC system by way of price control, better disclosure of fees, and prohibition of bed-holding fees to make access more equitable for those "deserving" of state-funded care. It is instructive to consider the social and economic context in which these residents may find themselves.

The economic characteristics of older Canadian women help contextualize the cost of care on residents. The key is that how the cost for LTC is allocated to individuals needs to be examined with a gender lens. There has been a long-term decrease in low income rate among seniors (65 years old or older) since the late 1970s.[1958] Although the prevalence of low income among seniors has dropped significantly, a gender gap in low income rates is evident among the senior population.[1959] From 1995 to 2013, the low-income rate increased by 8.1 % among senior women and 6.4 % among senior men.[1960] More importantly, senior women not living in an economic family were the most vulnerable to being in a low-income situation. The prevalence of low income has risen the most among this group of seniors over the last two decades.[1961]

There are some obvious gaps in the LTC system that impact not just those who reside there but also those who are waiting from the community. As noted earlier, there are some nuances in the wait time data that are concerning. Not only has the median wait time for LTC placement steadily increased, some groups appear to have to wait longer. I am not suggesting that the eligibility criteria and prioritization scheme impose adverse differential treatment on

---

[1958] Statistics Canada, *Low Income in Canada - A Multi-line and Multi-index Perspective* (Ottawa: Statistics Canada, 2012) at 29.

[1959] Chantal Collin & Hilary Jensen, *A Statistical Profile of Poverty in Canada (PRB 09-17E)* (Ottawa: Library of Parliament, 2009) at 15.

[1960] Statistics Canada, *supra* note 25 at 20.

[1961] *Ibid* at 21.

older women or racial or religious minorities that amount to discrimination. However, it is worth exploring the impact of longer wait times from the perspective of reallocating responsibility for dependency.

9.6.1.2 Growing pressure for LTC solutions

It is worth exploring the circumstances of those who apply to LTC homes in the community. While a lot of media attention is on Alternative Level of Care patients (or "bed blockers" as portrayed in the media), about 42% of residents entered LTC homes from the community in 2016-17. More importantly, about 29 % of residents did not have home care at the time of admission. This percentage has remained fairly stable in the past 5 years. It is reasonable to assume that for those without home care, their informal (unpaid) or paid caregivers were providing care that they need. Since they were waiting to enter LTC, it is extremely unlikely that they did not have any care needs.

Table 32: Sources of entry to LTC in Ontario (percentages) [1962]

Sources of Entry	2012-13	2013-14	2014-15	2015-16	2016-17
Hospital	37.5	36.5	37.0	35.5	35.4
Residential care	22.4	22.3	22.6	23.8	22.2
Home	39.8	40.9	40.0	40.3	42.0
With home care	11.0	11.6	12.2	12.4	13.1
Without home care	28.8	29.3	27.8	27.9	28.8
Other or unknown source of entry	0.3	0.4	0.4	0.4	0.4
Total	100.0	100.0	100.0	100.0	100.0

In particular, the timeliness of this reallocation of dependency will have implications for older Ontarians and their caregivers (who themselves may also be older Ontarians requiring care), possibly mediated by gender and other factors. Unpaid caregivers often assist with housework, groceries and meal preparation etc, and in many cases, help the care recipient navigate the health care system and advocate on their behalf.[1963] In a more recent longitudinal

---

[1962] I compiled this table by reviewing the Continuing Care Reporting System (CCRS) Quick Stats which include data on demographics, clinical and functional characteristics, treatments and medications, resource utilization, and admissions and discharges. The data is from the tab "Table 4 Source of admission for residents admitted into continuing care facilities". The Canadian Institute for Health Information publishes the data annually.

[1963] The Healthy Aging survey was conducted by Statistics Canada. The survey was not repeated. See Statistics Canada Government of Canada, "Canadian Community Health Survey - Healthy Aging (CCHS)", (26 March 2008), online: <http://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&Id=47963>.

study on aging, results of a subsample of participants who report providing care, receiving care, or both caregiving/receiving are available. Women make up a greater proportion of those who report caregiving (53.9% of the subsample study participants), receiving care (57.7% of the subsample study participants), and both caregiving/receiving (64.0% of the subsample study participants) than men.[1964] Caregiving can entail substantial economic, social, physical, and psychological costs, which caregivers often bear.[1965]

The troubling implication about the changes to the admission criteria is that making it more difficult to get into LTC homes, or delaying LTC admission until applicants are closer to death, will increase the burden on caregivers unless more support for care recipients and their caregivers — in the form of home care or other support — is made available. In a 2016 report entitled *The Reality of Caring*, Health Quality Ontario noted that over a five-year period (2009–10 to 2013–14), long- stay home care patients were becoming collectively older and were increasingly affected by cognitive impairment, functional disability, and frail health. The report also found that family members and other unpaid caregivers were generally more distressed the more cognitively impaired, functionally disabled, and in frail health the patients were. Higher rates of distress were also associated with providing more hours of care.[1966] Equally important, informal care provided in an inadequate manner jeopardizes the care recipient's physical or mental health. Excessive demands on informal caregivers may prompt harmful neglect or violent behavior.[1967] That is not to say the abused person is the real cause of abuse.[1968] It should also be noted that care recipients may also experience distress. In the longitudinal study on aging, care receivers (20.3%) and those who are both caregivers/receivers (19.5%) report dissatisfaction with life at nearly twice the rate of caregivers (10.6%).[1969] It is important to be mindful of the perils of "aging at home" for older disabled adults and their informal caregivers, especially when access to LTC is very difficult.

[1964] Sheets et al, *supra* note 1949 at 75.

[1965] Ministry of Health and Long-Term Care, *supra* note 562 at 174–175.

[1966] Health Quality Ontario, *The Reality of Caring: Distress among the caregivers of home care patients* (Toronto: Health Quality Ontario, 2016) at 11.

[1967] Schneider et al, *supra* note 481 at 223. For a more detailed discussion about abuse and caregiver distress, see Herring, *supra* note 112 at 275–279.

[1968] Herring, *supra* note 112 at 276.

[1969] Sheets et al, *supra* note 1949 at 82.

One could argue that a gap in LTC (as an institution) is that some of the changes in law appear to be gender-neutral but may have a disproportionate negative impact on women that warrants further research. The intention here is not to categorize care as "dyadic and one directional" — that is, one person, often female, caring for another person, typically frail.[1970] Rather, we need to explore how assumptions about care are embedded into LTC regulation. LTC is perceived to be a very expensive type of publicly funded care and the admission process is a way of dividing, sorting, and classifying disabled people — mostly older, disabled women — co-opting some as eligible for LTC while repositioning others as suitable to continue to age in the community. Those who are eligible are further divided into crisis and non-crisis and the wait time for a bed can have consequences, not just for LTC applicants, but also for their families and friends who step into the role of informal caregivers as explained above. The changes to the eligibility criteria for LTC may reflect assumptions that the most expensive type of state support should only be made available when informal care and much cheaper forms of home care have been exhausted. Also, with additional information and other consumer protection measures, residents and their families are expected to make the right "choice" about LTC and to be able to advocate for themselves.

One could argue that while laws governing care are still predominantly gender-neutral, caregiving experience is shaped by assumptions about care and gender and disability. In a review of advice literature about care (caregiver guidebooks), Chivers explains that the female caregiver is "expected to sacrifice her own financial and physical wellbeing rather than pass any 'burden' on to the state, she is also expected to take care of herself and the family members so that no further complications arise".[1971] In a critical review of the research literature on gender differences in dementia care, Bartlett *et al*. argue that gender is a key factor structuring the lives of those living with dementia. They also point out that there are gender differences in the caregiving experience.[1972] Interrogating the effectiveness of LTC as an institution in terms of reallocating responsibility for dependency will depend on whether we can unpack assumptions

---

[1970] Sally Chivers, "Cripping Care Advice: Austerity, Advice Literature, and the Troubled Link between Disability and Old Age" in Katie Aubrecht, Christine Kelly & Carla Rice eds, *Aging / Disability Nexus* (Vancouver: UBC Press 2020).

[1971] *Ibid*.

[1972] Bartlett et al, *supra* note 116.

about care and measure the impact of law through a gender lens. The language of choice and autonomy illustrates how choice is elevated in law, which will be addressed later.

While the discussion above clearly presented a critical view of the provincial government's role in controlling access to LTC through the establishment of admission criteria and managing capacity of the system, it should be noted what constraints are faced by the provincial government. As noted in Chapter 4, the Ontario government does not operate or own LTC homes. Any expansion of (or mere maintenance of) LTC capacity will rely on the co-operation of home operators. One strand of research in the feminist political economy literature is the relationship between quality of care and non-profit delivery, which includes municipal homes.[1973] To extend this debate, I suggest that we need to consider whether the state has any role to play in promoting non-profit delivery. Reflecting on the appropriate role of municipalities in LTC is a useful way to explore the tensions inherent in the state's responsibility towards its citizens.

9.6.1.3 Creating LTC capacity

The provincial government uses its power to legislate to mandate each municipality to operate at least one LTC home (with some exceptions).[1974] From a quality of care perspective, this would appear to be consistent with the research findings in the feminist political economy literature. But viewed from a municipal lens, the picture is more complex. I asked two interviewees, representatives from an industry association and the Association of Municipalities of Ontario, about the challenges of running municipal homes. It is not surprising that they both reported challenges such as higher labour costs due to arbitration awards and the highly prescriptive nature of the LTCHA and other reporting requirements.[1975] The perspectives from the Association of Municipalities of Ontario revealed more fundamental questions and tensions about the appropriate role of the municipal government in LTC delivery.

[1973] McGregor & Armstrong, *supra* note 719; Margaret J McGregor et al, "Complaints in for-Profit, Non-Profit and Public Nursing Homes in Two Canadian Provinces" (2011) 5:4 Open Med e183.

[1974] This requirement applies to any Southern municipality that is an upper or single-tier municipality and Northern municipality that has a population of more than 15,000. Municipalities may operate joint homes. *Long-Term Care Homes Act, 2007*, *supra* note 425, ss 119–124.

[1975] Interviewee # 16, *supra* note 620; Interviewee # 17, *supra* note 620.

By way of background, the Association of Municipalities of Ontario released a number of policy documents about the municipal role in providing services to seniors.[1976] An important theme in the Association of Municipalities of Ontario's 2019 paper is municipal flexibility with respect to the types of seniors' services that municipal governments provide.[1977] In a 2016 paper about age-friendly communities and seniors' services, the Association of Municipalities of Ontario urged the provincial government to engage the municipal sector in policy and program decisions as partners.[1978] The Association of Municipalities of Ontario interviewee explained that no consensus exists across the whole municipal sector about whether this mandatory requirement should exist at all.[1979] The nature of LTC is a matter of contention:

> We always had debates in the municipal sector about what the appropriate municipal role should be in service delivery ... Health is a very contentious policy field area, especially in the municipal sector. Municipalities are involved in delivery, and funding, and we're the employers in health services that includes long-term care, ambulance services, public health, etc ... Many people are viewing long- term care as healthcare and palliative care - a little different from the residential care that it used to be when it was first established.[1980]

In another 2019 document, the Association of Municipalities of Ontario explains its position: "Given the evolution of long-term care into complex health care service, property tax base is neither a sufficient nor a fair source to top-up provincial funding for what is essentially is an area of provincial jurisdiction."[1981] The interviewee explained that:

> we [Association of Municipalities of Ontario] don't always think it's appropriate that a municipality should have to fund healthcare services because that's an area of provincial jurisdiction under the constitution. So, with long-term care homes, they're funded primarily by the province through the funding that we receive, but municipalities have to top-up that funding. We contribute more than what the provincial funding costs, especially when it comes to capital redevelopment cost we're responsible for that as well. So, there's not a consensus because it's viewed as healthcare.[1982]

[1976] Association of Municipalities of Ontario, *Coming to a Crossroad: The Future of Long Term Care in Ontario* (Toronto: Association of Municipalities of Ontario, 2009); Association of Municipalities of Ontario, *Coming of Age: The Municipal Role in Caring for Ontario's Seniors* (Toronto: Association of Municipalities of Ontario, 2011).

[1977] Association of Municipalities of Ontario, *A Compendium of Municipal Health Activities and Recommendations* (Toronto: Association of Municipalities of Ontario, 2019) at 9.

[1978] Association of Municipalities of Ontario, *Strengthening Age-Friendly Communities and Seniors' Services for 21st Century Ontario* (Toronto: Association of Municipalities of Ontario, 2016).

[1979] Interviewee # 17, *supra* note 620.

[1980] *Ibid*.

[1981] Association of Municipalities of Ontario, *Long-Term Care: Municipal Challenges in Ontario* (Toronto: Association of Municipalities of Ontario, 2019).

[1982] Interviewee # 17, *supra* note 620.

Besides concerns about funding,[1983] the Association of Municipalities of Ontario also cites other challenges such as increased regulatory burden, need to improve provincial-municipal conversations about LTC and seniors' services, recruitment issues and governance.[1984] The Association of Municipalities of Ontario's most recent position is that it is not advocating for municipal governments to get out of the LTC home business. However, communities have different populations, existing services, and assets. Accordingly, local municipal governments each face different challenges.[1985] The interviewee was also careful to point out that the Association of Municipalities of Ontario was not advocating for the municipal sector to get out of LTC, and he reiterated that some municipalities wished to remain involved in the delivery of LTC:

> Many [municipalities] do this because they know they're responding to the needs of vulnerable residents in their communities. As well, there are high community expectations of long-term care . . . they have a very high standard of care so it really meets the need in the community where other for profit, nonprofit operators might not be able to meet.[1986]

Some of the issues referenced by the Association of Municipalities of Ontario could be solved by additional provincial funding or by modifying some aspects of the regulatory framework to better reflect the distinctions of different types of homes. For example, monitoring and compliance of municipal homes could be streamlined to reflect the additional oversight and accountability mechanisms of municipal homes (e.g. oversight of the responsible municipal Ombudsman and Auditor). But the fundamental unease (at least among some municipalities) with being involved in LTC delivery is more difficult to resolve. The question is whether one level of government should continue to mandate another level of government to deliver a service that is arguably of better quality than other providers when there is no clear consensus as to the distribution of collective responsibility for LTC among different levels of government. Allowing municipalities to choose whether they wish to operate LTC homes may exacerbate unequal access to services based on geographic locations, although for-profit and other non-profit homes may be able to fill in the gap. However, the practical reality of operating a municipal LTC home may be in tension with the objective of equal access regardless of geographic location.

[1983] Association of Municipalities of Ontario, *supra* note 1977 at 11.
[1984] *Ibid* at 10–13.
[1985] *Ibid* at 9.
[1986] Interviewee # 17, *supra* note 620.

9.6.2 Illusion of "choice" and autonomy

The language of choice and autonomy further obscures questions about the role of the state in the LTC system.[1987] Autonomy, the usual argument that people should be free to develop and live out their own version of the good life, is closely linked to the claim that people are responsible for the choices they make.[1988] Recall that in the feminist political economy literature, it is argued that choices "involve how the system is structured, how funding is allocated, who is eligible for care, and who is available to provide that care."[1989] Scholars have been asking important questions about what exercising choice means for residents in LTC.[1990] Following the scholarly debate that takes a more critical and nuanced view of choices in LTC, I add that the ability to make a choice is unevenly distributed due to factors such as age, gender, race, ethnicity, disability and class.[1991]

9.6.2.1 Making choices

The problem of LTC placement wait times illustrates the practical restrictions on choices, despite promises made in laws governing LTC admission. At face value, the LTCHA provides many choices in accommodation; it appears that applicants should share the responsibility for extended wait times, for example, because they decide to choose a religious or cultural home instead of choosing as many homes as possible.[1992] But the reality of making accommodation choices can be rather different.

The exercise of choice of accommodation may be even more restricted for those affected by poverty. Late life poverty is not only systemic, it is unequally distributed.[1993] Those who are eligible for co-payment reduction, for example, cannot choose semi-private or private rooms. The elder law lawyer explained why applicants or their families may choose certain homes. She reflected on her clients' experience to illustrate the practical difficulties of choosing a home when they were pressured by the hospitals:

[1987] Lai, *supra* note 637.
[1988] Herring, *supra* note 112 at 21.
[1989] Armstrong & Daly, *supra* note 163 at 11.
[1990] *Ibid* at 13.
[1991] Lai, *supra* note 637.
[1992] *Ibid*.
[1993] Grenier, Griffin & McGrath, *supra* note 23 at 17.

> A client's husband had dementia. . . He was fairly violent. But when she was there, he was calm. . . Her commitment to her husband was that she was going to be with him [at the LTC home] every day so that they could help take care of him, because she didn't want to see him restrained or anything else. She was blind in one eye. This was such a terrible case. She couldn't drive. And they [hospital] wanted him to go to a home that was about 40 kilometres away. She's poor. She could not get there.[1994]

Further,

> [t]here are different reasons why you'd be attracted to different homes. But in some cases, people need to apply to certain places because of accessibility. . . But there are good reasons why people pick places, particularly poor people, because they can't get from here to there.[1995]

The lack of alternatives is captured by her comment:

> The systems don't work well in terms of your rights to choose because there aren't enough of the long-term care home beds out there. And so we've got these huge long waiting lists now. It's a terrible situation.[1996]

In other words, in the LTC context, the formal right to choose is simply a poor substitute for substantive equality.

Even without the hardest cases such as those explained by the elder law lawyer, access to LTC is also a problem not simply because the system's capacity does not match the demand. Part of the problem lies in the processes of application and admission, despite the procedural safeguards in place (see Chapter 8). Herring reminds us that "The typical presentation of an unencumbered, free, rational decision maker is simply a fiction."[1997] Unsurprisingly, the LTCHA is intended to protect individuals from undue influences while empowering them with more information. The Concerned Friends also commented that "access to long term care is very difficult."[1998] Since the Concerned Friends receives calls from people who are looking for LTC homes, it is in a position to explain how applicants experience the application and admission process. When I asked the interviewees whether they were aware that applicants would be pressured into selecting LTC homes that have the shorter waitlists, they responded:

> Basically, they're [applicants] told: here's the list of homes in your geographic area, tour them, here's some considerations you might want to think, and then

---

[1994] Interviewee # 12, *supra* note 1699.
[1995] *Ibid*.
[1996] *Ibid*.
[1997] Herring, *supra* note 245 at 22.
[1998] Interviewee # 5 and 6, *supra* note 1890.

> pick five, and we really highly encourage you to pick at least one shortlist home, if not more. And so, that's the only information they're given. And they're given a very tight deadline, especially for those who apply from hospital.[1999]

The issues facing those applying to LTC while remaining in hospitals are not new. Jane Meadus of the Advocacy Centre for the Elderly has written on the "choices" being offered to those remaining in hospitals and how hospital policies are inconsistent with the applicable law.[2000]

The Concerned Friends interviewees elaborated on the reality of making LTC decisions.

> Caregivers who are not experts feel very worried, anxious, that they're going to make a decision in haste that they're not comfortable with. So they often ask us . . . what should I do? . . . because everyone's standards and everyone's expectations are so different, we can give some general information about homes maybe to stay a little bit clear from, but, in general, it's only the feeling that you get once you get there and you have to go and look at all these items. So we can give them lots of advice about what to look for, but the time pressure of choosing is very high.[2001]

They agreed that more information would be helpful to LTC applicants and their families:

> people are still confused, or maybe there's a lack of communication with their particular [placement] coordinator. It might be just coordinator to coordinator. And I know some are amazing, really amazing and others are just doing the bare minimum. So, yeah, I think information would help . . . hopefully this new [Ministry] website will help in terms of people having enough information to make decisions about it. . . I think having something that clearly walks them through the process, because oftentimes, even if they're not giving a time pressure and they're in the community, a lot of people don't really understand what the process is.[2002]

9.6.2.2 Deciding without choices?

Another way of illustrating the issue of lack of choice in accommodation is to examine the experience of younger disabled people. LTC is frequently associated with aging in public discourses. What is missing is how and why some younger disabled people come to reside in LTC. This topic is important for my research for the following reasons. First, it shows how aging affects caring relationships, for example, between aging parents and their disabled children. Second, it illustrates how LTC may be a mismatch of impairment and the social environment.

[1999] *Ibid*.

[2000] Jane Meadus, *Discharge from Hospital to Long-Term Care: Issues in Ontario - Updated in February 2014* (Toronto: Advocacy Centre for the Elderly, 2014).

[2001] Interviewee # 5 and 6, *supra* note 1890.

[2002] *Ibid*.

Third, it provides an example of how the rhetoric of choice (enshrined in law) is used to legitimize structural problems in the health care system. The presence of younger disabled people is indicative of law as an inadequate response to a particular type of caring relationship. LTC has become a forum where tensions about aging and disability surface.

I decided to focus on younger people with intellectual disabilities because of the availability of information about their experiences and the history of institutionalization in Ontario. This is not to say other younger residents with other types of illnesses or impairments do not require attention. By way of example, the Multiple Sclerosis Society of Canada has argued that the LTCHA "does not contain any provisions that would facilitate the development and delivery of age-appropriate care within long-term care homes."[2003] Further, "Although only a minority of people younger than age 65 with MS require care in a long-term care home . . . Too often, they are placed with much older individuals in settings designed for frail, elderly people. This can result in a significantly reduced quality of life, which can lead to depression and mental health problems."[2004] As one elder law lawyer remarked:

> There are also people 18 and over in long-term care. . . I always remember one of the women who was my client. She was in her 40s. She had MS. Her husband had been taking care of her at home, but then they just couldn't manage. It was awful.[2005]

Clearly, aging affects familial caring relationships. As explained in Chapter 4, younger people with intellectual and other disabilities may end up in LTC homes because they have nowhere else to go. There is a consensus among interviewees[2006] that sometimes LTC homes serve as the last resort care setting for younger disabled adults and such an arrangement is inappropriate for many reasons. As representatives from a community living organization explained, a person with intellectual disability may have been living with their elderly parents and eventually, they need to move into a retirement home or LTC home because of their own

---

[2003] Multiple Sclerosis Society of Canada (Ontario Division), *The Need for Age-Appropriate Long-Term Care: MS Society of Canada Views on Bill 140, Long-Term Care Homes Act, 2006* (Toronto: Multiple Sclerosis Society of Canada (Ontario Division), 2007) at 2.

[2004] *Ibid* at 3; Multiple Sclerosis Society of Canada (Ontario Division), *Finding My Place: Age-appropriate housing for younger adults with multiple sclerosis* (Toronto: Multiple Sclerosis Society of Canada (Ontario Division), 2006).

[2005] Interviewee # 12, *supra* note 1699.

[2006] Interviewee # 7 and 8, (2017); Interviewee # 11, *supra* note 1711; Interviewee # 13, *supra* note 1838; Interviewee # 15, *supra* note 1714.

health or capacity problems, and a decision has to be made so that the adult child could move at the same time.[2007] A government guideline also reaches a similar conclusion:

> People with developmental disabilities often rely on family caregivers throughout their lifetime. These family members with caregiving responsibilities may also be aging and facing their own health issues. The Aging Project found that caregiver burden was as predictive of admission to LTC home as was frailty.[2008]

The disability lawyer also confirmed that she had encountered a number of situations where people with disabilities were living with their families, such as parent(s). The aging parent(s) experienced some kind of health crisis and required hospitalization. From there, another family member may become the substitute decision-maker for the parent according to the hierarchy in the *Health Care Consent Act* (section 20) or become the attorney if there is a power of attorney. The substitute decision-maker or attorney may consent to LTC admission for the parent.[2009] The substitute decision-maker or attorney may then decide to sell the family home.

> The problem becomes what happens to that person with the disability who was living with the parent in the family home? With family dynamics in the background, questions may arise, such as who gets to be the power of attorney, who gets to make those decisions, and do they take into account the wishes of the person with the disability, or the other family members. There is an absence of a good, accessible, legal, or quasi-legal process to handle or resolve those kinds of dispute. Going to court is not really an accessible, or practical option in those kinds of situation.[2010]

Aging also affects more formal caring relationships. The representatives from the Community Living Association summarized the lack of flexibility to support aging with intellectual disability. Organizations have different capacities to deal with the changing needs of their clients. A person with an intellectual disability may have been living in supportive housing such as a group home, but without additional support, the home may not be able to adapt to his or her changing needs due to aging, coupled with health issues not adequately addressed. This may necessitate consideration of LTC as a living arrangement.[2011] It is challenging to manage his or her changing needs because in the developmental services sector, the funding for the

---

[2007] Interviewee # 7 and #8, *supra* note 2006.

[2008] Ministry of Community and Social Services, *Guidelines For Supporting Adults With A Developmental Disability When Applying To, Moving Into And Residing In A Long-Term Care Home* (Toronto: Ministry of Community and Social Services, 2017).

[2009] Interviewee # 13, *supra* note 1838.

[2010] *Ibid*.

[2011] Interviewee # 7 and 8, *supra* note 2006.

individual basically remains the same once an agency accepts the individual into a formal support arrangement.[2012] Further, the health care system needs to intervene more to help support the health needs of people with intellectual disability while the community living sector continues to focus on supporting the daily activities of people with intellectual disability.[2013]

A clear concern that emerged from the interviews is the lack of choice in housing and community support options for those younger disabled adults and I would argue that this is an affront to autonomous decision-making. The interviewees representing the community living associations considered the findings of the Ombudsman report, waitlists for formal residential support and stories from families and pointed out that "people start looking for what the alternatives are. And long-term care is one door that's open to people and you can see people will try to get through that door, even if it's not really the appropriate place for them to go."[2014]

The disability rights lawyer also expressed similar frustrations with a system that does not address some very challenging needs that people have:

> The Ministry will say, well we don't have anywhere, that's the most appropriate setting for the person, like there's nowhere else for them to go. How could it be that's the most appropriate setting when that setting doesn't even have the mandate to manage that person's disabilities, or provide disability services to that person.[2015]

She remarked, "I've had clients who, given the option of living in a hospital or a long term care, or being homeless, will choose to be homeless. I don't think that that is a meaningful choice. But, you know, some people do make that choice."[2016]

The bottom line is that autonomy for some younger disabled people (or their substitute decision-makers if they are incapable), as it appears in this scenario, is reduced to choosing between physical survival in an inappropriate setting and homelessness. One could argue that admission to a LTC home is not the result of arbitrary state interference and therefore, the state is absolved of any responsibility. However, I contend that it is an inaction of the government that makes the assertion of autonomy impossible for some younger disabled adults. While the legal rules about

---

[2012] *Ibid.*
[2013] *Ibid.*
[2014] *Ibid.*
[2015] Interviewee # 13, *supra* note 1838.
[2016] *Ibid.*

consent may have been followed, the fundamental value of being able to choose one's destiny is sacrificed.

The problem is not so much about the impairments, illnesses or disabilities of these younger residents. Rather, it is the mismatch between what LTC is resourced and mandated to do and the needs and preferences of these younger residents. In earlier chapters, I have argued that the impairment and loss of functionalities due to age-related illness and health conditions drive how care is structured legally. By referencing certain impairments, it is easy to lose sight of the diverse range and extent of impairments experienced by residents and to exclude those who do not have the specified impairments. One disability rights lawyer reflected on the experiences of some of her clients with intellectual disabilities or addiction disabilities [alcohol and drug addictions] who ended up in LTC. She pointed out that people were placed in inappropriate settings because those were the only places where their behaviours could be managed:

> staff in long term care facility don't have training around mental health and addiction or intellectual disabilities because the facility is not, no fault to the facility, set up to provide those kinds of services. The facility was not actually providing any services other than basic needs such as food, hygiene and shelter to those individuals.[2017]

A union representative interviewee expressed strong reservations about LTC homes' ability to provide quality care for all residents:

> the homes were not built thinking about what kind of residents truly were going to be in them. How do you mix and keep busy and keep good quality of care for a 40-year-old developmentally handicapped adult in the same facility, perhaps sharing the same bedroom, as a 92-year-old man who is just a frail, elderly man? When you put all that together and you look at the things that trigger more aggressive responsive behaviours, that's when the challenges come.[2018]

Another union representative remarked that the lack of staffing simply exacerbated the situation:

> . . . when you look at long term care facilities and you look at a lot of the closures in psychiatric hospitals and downsizing and downloading and you look at the closing of facilities that supported people with developmental disabilities, a lot of those people wound up in long term care facilities. And they have significant behaviours and again, when you've got a 12 to one staff ratio you don't have the resources to deal with that stuff.[2019]

[2017] *Ibid* at 13.

[2018] Interviewee # 11, *supra* note 1711.

[2019] Interviewee # 15, *supra* note 1714.

The point here is not that younger disabled people should never be allowed to live in LTC homes. Indeed, program eligibility criteria based on chronological age could be highly problematic too because it could be a form of age discrimination and therefore may offend the *Charter* and/or the provincial human rights codes. But of course, as the Supreme Court states in *Withler*: “a distinction based on an enumerated or analogous ground is not by itself sufficient to found a violation of s. 15(1).”[2020] As well, ageism is clearly no more acceptable than disablism. Assumptions made about younger disabled people can also be used to worsen their situation. For example, incorrect assumptions about their capacity for making decisions can be detrimental to their autonomy. I do not suggest that disabled people of different ages can never share space (including living space) together as beneficiaries of a public benefit scheme. Otherwise, we are at risk of creating a distinction that discriminates by “perpetuating the group’s disadvantage or by stereotyping the group”.[2021]

The lessons here are as follows. First, the admission eligibility requirements in the LTCHA have been tightened to ensure that only the highest acuity candidates for LTC are prioritized for admission by the government’s narrow criteria. It is evident that the “appropriateness” of particular LTC admissions is debatable and we know that for the younger disabled residents, LTC may not be appropriate for them but these eligibility requirements do nothing to prevent a system from assigning them to care / housing options that are not appropriate for them. Second, for a LTC system that emphasizes “choice” and “consent”, it is concerning that the ability to make choices and consent to LTC admission is severely constrained by structural issues (in our case, problems created by the developmental services system as well as the health care system). Third, while I agree that it is not possible to have a single policy solution that attends to all the needs of beneficiaries of a program, we need to be mindful of the implications of a program that is singularly focused on the needs of people with very specific impairments. While it may be positive for those with behavior issues that additional resources have been made available (e.g. Behavioural Supports Ontario, *infra*), this also means that needs stemming from other impairments have not been adequately addressed. In a LTC system where patient-centred or resident-centred care is emphasized in hard and soft law, the lack of

---

[2020] *Withler*, *supra* note 1226 at para 34.
[2021] *Ibid* at para 54.

responsiveness to younger disabled residents' needs, values, cultural backgrounds and beliefs, and preferences clearly demonstrates the mismatch between residents and their environment.

Finally, addressing the needs of these younger disabled adults is also a means of relieving the pressures in the system, and it is achievable. One interviewee representing medical directors encouraged me to take a look at the people who are discharged back to the community:

> They are, in my experience, usually younger individuals with something like an acquired brain injury or a severe neuropsychiatric illness or drug and alcohol abuse that has caused difficulties, for example. Their condition has been stabilized in long-term care and they can go into a supportive living arrangement in the community, which is often more suitable for them, because, again, they're young people and they don't like being in long-term care, because they're in care with what they view as a bunch of old people . . . So, though their numbers are few, when you look at their lifespan, the number of years that they're out of long-term care then becomes significant and they're living a relatively more independent life in the community.[2022]

The interviewees representing the community living associations also agreed that some agencies can show some creativity in terms of how they support a person:

> Some of the more progressive organizations plan around the individual. And I think that can accommodate a person's needs as they age better than, we have this group home model or we have this model of support, and the person doesn't fit into it. So, those progressive agencies are better suited to change with the needs of the individual, where the more traditional agencies, it's more static and a person's increased needs don't necessarily match with the model that they're being provided with.[2023]

To be fair, the issue of adults with developmental disabilities living in LTC has received some attention and work is being done. This is likely to be prompted by the Ombudsman report and the human rights case *Cole v Ontario (Health and Long-Term Care)*.[2024] In 2013, Mr. Cole filed an Application with the Human Rights Tribunal of Ontario (Tribunal) against the Ministry of Health and Long-Term Care (Ministry), through his litigation guardian, Audrey Cole (his mother). Mr. Cole alleged that the funding limit in the regulation discriminated against him and other people with complex disability-related needs because they are denied the level of services

---

[2022] Interviewee # 4, *supra* note 1744.

[2023] Interviewee # 7 and 8, *supra* note 2006.

[2024] Ontario Human Rights Commission, "Cole v Ontario (Health and Long-Term Care) : Challenging the funding limits to live in community settings", online: <http://www.ohrc.on.ca/en/cole-v-ontario-health-and-long-term-care-challenging-funding-limits-live-community-settings>.

that they require to remain outside of institutional care.[2025] On August 16, 2016, Mr. Cole and the Ministry entered into a settlement agreement. The Ministry acknowledged that the previous regulation, with its rigid caps, "had the potential to create hardship and disadvantage for individuals with intellectual and developmental disability living in community settings or long-term care homes." The Ministry also agreed to recommend that CCACs [Community Care Access Centres] be granted discretion to exceed the nursing caps in the regulation for those with "complex care needs".[2026]

By way of example, the Ministries of Community and Social Services and Health and Long-Term Care have developed a guideline to help adults with developmental disabilities who are applying to, moving into and residing in a home. This document provides information about the developmental services sector, how to apply to LTC homes, and processes that impact LTC home residents. For the purpose of this dissertation, I should highlight the principles articulated in the guideline: Flexibility and Choice, Inclusion, Access and Co-Ordination, and Health and Independence.[2027] Not surprisingly, the government's position is that people choose to live in LTC: "In some cases, a person with a developmental disability or their substitute decision-maker (SDM), if any, may feel that a LTC home may be an appropriate place if the individual meets the eligibility criteria . . . It is an individual's choice or that of their SDM, if any, to move into a LTC home (for those who meet the eligibility criteria and receive a bed offer)."[2028] Based on the findings from the interviews, it is questionable whether this group of residents actually has much choice in consenting to LTC admission. But the document makes it clear that the different providers from the development services sector and the health care system must work together on the identification and provision of developmental services and supports in LTC homes.[2029] It remains to be seen as to whether such a guideline can actually help people with developmental disabilities to assert their rights to demand services to accommodate their disabilities.

[2025] *Ibid*.
[2026] *Ibid*.
[2027] Ministry of Community and Social Services, *supra* note 2008.
[2028] *Ibid*.
[2029] *Ibid*.

9.6.3 **Law without enforcement (or with too much enforcement)?**

This last section will analyze enforcement as a function of the state to protect residents from risks of harm. And I will link enforcement to some of the logics of the safety and security provisions of the LTCHA (see Chapter 6). It is probably uncontroversial to claim that in LTC the importance of enforcement cannot be under-estimated and enforcement may take many forms.[2030] The choices made with respect to enforcement are illustrative of the responsibilities of the state towards those in caring relationships.

The previous chapters have touched on the state's responsibilities under the *Charter* and various statutes. But the courts have been very cautious about holding the government liable for any harm suffered by those in institutional care. In *Alberta v. Elder Advocates of Alberta Society*, the Supreme Court makes it clear that no matter how vulnerable LTC residents are, the provincial government does not owe them a fiduciary duty:

> Vulnerability alone is insufficient to support a fiduciary claim. Since the government, as a general rule, must act in the interest of all citizens, governments will owe fiduciary duties only in limited and special circumstances. The interest affected must be a specific private law interest to which the person has a pre-existing distinct and complete legal entitlement, and the degree of control exerted by the government over the interest in question must be equivalent or analogous to direct administration of that interest.[2031]

There is no comparable case to *Alberta v. Elder Advocates of Alberta Society* involving Ontario LTC residents yet. However, there are similarities between those who were institutionalized because of their intellectual and other disabilities prior to de-institutionalization and current LTC residents in the sense that to various degrees, the respective institutions are funded and controlled by the government. The Ontario cases concerning the facilities Huronia, Rideau and Southwestern were settled so we could not say for certain if or how the courts would have decided on the claims of fiduciary duty since the Ontario facilities were funded and directly operated by the provincial government. It is reasonable to conclude that it would be difficult for LTC residents to make a case against the Ontario government in private law. Thus, it is even

---

[2030] Helen Meenan, Nicola Rees & Israel Doron, "Introduction" in Helen Meenan, Nicola Rees & Israel Doron, eds, *Towards Human Rights in Residential Care for Older Persons: International Perspectives* (Abingdon, Oxon: Routledge, 2016) 1.

[2031] *Alberta v Elder Advocates of Alberta Society*, 2011 SCC 24, [2011] 2 SCR 261.

more important to decipher how the relationship between the state and residents (as citizens) is constructed in the enforcement of relevant statutes.

I suggest that regulatory aspects of social programs are under-explored in disability studies but can actually illustrate the state's responsibility towards its (disabled) citizens. Scholars in disability studies have written extensively about how policy and program design pertaining to social programs affects disabled people. Points of contention include the state's responsibility in defining who are "deserving" and who are not and the techniques used. Borrowing insights from other disciplines, such as feminist political economy and regulation literature, is a step towards more nuanced understanding of the regulatory aspects of caring.

The Ontario government frequently refers to the fact that there is a LTCHA and that the government enforces compliance with the LTCHA. The government clearly accepts its responsibility in regulatory matters. But a closer look at how the government carries out its regulatory responsibility can tell us something important about the state / citizen relationship. The Long-Term Care Quality Inspection Program has been subject to extensive and widely divergent commentary, and I do not aspire to resolve it here. In Chapter 8, I described how the range of enforcement tools and sanctions have expanded. Earlier in this chapter, I examined how stakeholders participated in giving feedback for the purpose of making improvements to the LQIP. The earlier analysis concerns the techniques of participation and engagement. The concern here is what the law can tell us about what the perceived risks in LTC are, who are responsible for reducing those risks (or the impact of the consequences) and how. In particular, the notion of 'risk-based' has been used by the government to describe its approach to enforcement, and this section attempts to unpack this notion. The notion of "risk-based" is also embedded in the design of the LTCHA. This provides a way to show how "risk-based" approach is used to define the government's accountability, including resources allocation. This section begins with a discussion on the role of risk in enforcement, followed by an examination of the limitations of a risk-based approach.

9.6.3.1 The role of risk

For Julia Black, risk plays four roles in regulation: "providing an object of regulation; justifying regulation; constituting and framing regulatory organizations and regulatory procedures; and framing accountability relationships."[2032] Governments have to consider how to rationalize or stabilize decision-making on questions such as: which risks should be selected for attention, the nature of that attention and how much should be applied; and who should be involved in making those decisions.[2033] To do so, governments and regulators attempt to develop decision-making principles and procedures to render risk calculable and commensurable.[2034]

Risk's role as "constituting and structuring regulatory processes and accountability relationships"[2035] is most evident in the new inspection program. It is not surprising that given the volume of rules that homes must comply with, the Ministry needs to determine its regulatory objectives and risk appetite as a regulator. Three related roles of legal rules can be identified here. Legal rules are adopted in response to previous regulatory failures – and Ontario has no shortage of those in LTC – and to provide a "political defence to charges of either over- and under-regulation."[2036] The changes to the sanctions available to the Ministry fit into this category and the language of risk helps to legitimize a more adversarial approach. Further, legal rules about how inspections are to be conducted such as actions to be taken in the event of non-compliance are used to improve consistency in the regulator's assessment of homes across a widely varying, regulated population.[2037] As well, legal rules are used by the government to attempt to define the terms by which the government should be made accountable.[2038] The changes to the intensity of the annual comprehensive inspections based on risk are essentially about managing the parameters of blame. Black explains the issue eloquently: "In the context of risk, regulators are asking, implicitly or explicitly, … that they should not be expected to prevent every negative occurrence in the regulatory system … and that they should not be blamed for all those that occur."[2039] I am not suggesting that the recent "risk-focused" approach is used by the Ministry to completely shift blame to the homes, but that it is used to articulate and define what level of risks of non-compliance is tolerable given the resources available to the Ministry.

[2032] Julia Black, "The Role of Risk in Regulatory Processes" in Robert Baldwin, Martin Cave & Martin Lodge, eds, *The Oxford Handbook of Regulation* (Oxford: Oxford University Press, 2010) 302 at 303.
[2033] *Ibid* at 340.
[2034] *Ibid*.
[2035] *Ibid* at 339.
[2036] *Ibid* at 332.
[2037] *Ibid* at 331.
[2038] *Ibid* at 336.
[2039] *Ibid* at 337; Henry Rothstein, Christopher Hood & Michael Huber, "Risk and the limits of governance: Exploring varied patterns of risk-based governance across Europe" (2013) 7:2 Regulation & Governance 215 at 218.

Unsurprisingly, very divergent views about the Ministry's compliance and enforcement efforts emerged from the interviews. It is clear that the interviewees all have identified shortcomings with the LQIP and they were concerned for different reasons. It is also evident that they interacted with the Ministry in different ways and had different experiences in the evolution of the LQIP since its inception.

One could conclude that the narrative of risk in the development of regulations about safety and security and inspections gives rise to questions that are both normative and instrumental in nature. The key informant interviews provide some indications as to the limitations of how the government selects which risks to address, how much attention should be given to those risks and how they should be responded to. The interviews are intended to generate questions about the current risk-based approach.

9.6.3.2 Limitations of a risk-based approach

The first limitation is that safety in a home is constructed predominantly in terms of risks that will harm the physical or bodily integrity of residents. Such a construction limits the government's responsibility towards residents in that the welfare of workers has not been addressed explicitly as integral to the safety of residents. In a caring relationship, Herring argues, the interests and identities of the two people become intermingled. Thus, it becomes impossible to consider the welfare or rights of any one party in isolation.[2040] It follows that discussion about resident safety cannot be complete without including consideration of the safety of formal and informal caregivers. The intertwined nature of caregiving is evident when the interviewees discussed safety in LTC homes. One could argue that a clear gap in approaching safety in LTC homes is that resident safety and worker safety are addressed separately, often at different policy tables, and then are regulated by distinct statutes and regulators. While the measures in the form of legal rules to protect resident safety are extensive (as discussed in Chapter 7 and section 9.3.1), the right to a safe workplace is more circumscribed. One interviewee described the daily occurrences of physical or verbal assaults experienced by his union members in LTC and remarked, "unfortunately, a lot of the incidents of patient to staff violence, you don't hear about them in the public like you would if it was the reverse."[2041] He further explained that his union's

---

[2040] Herring, *supra* note 112 at 4.
[2041] Interviewee # 15, *supra* note 1714.

'Dignity 4.0, Time to Care Campaign' is about allowing staff to have enough time to care for residents so that not only would residents not be neglected, but the safety of residents and staff would also be improved.[2042] Further, she explained that her union has tried to promote a culture of safety for a long time, and said,

> We at ONA [Ontario Nurses' Association] try to have the same people involved in many of these discussions and at many of these tables so we're messaging things the same way. . . but let's be clear, some of the solutions are the same, we're just talking about it at a different table. . . All of that stuff costs money and the question becomes, at what point government can't ignore the fact any more, they just got to fund it properly.[2043]

There are indications that the issue of safety for residents and staff will be addressed in a more integrated manner. Recent initiatives including the Workplace Violence Prevention in Health Care Leadership Table[2044] and reporting of workplace violence prevention initiatives in annual Quality Improvement Plans[2045] show that the safety risk of workers is finally being selected for attention and responded to in the LTC sector.

The second limitation is that the risk-based approach has not eliminated the need to have a consensus about the purpose of the inspection results. Stakeholders offer different understandings of what the Ministry should be doing in terms of the inspection results. The views of the Concerned Friends represent one perspective as to what the Ministry should be doing with the results of inspections. The Concerned Friends also wanted to see improvement: "we want homes to improve, we don't want to just see people publicly shamed, we want the improvement to come out of it."[2046] They elaborated on what they perceived to be as the limitations of the Ministry's approach to enforcement and compliance. In particular, they observed that until recently (2016), there was a small subset of homes that got compliance orders repeatedly, yet the issues were still not resolved. They said,

> we weren't seeing a director's referral come after that to say you have to resolve a issue. . . where's the enforcement policy? Why is this small subset of homes getting away with not being compliant? So actually it was only last year really

---

[2042] *Ibid.*
[2043] *Ibid.*
[2044] Ministry of Labour, *supra* note 1713.
[2045] Health Quality Ontario, *supra* note 1721.
[2046] Interviewee # 5 and 6, *supra* note 1890.

> when we saw a huge increase in director's referrals where there were outstanding compliance issue.[2047]

They also noted that they supported the Ministry's new measures of enforcement, including financial penalties, and that they have advocated for such measures for a long time.[2048] In sum, one could argue that the Ministry was aware of problems in that small subset of homes as evident by the issuance of compliance orders but did not use that knowledge to get those homes to comply.

Another theme is the Ministry's role in resolving problems in the homes identified through inspections. At a standing committee meeting, one government official emphasized that "[t]his is not just about assigning blame or identifying error; this is a solutions-based inspection process."[2049] Another government official also stated that the Ministry would meet with the home and the LHINs are also involved to discuss the issues.[2050] The Concerned Friends also supported developing a closer working relationship between the Ministry and the LHINs on compliance issues.[2051] But one industry association is more skeptical about whether the Ministry is actually trying to problem-solve:

> They probably bring them in and say how come this is happening and the person will say this is why it's happening. They'll say well you have to comply, what's your plan, you have to fix that.[2052]

The lawyer representing homes did not object to the idea of having meetings where the Director and others from the Ministry meet with the LHIN and the home in question, but noted that the process could be more meaningful:

> . . . . having this type of a meeting in the context of a referral to the Director (after findings of non-compliance have already been made against a home) is consequential as opposed to collaborative . . . In such a meeting, the Director – who may or may not involve the LHIN – gives a directive to the home in terms of what it must do to come into compliance. Why not have discussions with the home before it gets to a point where a referral to the Director is necessary? Why not have guidance and advice available to homes from the outset of an issue? I

[2047] *Ibid*.
[2048] *Ibid*.
[2049] *Official Report Journal of Debates (Hansard) (*26 October 2016), *supra* note 1696 at 38.
[2050] *Ibid* at 27.
[2051] Interviewee # 5 and 6, *supra* note 1890.
[2052] Interviewee #10, *supra* note 1743.

> think that that would change what is perceived as an adversarial process to a more collaborative process.[2053]

Another concern that emerged is that users (other than the Ministry) may not be able to utilize the results of the RQIs. A common theme is the utility of the inspection reports. The OARC reported that there is frustration among some Residents' Councils about the inspection reports because the language used is vague and legalistic. The OARC supported and worked with the Ministry's project to create executive summaries for the inspection reports so that residents can truly understand and have meaningful discussions around the inspection reports.[2054] The Concerned Friends also reported similar frustrations among families and friends. They advised people how to find inspection reports and other LTC information on three different websites but people may not understand the information because of the language written. They also supported the Ministry's efforts to update the relevant websites so that the information about the home actually mean something to users.[2055] The OLTCC also felt that the inspection reports are not very helpful in the way they are currently written. It is very hard for the public to determine from the reports why inspections are done and why there are written notifications and compliance orders.[2056]

The third limitation is that emergent and systemic risks that require difficult policy discussions and funding commitments have taken a back seat. The Ministry focuses on risks that occur at individual sites (i.e., homes) by using more command-and-control[2057] type of legal rules and then adopts more adversarial inspection strategies in specific sites. One industry association representative pointed out the strengths and limitations of the Ministry's approach to inspection. She recognized that the Ministry's system is a very robust system to detect incidents of non-compliance and identify individual homes where non-compliance poses high risks:

> So they [Ministry] have a very robust inspection system . . . the tool has built-in algorithms to detect non-compliance. . . probably after 7 years of experience with the tool, it's probably proving to be very effective in identifying homes where there is a high risk of non-compliance that potentially could result or actually results in harm so that's a good thing.[2058]

[2053] Interviewee # 18, *supra* note 1761.
[2054] Interviewee # 14, *supra* note 1762.
[2055] Interviewee # 5 and 6, *supra* note 1890.
[2056] Interviewee # 4, *supra* note 1744.
[2057] For a comprehensive discussion on the concept of command-and-control, see Short, *supra* note 70.
[2058] Interviewee # 10, *supra* note 1743.

Another union representative also questioned the value of the compliance system but from a different angle. From a practical perspective, the RQI happens once a year and it is "like finding a needle in a haystack".[2059] But more fundamentally, he believed that the problem is not inadequate enforcement; but rather, that the lack of a standard of care for residents is the root of residents suffering in LTC.[2060]

However, it is not clear if the RQI data (cumulated over a seven-year period) is being used by the Ministry to anticipate and address system-wide issues. On the one hand, the Ministry claimed that it was looking at what the data can tell beyond performance of individual homes. At a standing committee hearing, one government official claimed: "I think the other critical piece is that the information from our inspections is being fed into policy development options in the licensing and policy area of our division."[2061] On the other hand, one industry association representative expressed reservations about how data is used for addressing systemic issues:

> . . . what happens in one home and the results of that inspection is completely independent of what happens in another home . . . What the ministry has been doing is it provides us with totals [of different sanctions issued]. [This data] also tells you which category, which area, which line, which provision in the Act has the highest number of non-compliances. They're able to count these non-compliances, but … these counts don't give us a true picture of what is going on.[2062]

She used a metaphor to illustrate her point:

> the data is still looking at the trees and it's not looking at the forest. If you have eight rural homes that are closed to admission because inspections identified non-compliance associated with high risks, not all of the issues may be related to the operator. From a system perspective, it begs the question: is this a predictor potentially of future collapse of small rural homes? The ministry is not asking those policy questions. The ministry branch in charge of inspections doesn't involve itself in asking those policy questions. The ministry only cares that the homes are in compliance because its focus is on the safety of the individuals in the home … they don't have tools that explore root causes of non-compliance and how the sector as a whole can benefit from the outcomes of the compliance program . . . and where we could work together to actually improve performance?[2063]

[2059] Interviewee # 15, *supra* note 1714.
[2060] *Ibid*.
[2061] *Official Report Journal of Debates (Hansard)* (26 October 2016), *supra* note 1696 at 38.
[2062] Interviewee #10, *supra* note 1743.
[2063] *Ibid*.

I am not suggesting that the more systemic risks are not addressed at all. For example, in a 2017 consultation paper on aging, the government asked questions about the future of rural and smaller homes,[2064] so this can be an indication that the government is fully aware of the risk of rural homes and plans to take action in the near future. The government has also introduced a small homes sustainability fund.[2065] The question is whether the current 'risk-based' approach can help policy-makers to find a right balance between acting on systemic risks and controlling risks at individual homes.[2066] Another way of looking at this is that dealing with immediate problems can occupy so much attention and resources that risks that may materialize in the future fail to be dealt with.[2067]

The final limitation is the nature of the responses in the form of legal rules to the risks identified as threats to the safety and security of residents. Many additional requirements imposed on homes are procedural in nature, such as having the necessary policies and procedures in place, annual evaluation of various policies and programs, more documentation, and regular reporting. A number of interviewees expressed reservations about the current inspection system. From the perspective of client advocacy, one interviewee who is a lawyer explained her reservation about the Ministry's inspection system in the context of a discussion about the requirement for home to have policies and forms: "But the inspection system, there's definitely value in it, but it doesn't work the way people think it works. . . They only look at the surface."[2068] She used the example of her own research on health care consent forms and tools[2069] to illustrate the problem of a 'check-box' mentality on the Ministry's part:

> We reviewed 100 sets of forms. Not a single set were completely correct. And the Ministry just goes, oh, well, we don't have to deal with the substance. We're only looking at the surface. So, even in the inspection systems, they're not really

---

[2064] Government of Ontario, *Aging with Confidence: Ontario's Action Plan for Seniors* (Toronto: Government of Ontario, 2017). The paper asks the following questions: "What can be done to ensure it is viable for smaller long-term care homes to stay in their community rather than amalgamated into larger facilities? What is a reasonable distance for family to have to travel to visit with their loved ones in long-term care?"

[2065] Ontario Long-Term Care Association, *Seniors in need of long-term care to benefit from landmark 2018 Budget* (Toronto: Ontario Long-Term Care Association, 2018).

[2066] Black & Baldwin, *supra* note 1886. Black and Baldwin explain that which risks to focus on is a political—not a technical—issue and judgments have to be made on such matters as the right balance between acting on systemic risks and controlling individual risks.

[2067] Baldwin & Black, *supra* note 83 at 578.

[2068] Interviewee # 12, *supra* note 1699.

[2069] Judith Wahl, Mary Jane Dykeman & Tara Walton, *Health Care Consent, Advance Care Planning, and Goals of Care Practice Tools: The Challenge to Get It Right* (Toronto: Law Commission of Ontario, 2016).

> looking at the content of things. They don't look at the content of consent. They see that residents consent. They just say, oh, there's consent on the chart, fine.[2070]

An industry association representative also questioned the current emphasis on processes in homes and explained: "they're [Ministry] not inspecting for outcomes of care. They just care about the processes in the homes and that the processes will not result in harm."[2071] She identified a more fundamental issue of the LTCHA:

> If you think of how Donabedian's model of quality is, you have structure, process, and outcome. What the legislation does is it provides structure and process. Structure is the law, process is the regulations and they're hoping it gives the outcomes. But the only outcome they're looking for is compliance with the legislation. They're not looking for the care outcomes, although they say they are.[2072]

This last part draws on scholarly debates about 'risk' and 'risk-based' regulation, which are used frequently in public policy discussions but rarely questioned. The analysis here is intended to provide a new angle to illustrate the state / citizen relationship. It is hard to argue with the observation that the safety and security of residents are prioritized by measures that are intended to minimize certain types of risks. In other words, in the LTC setting, to minimize risk is to reduce harm that is easily recognized and can be measured and controlled. The risks are not necessarily new, for example, the use of physical restraints is not new in LTC (or other parts of the health care system), but our understanding of whether and how to respond to those risks have changed. Not interfering in abusive or harmful situations can leave residents without protection and therefore the legislative intent of the new legal framework is to keep residents free from harm inflicted by workers, volunteers, and other residents. As well, the new inspection program was outlined to demonstrate how the Ministry intends to monitor and enforce homes' compliance wtih these rules in response to the 'risks' posed by the homes. I have outlined the relationship between the notion of 'risk' and legal rules. The analysis here is not intended to reject a risk-based approach to regulation in LTC, but to suggest that careful considerations of its limitations are needed in law reform initiatives.

[2070] Interviewee # 12, *supra* note 1699.

[2071] Interviewee #10, *supra* note 1743.

[2072] *Ibid*.

9.6.4 **Summary**

The last part of the analysis concentrates on the broader structural issues of the LTC sector. The issue of funding, as a critical factor that determines care conditions, has been subject to much scholarly and public debate. I built on the insights from the feminist political economy literature. The structural problems of the sector are evident in the following issues: access to LTC, illusion of choice and autonomy, and enforcement and compliance. It is evident that LTC presents a dilemma to the state: the provincial government is expected to be responsible for LTC because the residents are considered to be "vulnerable" or "dependent" and more importantly, "deserving" but there are few regulatory and non-regulatory tools available to address the structural issues. While the provincial government accepts, perhaps reluctantly, its responsibility towards LTC residents, it also attempts to use different techniques to limit its own responsibility. On paper, some of the legal rules could respond to potential harms in care and indeed advance the rights of LTC residents. However, it is more likely that the legal rules simply create an appearance of unwarranted legitimacy and are in fact means to avoid the reality of LTC today.

9.7 Summary of the claims and theoretical contributions

The regulation of "care" in LTC has been used as a point of entry to examine the potential implications of changes to regulation and governance introduced by the LTCHA and amendments to statutes such as the *Health Care Consent Act*. I share disability scholars' concerns about the dark side of care but accept the possibility of refurbishing institutional care for a very specific group of older disabled adults who are also living with serious illnesses including dementia. Social regulation is integral to refurbishing institutional care but over-regulation of caring relationships may actually undermine concepts such as autonomy. The discussion above should not be construed as an uncritical acceptance of the current legal framework or as a call for more regulation. Rather, the limitations identified in this research invite us to re-think strategies for law reform in this area. Equally important, the gaps in the current legal framework encourage us to explore how debates about disability, gender and aging can be extended.

9.7.1 **Summing up: A regulatory perspective on care in LTC**

Before proceeding to the theoretical contributions of this case study, I will synthesize the claims made in this chapter. Informed by a mixed methodology that included document review, doctrinal analysis and key informant interviews, this dissertation sought to test the hypothesis that the changes to LTC regulation and governance made in Ontario between 2004 and 2018 – if properly understood and implemented – are significant for persons with disabilities. To begin, I established that four themes emerged from a comparison of the current and previous regulatory frameworks applicable to the LTC sector.

The first theme is that the core of the changes to improve care is premised on the notion that residents' medical and clinical needs must be met by highly prescriptive requirements (i.e., what must be done and how). There are indications that "rights" and choices are built into the legal framework and that therefore, individual residents have some control over how care is delivered – at least from a "law on the books" perspective. Quality of care is also supported by ad hoc accommodation of certain types of disability. The second theme is that the new legal framework emphasizes resident safety and security as integral to care. Our understanding of risk of harm is central to the law's response to residents' impairments. The law permits more intense monitoring, documentation of and interference with the person under certain restricted circumstances to keep the resident free from harm inflicted by workers, volunteers and other residents but could also interfere with the autonomy of residents. The third theme is that inclusion and participation are enabled by a variety of rights, duties and safeguards enshrined in the *Charter*, the Ontario Human Rights Code as well as in statutes including the LTCHA, the *Health Care Consent Act* and *Substitute Decisions Act*. At the individual level, participation and inclusion mean that capable residents may exercise control over admission to or being confined in LTC, over treatments and over personal care. The law has not changed significantly but there are some procedural changes that purport to protect autonomy. At the collective level, the new or formalized mechanisms allow LTC residents and their families and friends to have some influence over the activities in their respective homes but not over policy-making at the regional or provincial level. The fourth theme concerns the nature and rationale of the state's relationship with citizens. The changes enhance the state's ability to exercise discretion over LTC policy decisions to ensure system sustainability while distancing itself from some of the operational and financial decisions. A more robust compliance system holds those in charge of providing care accountable for actual or perceived harm. To protect residents as consumers, the state facilitates transactions and exchanges in the LTC market in order to reflect the inherent power dynamics in a home.

Then I explored the consequences of these changes for residents and those around them. Not all of the changes have significant consequences as many of them are simply changes in legal form. The discussion in this chapter focuses on the few substantive regulatory and governance changes. The Ontario LTC system is primarily preoccupied with the physical survival of residents, in particular, safety and security of residents. This preoccupation leads to the myriad of ways through which care is regulated – some in the form of command-and-control type rules and soft law for homes and some through creation of residents' rights and entitlements. I contend that many of the changes actually have taken into account the criticisms of care, including the harm that can result from care. In fact, some governance changes in fact are consistent with concepts such as "choices", "control", "empowerment" and "autonomy". The main problem, I contend, is that the legal mechanisms were designed without careful consideration of how the actual circumstances of residents, connected to the intermeshing of disability, gender and age will impact their proper implementation. The result is that some LTC applicants and residents cannot benefit from the protections offered by law. I have demonstrated that legally-enabled participation – for residents as well as families - is contingent upon having the necessary supports in place. The sum of these claims reinforces the conclusion that the regulatory changes are significant for residents because they formalize and strengthen a number of procedural and substantive rights, entitlements and protections in caring relationships. However, the actual immediate impact of these changes in terms of promoting substantive equality for those living in LTC is minimal in terms of the state's attention to differences – in our case the actual circumstances and needs shaped by age, gender and disability – in the design of a regulatory regime.

9.7.2 **Theoretical contributions**

This case study demonstrated how the insights of disability scholarship (in law as well as in the social sciences) could inform policy debates about our collective responses (including law) to impairments, illnesses, and other differences in later life. At the same time, this case study also touches on topics that have traditionally received less attention in disability studies, such as the experiences of those who have chronic illness and of older people.[2073] While this dissertation

---

[2073] Shakespeare, *supra* note 106 at 6–7.

touches upon a few strands of debates in disability and legal scholarship, I contend that my case study has made contributions in the following areas.

9.7.2.1 Dementia as disability

Scholars such as Carol Thomas and Tom Shakespeare have noted the growing trend of identifying ‘dementia’ with ‘disability’, which is fuelled by the expansion of dementia-related activism and research.[2074] My case study contributes to the debate about regarding dementia as disability as it follows Shakespeare’s interactional model of disability to illuminate some of the long-standing issues in disability, including physical harm suffered by disabled people in care relationships and the role of over-medicalization in care. I expand Shakespeare’s interactional model by focusing on how law mediates the interplay of many different factors that results in disability. The weakness of Shakespeare’s model is that it never really explains in detail how that interplay occurs. Law ought to be an important focus in research on dementia as disability because law can be described as an extrinsic factor that also modifies other extrinsic factors, for example the social environment by mandating certain accommodations such as communication. Law also plays the role of acknowledging or neglecting the intrinsic factors of people living with dementia by defining, emphasizing, and responding to certain aspects of dementia, such as behavioural issues. For many in LTC, their impairments are profound and an anti-discrimination human rights approach alone is inadequate to respond to their needs. This is a concrete study to examine how the law shapes the life of a sub-group of people with cognitive impairments such as dementia (especially those exhibiting aggressions and deemed to be a safety risk) in a particular setting.

This study challenges us to find more respectful ways to theorize how the law responds to the impairment effects of people living with dementia. For Boyle, the presence of dementia is used to justify the denial of human rights to cognitively disabled, older people. In particular, erroneous assumptions about their capacity have led to them being detained in institutions against their wishes.[2075] Not everyone living with dementia resides in an institutional setting, but

---

[2074] Carol Thomas & Christine Milligan, “Dementia, Disability Rights and Disablism: Understanding the Social Position of People Living with Dementia” (2018) 33:1 Disability & Society 115; Tom Shakespeare, Hannah Zeilig & Peter Mittler, “Rights in Mind: Thinking Differently About Dementia and Disability” (2019) 18:3 Dementia 1075.

[2075] Boyle, *supra* note 212 at 512.

some do, and institutions will continue to exist in the foreseeable future even if more state support for community care becomes available. This is true for Canada well as for other OECD countries. While a Marxist / realist perspective may conclude that a regulatory regime that permits confining and restraining residents corresponds neatly to the proposition that capitalist economies have no use for people who live with dementia and therefore they must be "warehoused" in residential care institutions,[2076] there is no clear theoretical explanation as to the variety of residential settings, including the range of substantive and procedural safeguards in place to protect residents. Some safeguards are related to security and safety of the person while others concern autonomous decision-making. By examining how legal safeguards for LTC residents evolved in one jurisdiction, albeit within a relatively short period of time (13 years), this study provides an empirical account of the implication of the changes within the context of other legal developments, such as *Charter* jurisprudence and human rights legislation.

My case study reflects the benefits of looking across different areas of law in order to identify the rights and entitlements of those who live with cognitive impairments and need care. In a recent book about dementia and care in the UK, Rosie Harding observes that dementia has not yet been studied in-depth in the socio-legal literature. This is because dementia raises problems in a range of intersecting areas of law, including health law, tort law, property law and human rights law, and there is a need to look laterally across these areas of law.[2077] In particular, by attending to how law constructs the social and physical environment and caring relationships in residential care, I have added to our knowledge about the need for recognition of the rights of people living with cognitive impairment such as advanced dementia, and why such recognition is fraught with tensions in our current legal system (and by extension, jurisdictions that maintain a more individualistic approach to rights and a binary understanding of capacity).

9.7.2.2 Incorporation of caregivers' perspective in disability research

Equally important, this study builds on more recent work on care that is inclusive of the perspectives of formal and informal (unpaid) caregivers. Earlier rejection of the concept of care by disability scholars and activists meant a strict theoretical separation from care research. More recent disability scholarship looks for mutual learning between research on care and research on

---

[2076] Thomas & Milligan, *supra* note 2074.
[2077] Harding, *supra* note 275 at 2.

disability.[2078] I have contributed to this debate about care by attending to how law constructs caring relationships and by explaining why a binary understanding of "helper" / "helped" and caregiver / recipient is an obstacle to identifying common theoretical ground. Herring's idea that the interests of those involved in caring relationships are inter-mingled is demonstrated empirically by my exploration of workplace violence issues in LTC. Herring's work provides a strong justification for state support for informal carers (such as families) such as combining caring responsibilities with paid employment.

I extended the debate by focusing on support for formal carers in terms of safety and security of health care providers. Recall that one of the markers of care is an acceptance of responsibility.[2079] My account of workplace violence suggests that assuming a responsibility to care for another can be harmful for all parties involved in a caring relationship if the right supports and protections are not in place. The Ontario case study shows that devoid of the socio-economic contexts of caring (such as gender and immigration status of health care providers), legal protections, such as whistleblower protections and mandatory reporting, are unlikely to be effective. Harding reflects on the emergence of "carers" as social and legal subjects.[2080] She is right to point out that "new regulatory instruments have defined and delineated the socio-legal 'carer' as part of a legally recognized relational network with the cared-for."[2081] My case study adds to the growing body of work that examines the complex effects of regulatory instruments on formal and informal carers, who are supported (albeit minimally) and regulated in order to address different forms of risk and harm.

9.7.2.3 Participation in Care

Finally, this case study contributes to the debates about the conditions necessary for successful New Governance experiments by focusing on a novel context, that of LTC. I used New Governance literature to study various governance mechanisms within a home from the perspective of caring relationships. Recall that participation is one of the organizing principles in the New Governance model.[2082] My contribution is to explore whether participation mechanisms

---

[2078] Kröger, *supra* note 156; Hughes et al, *supra* note 186; Watson et al, *supra* note 196.
[2079] Herring, *supra* note 112 at 19–20.
[2080] Harding, *supra* note 275 at 38.
[2081] *Ibid* at 50.
[2082] Lobel, *supra* note 319.

such as those mandated by the LTCHA have the potential to reconcile dependence and autonomy in caring relationships in LTC. The significance of participation is that it involves LTC residents – regardless of how dependent they are on others to meet their needs – in problem-solving around certain aspects of LTC living.

Factors such as gender, poverty and sexual orientation have been examined in New Governance studies. One of the challenges is developing outsider groups' capacity to engage effectively and thus participate as "equals" in the deliberative process.[2083] I provided a concrete example as to how the accommodation of impairment / disability is a condition necessary for the implementation of participation mechanisms. More crucially, this study demonstrates what participation may have to look like for those with profound impairments and disabilities. The deliberative process of residents may not look like anything familiar to us. Providing support to residents with profound impairments may not allow them to participate in conventional deliberations. Rather, the mechanisms of participation are intended to facilitate residents making claims about using their lived experiences in making decisions at the home level and to a lesser extent, in provincial policy-making. Such participation is a way for LTC residents to exercise autonomy collectively beyond expressing “choices” when they receive care.

I close this chapter with a quote from the health law lawyer I interviewed: “there are only so many tools in the toolbox and some of them are a bit blunt. They’re blunt instruments.”[2084] The toolbox is a good metaphor that captures the range of legal devices available to change the behavior of participants in the LTC sector in order to pursue various public policy objectives. This dissertation essentially is a close look at the toolbox and what the tools mean for those who use the tools and who attempt to change the tools (or to use them creatively) because some of them are either ineffective, unjust or actually become the source of problems. I have added equality (especially in relation to disability, gender and age) as the normative value that guides my own assessment of the potential implications of the toolbox. It is my hope that by taking a hard look at LTC in Ontario today, we are better positioned to problem-solve the issues in the sector. The next (and final) chapter will conclude this dissertation with some brief final words about the future of researching regulation and governance in LTC and other public benefit

---

[2083] Sturm, *supra* note 351 at 269.

[2084] Interviewee # 1, *supra* note 1700.

schemes from a legal and public policy perspectives. Through this work, I hope to re-invigorate the debate about how regulation and governance recognize the particular circumstances connected to disabled Canadians and people around them.

10 Conclusion

10.1 Introduction

The concern that inspires this dissertation is the recognition of law's promise and limitations in removing barriers to inclusion of disabled Canadians in the social, economic and political domains. I looked at an unlikely place to study disability and the law: institutional care. In some ways, institutional care is a deserted place from both theoretical and practical perspectives. It is shunned by disability scholars due to the history of institutionalization and on-going struggle against different forms of incarceration.[2085] It is also feared by the general public because as one of interviewees insightfully remarked:

> A large part of the public really think that long-term care is a very threatening and unpleasant place to be. . . we all probably fear our own aging and vulnerability, and that we, ourselves, might end up as these individuals and what life is like when you do become dependent on other people for your most basic care needs.[2086]

There is a growing body of work in the social sciences that informs our understanding of LTC (as a form of institutional care mainly for older adults) and I hope I have demonstrated that LTC is a topic worthy of critical legal research. This dissertation also contributes to existing scholarship by going beyond framing LTC strictly as a population aging issue. Indeed, there is a strong case for bringing aging, disability and gender into the analysis.

In this chapter, I will begin by summarizing the arguments advanced in the previous chapters, followed by a discussion of the limitations – methodological and doctrinal – of this research. The last part will present my suggestions for future research.

10.2 Summary of findings

This dissertation has examined the changes to the regulation and governance of LTC homes in Ontario between 2004 and 2018. The implementation of a new legal framework, the

---

[2085] Ben-Moshe et al, *supra* note 159; Johnson & Traustadottir, *supra* note 17; G Allan Roeher Institute: Information Services & G Allan Roeher Institute: Library, *Deinstitutionalization in Canada: An Annotated Bibliography* (Downsview, Ont: G. Allan Roeher Institute, 1990); Canadian Centre for Policy Alternatives, "Freeing our people: Updates from the long road to deinstitutionalization", online: <https://www.policyalternatives.ca/publications/monitor/freeing-our-people-updates-long-road-deinstitutionalization>.

[2086] Interviewee # 4, *supra* note 1744.

LTCHA and its regulation, along with other changes in statutes and case law provided an opportunity to compare the new and previous regulatory regimes. But as the previous chapters demonstrated, what is “new” is not necessarily in the sense of never have been implemented. Chapters 5 to 8 presented my examination of the changes, divided up into four themes as informed by my literature review. Chapters 5 to 7 demonstrated how the law articulates expectations about what care is and how it is supposed to be delivered. There are indications that “rights” and choices are built into the legal framework, and that therefore, individual residents have some control over how care is delivered. Disability is being accommodated in care delivery: personal assistance, social environment and program design. The new legal framework also emphasizes resident safety and security as integral to care. The changes have important ramifications for the autonomy of residents and the caring relationship. Three dimensions of inclusion and participation have been explored: the equality guarantee under the *Charter,* autonomy in decision-making at the individual level, and collective rights to participate in the operation of home. The new or formalized participation mechanisms allow LTC residents and their families and friends to have some influence over the activities in their respective homes. Chapter 8 shifted the focus to explore the nature and rationale of the state’s relationship with citizens by examining the control of the supply and demand for beds, enforcement and compliance in LTC homes and the corporate and business activities within the home.

Chapter 9 offered some preliminary observations about the implications of the changes for older women who comprise the majority of LTC residents. I also explored, to a lesser extent, the implications of these for other parties in a caring relationship. I made a case for careful examination of the strengthened processes and procedures mandated by law as they represent a re-orientation of how problems will be solved in the LTC sector. These changes to regulation and governance – if properly understood and implemented - are significant for persons with disabilities. They afford more procedural protections to residents in caring relationships and allow residents to make claims for inclusion and participation in making decisions about their own care and influencing conditions within the home. However, there is a gap between the promise of law and the reality of those who require support in order to enjoy the protections conferred by law.

10.3 Limitations of the research (doctrinal and methodological)

There are three main sets of limitations from a doctrinal perspective. First, while it is beyond the scope of this dissertation to explore the changes in private law (e.g. tort and contract), it is plausible that concerns about liability risks play a critical role in how homes make decisions about their operations, such as the prioritization of safety risks of residents. I also have not considered remedies in private law (e.g. damages) and how such remedies may be available (or not) to LTC residents and their families. It is worth exploring the potential of using private law remedies to redress infringement of residents' rights in the Canadian context.[2087] Empirical examination of private law remedies should include careful consideration of availability of support to exercise legal capacity i.e., of the support that a person receives when he or she is making decisions with legal consequences and such support must respect the rights, will and preferences of the person.[2088] Another limitation of this research is that criminal law cases are outside of the scope of the legal analysis. Specifically, I excluded consideration of criminal cases involving LTC residents (as victims or offenders or both).[2089] While reported criminal law cases are few, and scholarship on criminal law cases involving persons in congregate setting is limited,[2090] these cases may shed some light on the most serious failures in care. They are likely to expose the limitations of using criminal law to respond to harm in the context of caring relationships. To examine cases where one or more resident with cognitive impairment is involved, one possible line of inquiry would be to borrow insights from disability scholarship about criminal responsibility, in particular, scholarly debates about recognizing people with disabilities as possessing equal criminal culpability as those without disabilities.[2091] Finally, the disciplinary cases from regulatory colleges (and any subsequent appellate level decisions)

[2087] There is scholarship on the use of private law in the American context. For example, see Kazin, *supra* note 1832; Jennifer L Troyer & Herbert G Thompson, "The Impact of Litigation on Nursing Home Quality" (2004) 29:1 Journal of Health Politics, Policy and Law 11; James A Brickley, Susan F Lu & Gerard J Wedig, "Malpractice Laws and Incentives to Shield Assets: Evidence from Nursing Homes" (2017) 14:2 Journal of Empirical Legal Studies 301; Richard J Mollot, "Residential Care in the United States: a Persistent Struggle for Quality, Dignity and Independence" in Helen Meenan, Nicola Rees & Israel Doron, eds, *Towards Human Rights in Residential Care for Older Persons: International Perspectives* (Abingdon, Oxon: Routledge, 2016) 167 at 178–180.

[2088] de Bhailís, *supra* note 1280 at 2. The author discusses the application of the Article 12 of the UN Convention on the Rights of Persons with Disabilities (CRPD).

[2089] For example, see *R v Lamsen*, 2014 ONCJ 670; *R v Letford*, 2016 ONCJ 616; *R v Brooks*, 2017 ONSC 439.

[2090] Grant & Benedet, *supra* note 227.

[2091] Anna Arstein-Kerslake, "Introduction to Criminal Responsibility" in Eilionóir Flynn et al, eds, *Global Perspectives on Legal Capacity Reform: Our Voices, Our Stories* (Abingdon, Oxon: Routledge, 2019) 19.

involving regulated professionals working in LTC have not been considered. These cases could potentially be a useful source of information as to why certain caring relationships fail and the law's response to such failure. Consideration of such cases may also illuminate the tensions in balancing individual and systemic accountability in the regulation of caring relationships.

The limitations in my research methodology are as follows. First, although this research has incorporated perspectives that are not normally captured in LTC studies in the feminist political economy literature (such as the perspectives of lawyers practicing in health law), this study did not benefit from the insights from those who are directly involved in LTC i.e., individual residents, their family members and friends, home administrators and paid caregivers. The analysis is limited to the perspectives of policy-makers such as industry associations and unions derived from key informant interviews and the examination of the grey literature. Second, the scope of my document review is restricted to publicly available documents produced by the province. However, some of these documents I examined are not readily accessible to the general public (such as compendium to a bill and government responses to standing committees) and my study has already made a contribution by examining those documents. This dissertation referred to a few reports produced by the Government of Canada. A close study of relevant federal government documents would probably reveal a broader and more nuanced narrative about aging in Canada[2092] and could inform my understanding of how Ontario's approach to demographic challenges is situated within the Canadian policy context. Third, some of the government information is more difficult to verify unless one could submit a freedom of information request and succeed in getting the relevant records. For example, the statistics about complaints and critical incidents in LTC in Ontario is from official documents such as Hansard and Auditor General reports. There is no way that I can ascertain the accuracy of the statistics.

[2092] For example see Special Senate Committee on Aging, *Canada's Aging Population: Seizing the Opportunity* (Ottawa: Senate of Canada, 2009); Canada, Department of Finance, *Economic and Fiscal Implications of Canada's Aging Population* (Ottawa: Department of Finance, 2012); Human Resources and Skills Development Canada, *2011 Federal Disability Report - Seniors with Disabilities in Canada* (Ottawa: Human Resources and Skills Development Canada, 2011); Employment and Social Development Canada, *Government of Canada — Action for Seniors report* (Ottawa: Employment and Social Development Canada, 2014); Standing Senate Committee on National Finance, *Getting Ready: For a New Generation of Active Seniors* (Ottawa: Senate of Canada, 2017).

10.4 Suggestions and justifications for future research

I conclude this dissertation by outlining three areas that deserve further research that integrates both legal analysis and public policy perspectives. Many interesting questions remain unanswered and my suggestions stem from the belief that law is pervasive in all areas of life and there are benefits to bringing law – not necessarily progressive or regressive - into any social policy discussion. First, there is a growing body of literature on LTC that is comparative in nature.[2093] The latest research studies provide a rich background on policy choices that different jurisdictions make or reject and include "on the ground" explorations of the implications of such choices. To explore the possibility of importing promising practices from other jurisdictions, it is worth exploring how law may both facilitate and constrain the successful adoption of such practices.[2094] A more purposeful and nuanced legal analysis of the LTC systems in other jurisdictions could illuminate the possibility of allowing these practices to flourish outside of their current locales. Israel Doron and colleagues are correct to conclude that every country has its own legal 'story' with regard to its regulation of the residential LTC of older persons.[2095] The challenge is to build a conceptual bridge between the 'legal story' and analysis from other disciplines, such as gerontology,[2096] so that promising practices are also legally sound when transplanted to other jurisdictions.

Second, if welfare goals and institutions will increasingly rely on regulation,[2097] what makes social regulation possible? For future research, a good starting point would be to assess institutional designs involving fiscal transfers, social regulation and economic regulation. The challenge for researchers is to reflect on the relations among fiscal transfer, social regulation and economic regulation in any institutional design over time. Future research should be directed

---

[2093] For example see Armstrong et al, *supra* note 171; Daly & Szebehely, *supra* note 739; Choiniere et al, *supra* note 515; Laxer et al, *supra* note 716; Harrington et al, *supra* note 515; Daly et al, *supra* note 672.

[2094] For example, the style of law and legislation is mainly characterised by the 'legal family' it belongs to: civil or common law. See Ulrich Karpen, "Comparative Law: Perspectives of Legislation" (2012) 6:2 Legisprudence 149.

[2095] Israel Doron, Nicola Rees & Helen Meenan, "Conclusion: From 'Residential Care' to 'Ageing with Dignity'" in Helen Meenan, Nicola Rees & Israel Doron, eds, *Towards Human Rights in Residential Care for Older Persons: International Perspectives* (Abingdon, Oxon: Routledge, 2016) 211 at 211.

[2096] For example, see Elias S Cohen, "Editorial: Law and Aging, Lawyers and Gerontologists" (1978) 18:3 Gerontologist 229; Nina A Kohn, Maria Teresa Brown & Israel Doron, "Identifying Connections between Elder Law and Gerontology: Implications for Teaching, Research, and Practice" (2017) 25:1 The Elder Law Journal 69.

[2097] Levi-Faur, *supra* note 20 at 608.

toward exploring how economic regulation and fiscal transfer make social regulation possible, rather than simply making general pronouncements about the need for publicly funded care.

Third, it should be clear that broad-based rejection or uncritical acceptance of regulation (and by extension, law) as a tool to advance the rights of disabled people is misplaced. Work by disability studies scholars casts light on the darker motivations and actions of actors involved in regulating the lives of disabled people – within and outside of institutions. A good example is the variety of legal capacity regulatory regimes.[2098] However, regulation is here to stay and the challenge is to conduct empirical research on the multiple (sometimes conflicting) objectives of a particular regulation and its implications. Benefit schemes that confer rights or entitlements to forms of care (home care,[2099] for example) provide a fertile ground for unpacking assumptions about aging, disability and gender often buried in complex and opaque legal rules. Making this less visible layer apparent is a promising way to enable disabled Canadians who require support to demand progress towards substantive equality, despite their dependency on the state to meet their care needs. This is important as we are all in different types of caring relationships over the life course.

People who cannot "take care of themselves" are perceived to be a burden on families, friends and the government. It must be acknowledged that our ability to "take care of ourselves" is subject to disadvantages and privileges due to disability, gender, age and other factors accumulated over a life time. I hope that for older disabled adults, one day LTC will become a safe place where any resident could still look after herself - in the sense of being autonomous in making decisions that matter to her - with the necessary support and assistance so that her age, impairment, illness or other personal characteristics will not prevent her from full participation and inclusion in Canadian society, even in later life. The toolbox that we have should be one of our collective responses to the call for more appropriate LTC, driven by a firm commitment to substantive equality.

[2098] Anna Arstein-Kerslake, *Restoring Voice to People with Cognitive Disabilities: Realizing the Right to Equal Recognition Before the Law* (Cambridge: Cambridge University Press, 2017).

[2099] The Ontario government was also making changes to the home and community services sector. See Ministry of Health and Long-Term Care, *Ontario Boosting Nursing, Personal Support in Major Expansion of Home Care* (News release October 5, 2017) (Toronto: Ministry of Health and Long-Term Care, 2017).

Bibliography

LEGISLATION

Accessibility for Ontarians with Disabilities Act, 2005, SO 2005, c 11.

An Act to Amend the Homes for the Aged Act, SO 1966, c 259.

An Act to amend, repeal and enact various Acts in the interest of strengthening quality and accountability for patients SO 2017 c 25.

An Act to amend various Acts in the interests of patient-centred care, SO 2017 c 25.

An Act respecting Charitable Institutions, SO 1931, c 79.

An Act to Provide for the Licensing and Regulation of Nursing Homes, 1966, SO 495, c 99

Broader Public Sector Accountability Act, 2010, SO 2010, C 25.

Broader Public Sector Executive Compensation Act, 2014, SO 2014, c 13, Sched. 1

Business Corporations Act, RSO 1990, c B.16.

Canada Health Act, RSC, 1985 c C-46.

Canadian Charter of Rights and Freedoms, Part I of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982* (UK), 1982, c11.

Charitable Institutions Act, 1956, S.O. 1956, c 6.

Charitable Institutions Act, R.S.O. 1990, c C.9.

Commitment to the Future of Medicare Act, 2004, SO 2004, c 5.

Community Care Access Corporations Act, 2001,
SO 2001, c 33.

Criminal Code, RSC 1985, c C-46.

Crown Liability and Proceedings Act, 2019, SO 2019, c 7, Sched. 17.

Drug and Pharmacies Regulation Act, RSO 1990, c H.4

Ending Mandatory Retirement Statute Law Amendment Act, 2005, SO 2005, c 29

Excellent Care for All Act 2010, SO 2010, c 14.

Food and Drugs Act, RSC 1985, c F-27.
Freedom of Information and Protection of Privacy Act, RSO 1990, c F.31.

Good Government Act, 2006, SO 2006, c 19.

Good Government Act, 2009, SO 2009, c 33.

Health Care Consent Act, 1996, SO 1996, c 2.

Home Care and Community Services Act, 1994, SO 1994, c 26

Homes for the Aged Act, 1949, SO 1949, c 41.

Homes for the Aged and Rest Homes Act, RSO 1990, c H.13.

Human Rights Code, RSO 1990, c H.19.

Jobs for Today and Tomorrow Act (Budget Measures), 2016, SO 2016, c 5.

Legislation Act, 2006, SO 2006, c 21, Sched. F.

Local Health System Integration Act, 2006, SO 2006, c 4.

Long-Term Care Homes Act, 2007, SO 2007, c 8.

Long-Term Care Statute Law Amendment Act, 1993.

Mental Health Act, RSO 1990, c M.7.

Ministry of Health and Long-Term Care Act, RSO 1990, c M.26.

Not-for-Profit Corporations Act, 2010, SO 2010, c 15.

Nursing Homes Act, RSO 1990, c N.7.

O Reg 104/96: Evaluators.

O Reg 187/15: Annual Quality Improvement Plan.

O Reg 191/11: Integrated Accessibility Standards.

O Reg 264/07.

O Reg 279/07

O Reg 456/16

O Reg 79/10: General.

O Reg 460/05.

Ontarians with Disabilities Act, 2001, SO 2001, c 32.

Patients First Act, 2016 SO 2016, c 30

Regulated Health Professions Act, 1991, SO 1991, c 18.

RRO 1990, Reg 832: General.

Social Work and Social Service Work Act, 1998, SO 1998, c 31.

Spousal Relationships Statute Law Amendment Act, 2005, SO 2005, c 5.

Statutory Powers Procedure Act, RSO 1990, c S.22.

Substitute Decisions Act, SO 1992, c 30.

Toby's Act (Right to be Free from Discrimination and Harassment Because of Gender Identity or Gender Expression), 2012.

INTERNATIONAL CONVENTIONS

Convention on the Rights of Persons with Disabilities, December 13, 2006, 46 ILM 433, UN Doc A/RES/61/106.

JURISPRUDENCE

8635 v. Director under the Accessibility for Ontarians with Disabilities Act, 2005, 2014 CanLII 53673 (ON LAT)

8647 v. Director under the Accessibility for Ontarians with Disabilities, 2014 CanLII 46363 (ON LAT)

8677 v. Director under the Accessibility for Ontarians with Disabilities, 2014 CanLII 46359 (ON LAT)

8750 v. Director under the Accessibility for Ontarians with Disabilities Act, 2005, 2014 CanLII 46587 (ON LAT)

A.B. (Re), 2004 CanLII 34873 (ON CCB).

A.C. v. Manitoba (Director of Child and Family Services), 2009 SCC 30, [2009] 2 S.C.R. 181.

Ahmed v. Mississauga (City), 2017 CanLII 19981 (ON OMB).

Alberta v. Elder Advocates of Alberta Society, 2011 SCC 24, [2011] 2 SCR 261.

AM (Re), 2010 CanLII 48694 (ON CCB).

Bobbie v. Health Science Centre, [1989] 2 W.W.R. 153 (Man QB).

C. (RE), 2005 CANLII 57860 (ON CCB).

CM v CR, 2013 CanLII 8103 (ON HSARB).

Canada (Attorney General) v. Canadian Doctors for Refugee Care, 2015 FCA 34 (CanLII).

Canada (AG) v PHS Community Services Society, 2011 SCC 44, [2011] 3 SCR 134 [*PHS]*

Canadian Doctors for Refugee Care v. Canada (Attorney General), 2015 FC 149 (CanLII) 24.

Canadian Union of Public Employees v. Royal Crest Lifecare Group Inc., 2004 ONCA 19809 (CanLII).

Carter v. Canada (Attorney General), 2015 SCC 5, [2015] 1 SCR 331.

City of Mississauga v. 1747114 Ontario Inc., 2013 ONCJ 623 (CanLII)

Cunningham v Canada, [1993] 2 SCR 143.

Cuthbertson v. Rasouli, 2013 SCC 53, [2013] 3 S.C.R. 341.

Decision No. 55/12I, 2012 ONWSIAT 1985 (CanLII).

Decision No. 537/10R2, 2014 ONWSIAT 960 (CanLII).

Dolmage v. Ontario, 2010 ONSC 1726 (CanLII).

Dolmage v Ontario, 2010 ONSC 6131 (CanLII).

Dolmage v. HMQ, 2013 ONSC 6686 (CanLII).

Dolmage, McKillop and Bechard v. HMQ, 2014 ONSC 1283 (CanLII).

EH (Re), 2014 CanLII 73473 (ON CCB).

Eaton v. Brant County Board of Education, [1997] 1 S.C.R. 241.

Eldridge v. British Columbia (Attorney General), [1997] 3 S.C.R. 624, 151 DLR (4th) 577.

FM (Re), 2016 CanLII 22547 (ON CCB).

FK (Re), 2013 CanLII 73956 (ON CCB).

Fernandes v. Manitoba (Director of Social Services, Winnipeg Central), [1992] M.J. No. 279 (Man. C.A.) (QL).

Friman v Toledo Estates Ltd, 2013 CanLII 41976 (ON SCSM).

Gan v. College of Physicians and Surgeons, 2014 HRTO 1324 (CanLII).

Gan v. College of Physicians and Surgeons, 2015 HRTO 1045 (CanLII).

Gan v. Sergeant Gowan, 2013 HRTO 2080 (CanLII).

Gan v. Sergeant Gowan, 2014 HRTO 38 (CanLII).

GM v North Simcoe Muskoka Community Care Access Centre, 2013 CanLII 73121.

Hamilton Health Sciences Corp. v. D.H., 2014 ONCJ 603.

He v. Sienna Senior Living Inc., 2016 HRTO 1261 (CanLII).

He v. Sergeant Gowan, 2013 HRTO 2081 (CanLII).

He V. Sergeant Gowan, 2014 HRTO 37 (CanLII).

J.C. v. Forensic Psychiatric Service Commissioner, (1992) 65 B.C.L.R. (2d) 386 at 9 (QL).

J.F. (RE), 2005 CANLII 48158 (ON CCB).

J.I. (Re), 2008 CanLII 40574 (ON CCB).

Kostiuk v. Toronto Community Housing Corporation, 2012 HRTO 388 (CanLII).

Law v. Canada (Minister of Employment and Immigration), [1999] 1 S.C.R. 497.

Law Society of Upper Canada v. Battaglio, 2014 ONLSTH 222 (CanLII).

Martino (Bankruptcy), Re, 2004 CanLII 17978 (ON SC).

McCorkell v. Director of Riverview Hospital, 1993 CanLII 1200 (BC SC).

McKillop and Bechard v. HMQ, 2014 ONSC 1282 (CanLII).

M.N. (Re), 2004 CanLII 6883 (ON CCB).

Morriston Park Nursing Home v Ontario (Health and Long-term Care), 2014 CanLII 62311 (ON HSARB), 2014.

Ontario (A.G.) v. Patient (2005), 2005 CanLII 3982 (ON SCDC), 250 D.L.R. (4th) 697.

Ontario Nursing Home Assn. v. Ontario, [1990] O.J. No. 1280, 74 O.R. (2d) 365.

Public Guardian and Trustee v Gan et al, 2014 ONSC 2145.

Quebec (Attorney General) v A, 2013 SCC 5.

R v Brooks, 2017 ONSC 439.

R v Grant, 2009 SCC 32, [2009] 2 S.C.R. 353.

R v. Kapp, 2008 SCC 41, [2008] 2 SCR 483.

R v Lamsen, 2014 ONCJ 670.

R v Letford, 2016 ONCJ 616.

R v Mills, [1999] 3 SCR 668.

R v Therens, [1985] 1 SCR 613.

Romanchook v. Garda Ontario, 2009 HRTO 1077 (CanLII).

Royal Crest Lifecare Group Inc v Ontario (Health and Long Term Care), 2009 ONCA 397.

Royal Crest Lifecare Group, Re (2003), 40 C.B.R. (4th) 146, aff'd (2004), 46 C.B.R. (4th) 126.

RTC (Re), 2007 CANLII 20001 (ON CCB).

Seniorscare Operations v Director, Performance Improvement and Compliance Branch, 2014 CanLII 81247 (ON HSARB).

Seniorscare Operations (HCL) LP v Director, Performance Improvement and Compliance Branch, 2015 ONSC 1964 (CanLII).

SOT-68407-16 (RE), 2016 CANLII 88178 (ON LTB).

TenBruggencate v. Elgin (County), 2009 HRTO 666 (CanLII).

TenBruggencate v. Elgin (County), 2010 HRTO 1467 (CanLII).

Thwaites v. Health Sciences Centre Psychiatric Facility, 1988 CanLII 5697 (MB CA).

Toronto Transit Commission v. Ontario (Finance), 2008 CanLII 67910 (ON SC).

Victoria (City) v Adams, 2008 BCSC 1363, aff'd 2009 BCCA 563.

Withler v. Canada (Attorney General), 2011 SCC 12, [2011] 1 S.C.R. 396.

SECONDARY MATERIALS

Abbas, Jihan and Jijian Voronka. "Remembering Institutional Erasures: The Meaning of Histories of Disability Incarceration in Ontario" in Liat Ben-Moshe, Chris Chapman, Alison C Carey eds, *Disability Incarcerated: Imprisonment and Disability in the United States and Canada* (New York: Palgrave Mcmillian 2014) 121.

Abelson, Julia. "Patient engagement in health technology assessment: what constitutes 'meaningful' and how we might get there" (2018) 23:2 J Health Serv Res Policy 69.

Abelson, Julia et al. "Assessing the Impacts of Citizen Deliberations on the Health Technology Process" (2013) 29:3 International Journal of Technology Assessment in Health Care 282.

———. "Supporting quality public and patient engagement in health system organizations: development and usability testing of the Public and Patient Engagement Evaluation Tool" (2016) 19:4 Health Expect 817.

Adams, Owen and Sharon Vanin. "Funding Long-Term Care In Canada: Issues and Options" (2016) 15:4 HealthcarePapers 7.

———. "It's Time for a National Conversation about Long-Term Care Funding" (2016) 15:4 HealthcarePapers 55.

Agarwal, Ranjan K. "The Road to the Promised Land Runs Past Conway: Administrative Tribunals and Charter Remedies" (2011) 48:3 Alta L Rev 783 (LegalTrac).

Agich, George J. *Dependence and Autonomy in Old Age: an Ethical Framework for Long-term Care* (Cambridge, U.K and New York: Cambridge University Press, 2003).

——— . "Respecting the Autonomy of Old People Living in Nursing Homes" in Eileen E. Morrison ed *Health Care Ethics: Critical Issues for the 21st Century* (Sudbury, Massachusetts: Jones And Bartlett Publishers, 2009) 184.

Ågotnes, Gudmund & Christine Øye. “Chapter 10 Person-Centred or Community-Centred Care? Why Doing It Wrong Is Sometimes Right” in Pat Armstrong & Ruth Lowndes, eds, *Negotiating Tensions in Long-Term Residential Care: Ideas Worth Sharing* (Montreal: Canadian Centre for Policy Alternatives, 2018) 97.

Alexander, Lisa T. “Stakeholder Participation in New Governance: Lessons from Chicago's Public Housing Reform Experiment,” (2009) 16 Geo. J. on Poverty L. & Pol'y 117.

——— . “Reflections on Success and Failure in New Governance and the Role of the Lawyer Symposium: New Governance and the Transformation of Law - Wisconsin Law Review Symposium Afterword: Part III” (2010) 2010 Wis L Rev 737.

Aliverti, Ana. “Exploring the Function of Criminal Law in the Policing of Foreigners: The Decision to Prosecute Immigration-related Offences” (2012) 21(4) Soc & Leg Stu 511.

Almond, Paul & Mike Esbester. “Regulatory inspection and the changing legitimacy of health and safety” (2018) 12:1 Regulation & Governance 46.

Ambrogi, Donna Myers and Frances Leonard “The Impact of Nursing Home Admission Agreements on Resident Autonmy” (1988) 28 (Suppl.) The Gerontologist 82.

Armstrong, Hugh. “Chapter 1 Tensions between Risk and Safety” in Pat Armstrong & Ruth Lowndes, eds, Negotiating Tensions in Long-Term Residential Care: Ideas Worth Sharing (Montreal: Centre for Policy Alternatives, 2018) 33.

———, Tamara J Daly & Jacqueline A Choiniere. “Policies and Practices: The Case of RAI-MDS in Canadian Long-Term Care Homes” (2016) 50:2 Journal of Canadian Studies 348.

Armstrong, Pat. “Chapter 7 Regulating Care: Lessons from Canada” in Gabrielle Meagher and Marta Szebehely, eds, *Marketisation in Nordic Eldercare: a Research Report on Legislation, Oversight, Extent and Consequences* (Stockholm Studies in Social Work 30). (Stockholm: Department of Social Work, Stockholm University, 2013) 217.

———. “Puzzling Skills: Feminist Political Economy Approaches” (2013) 50:3 Canadian Review of Sociology 256.

———. “Families and Choices” in Pat Armstrong & Tamara Daly, eds, *Exercising Choice in Long-Term Residential Care* (Toronto: Centre for Policy Alternatives, 2017) 105.

———. “Balancing the Tension in Long-Term Residential Care” (2018) 43:1 Aging Int 74.

———, Hugh Armstrong & Krista Scott-Dixon. *Critical to Care: The Invisible Women in Health Services* (Toronto: University of Toronto Press, 2008).

———, Hugh Armstrong, Albert Banerjee, Tamara Daly & Marta Szebehely. "Structural Violence in Long-Term Residential Care" (2011) 10 (1) Women's Health and Urban Life: An International and Interdisciplinary Journal 111.

———, Madeline Boscoe, Barbara Clow, Karen R. Grant, Nancy Guberman, Beth Jackson, Ann Pederson & Kay Willson. "Women-Defined Quality Care" in Pat Armstrong *et al,* eds. *Thinking Women and Health Care Reform in Canada* (Toronto: Canadian Scholars' Press and Women's Press, 2012) 215.

———, Hugh Armstrong & Tamara Daly. "The Thin Blue Line: Long-Term Care as an Indicator of Equity in Welfare States" (2012) 29:3 Canadian Women Studies 49.

——— & Susan Braedley. "Introduction" in Pat Armstrong & Susan Braedley, eds., *Troubling Care: Critical Perspectives on Research and Practices* (Toronto: Canadian Scholars' Press Inc. 2013) 9.

——— Hugh Armstrong & Krystal Kehoe MacLeod. "The Threats of Privatization to Security in Long-Term Residential Care" (2016) 41 *Ageing Int* 99.

——— & Tamara Daly. "Introduction" in Pat Armstrong and Tamara Daly eds, *Exercising Choice in Long-Term Residential Care* (Ottawa: Canadian Centre for Policy Alternatives, 2017) 11.

——— & Tamara Daly. "Exercising Choices: Ideas Worth Sharing" in Pat Armstrong and Tamara Daly ed, *Exercising Choice in Long-Term Residential Care* (Ottawa: Canadian Centre for Policy Alternatives, 2017) 121.

Aronson, Jane. "Conflicting Images of Older People Receiving Care: Challenges for Reflexive Practice and Research" in Sheila Neysmith, ed, *Critical Issues for Future Social Work Practice with Aging Persons* (New York: Columbia University Press, 1999) 47.

———. "Restructuring Older Women's Needs: Care Receiving as a Site of Struggle and Resistance" in Sheila Neysmith, ed, *Restructuring Caring Labour: Discourse, State Practice, and Everyday Life* (Toronto: Oxford University Press, 2000) 52.

Arstein-Kerslake, Anna. *Restoring Voice to People with Cognitive Disabilities: Realizing the Right to Equal Recognition Before the Law* (Cambridge: Cambridge University Press, 2017).

———. "Introduction to Criminal Responsibility" in Eilionóir Flynn et al, eds, *Global Perspectives on Legal Capacity Reform: Our Voices, Our Stories* (Abingdon, Oxon; Routledge, 2019) 19.

Atreya, Binod & Anona Armstrong. "A Review of the Criticisms and the Future of New Public Management" (2002) Victoria University of Technology School of Management

Working Paper Series No 7/2002. online: http://vuir.vu.edu.au/169/1/wp7_2002_atreya_armstrong.pdf

Aubrecht, Katie & Tamara Krawchenko. "Disability and Aging: International Perspectives." (2016) 12(2-3) Review of Disability Studies: An International Journal 3.

——— & Janice Keefe. 2016. "The Becoming Subject of Dementia" (2016) 12(2-3) Review of Disability Studies: An International Journal 137.

Aylward, Carol. "Intersectionality: Crossing the Theoretical and Praxis Divide" (2010) 1:1 Journal of Critical Race Inquiry 1.

Ayres, Lioness. "Thematic Coding and Analysis" in Lisa Given, ed, *The SAGE Encyclopedia of Qualitative Research Methods* (Thousand Oaks California: SAGE Publications, Inc., 2008) 868.

Bach, Wendy A. "Mobilization and Poverty Law: Searching for Participatory Democracy amid the Ashes of the War on Poverty" (2012) 20 Va J Soc Pol'y & L 96.

———. "Welfare Reform, Privatization, and Power: Reconfiguring Administrative Law Structures from the Ground Up" (2008-2009) 74 Brook L Rev 275.

Baines, Donna. "Neoliberalism and the convergence of nonprofit care work in Canada" (2015) 19(3) Competition & Change 194.

——— & Tamara Daly. "Resisting Regulatory Rigidity: Lessons from Front-Line Care Work" (2015) 95 Studies in Political Economy 138.

———, Sara Charlesworth & Tamara Daly. "Underpaid, Unpaid, Unseen, Unheard and Unhappy? Care Work in the Context of Constraint" (2016) 58:4 Journal of Industrial Relations 449.

——— & Diane van den Broek. "Coercive Care: Control and Coercion in the Restructured Care Workplace" (2017) 47:1 Br J Soc Work 125.

——— & Pat Armstrong. "Promising Practices in Long Term Care: Can Work Organisation Treat Both Residents and Providers with Dignity and Respect?" (2018) 1:001 Social Work and Policy Studies: Social Justice, Practice and Theory.

Baker, Dean. "Do Welfare State Liberals Also Love Regulation?" (2015) 12(1) Econ Journal Watch 15.

Baldwin, Robert, Martin Cave & Martin Lodge. "Introduction: Regulation – The Field and the Developing Agenda" in Robert Baldwin, Martin Cave and Martin Lodge, eds., *The Oxford Handbook of Regulation* (Oxford: Oxford University Press, 2010) 3.

———, Martin Cave & Martin Lodge. Understanding regulation: theory, strategy, and practice, 2nd ed. (Oxford: Oxford University Press, 2012).

——— & Julia Black. "Driving Priorities in Risk-based Regulation: What's the Problem?" (2016) 43 JL &Soc'y 565.

Banerjee, Albert. "Long-Term Care in Canada: An Overview" in Pat Armstrong et al, *A Place to Call Home: Long-term Care in Canada* (Balckpoint: Fernwood Publishing, 2009) 29.

———. "Chapter 6 The Regulatory Trap: Reflections on the Vicious Cycle of Regulation in Canadian Residential Care" in Gabrielle Meagher & Marta Szebehely, eds, *Marketisation in Nordic Eldercare: a Research Report on Legislation, Oversight, Extent and Consequences* (Stockholm Studies in Social Work 30) (Stockholm: Department of Social Work, Stockholm University, 2013) 203.

——— & Pat Armstrong. "Centring Care: Explaining Regulatory Tensions in Residential Care for Older Persons" (2015) 95 *Studies in Political Economy* 7.

——— et al. "Nursing Home Physicians Discuss Caring for Elderly Residents: An Exploratory Study" (2018) 37:2 Canadian Journal on Aging 133.

Barken, Rachel & Ruth Lowndes. "Supporting Family Involvement in Long-Term Residential Care: Promising Practices for Relational Care" (2018) 28:1 Qual Health Res 60.

——— & Pat Armstrong. "Skills of Workers in Long-Term Residential Care: Exploring Complexities, Challenges, and Opportunities" (2018) 43: 1 Ageing Int 110.

Bartlett, Ruth. "Citizenship in action: the lived experiences of citizens with dementia who campaign for social change" (2014) 29:8 Disability & Society 1291.

———, Trude Gjernes, Ann-Therese Lotherington & Aud Obstefelder. "Gender, citizenship and dementia care: a scoping review of studies to inform policy and future research" (2016) Health and Social Care in the Community doi: 10.1111/hsc.12340

Bê, Ana. "Feminism and Disability: A Cartography of Multiplicity" in Nick Watson, Alan Roulstone & Carol Thomas, eds, *Routledge Handbook of Disability Studies* (New York: Routledge, 2012) 363.

Béland, Daniel & Marier, Patrik. "Universality and the Erosion of Old Age Security" in Daniel Béland, Gregory P Marchildon & Michael J Prince, eds, *Universality and Social Policy in Canada* (Toronto; University of Toronto Press, 2019) 103.

Bender, Danielle & Paul Holyoke. "Bringing Person- and Family-Centred Care Alive in Home, Community and Long-Term Care Organizations" (2016) 19:1 Healthcare Quarterly, online: <http://www.longwoods.com/content/24605>.

Ben-Moshe, Liat. "Alternatives to (Disability) Incarceration" in Liat Ben-Moshe, Chris Chapman, Alison C Carey eds, *Disability Incarcerated: Imprisonment and Disability in the United States and Canada* (New York: Palgrave Mcmillian 2014) 255.

——— & Jean Stewart. 2017. "Disablement, Prison and Historical Segregation: 15 Years Later." In *Disability Politics in a Global Economy: Essays in Honour of Marta Russell*, ed. Ravi Malhorta, 87-104, Abingdon, Oxon and New York, NY: Routledge.

Bernard, H Russell. *Social Research Methods*, 2nd ed (Thousand Oaks, CA: Sage Publications, 2013).

Berta, Whitney, Audrey Laporte, Dara Zarnett, Vivian Valdmanis & Geoffrey Anderson. "A pan-Canadian perspective on institutional long-term care" (2006) 79 Health Policy 175.

Bhailís, Clíona de. "Theoretical framework for the VOICES Project" in Eilionóir Flynn et al, eds, *Global Perspectives on Legal Capacity Reform: Our Voices, Our Stories* (Abingdon, Oxon ; Routledge, 2019) 1.

Bickenbach, Jerome E. "Disability Human Rights, Law, and Policy" in Gary L. Albrecht, Katherine D. Seelman & Michael Bury, eds, *Handbook of Disability Studies* (Thousand Oaks, CA: Sage Publications Inc., 2001) 565.

———. *Ethics, Law and Policy* (Thousand Oaks, CA: Sage Publications Inc., 2012).

——— Franziska Felder & Barbara Schmitz ,"Rethinking the Good Human Life in Light of Disability" in Jerome E. Bickenbach, Franziska Felder & Barbara Schmitz, eds, *Disability and the Good Human Life* (Cambridge: Cambridge University Press, 2014) 1.

Black, Julia. "Decentring Regulation: Understanding the Role of Regulation and Self-Regulation in a 'Post-Regulatory' World" (2001) 54 Current Leg Probs 103.

———. "The Role of Risk in Regulatory Processes" in Robert Baldwin, Martin Cave & Martin Lodge eds., *The Oxford Handbook of Regulation* (Oxford: Oxford University Press, 2010) 302.

——— & Robert Baldwin. "Really Responsive Risk-Based Regulation" (2010) 32:2 Law & Policy 181.

——— & Robert Baldwin. "When risk-based regulation aims low: Approaches and challenges" (2012) 6 Regulation & Governance 2.

Blum, John D. "New Governance and Health Care Regulation" (2007) 2 Asian J WTO & Int'l Health L & Pol'y 125.

———. "A Revisionist Model of Hospital Licensure" (2008) 2 Regulation & Governance 48.

Bogart, W.A. *Consequences: The Impact of Law and Its Complexity* (Toronto: University of Toronto Press, 2002).

Boyle, Geraldine. “Autonomy in long-term care: a need, a right or a luxury?” (2008) 23:4 Disability and Society 299.

———. “Social policy for people with dementia in England: promoting human rights?” (2010) 18(5) Health and Social Care in the Community 511.

Braedley, Susan & Rosemary Warskett. “Regulating Care: An Introduction” (2015) 95 Studies in Political Economy 3.

——— & Gillian Martel. “Dreaming of Home: Long-Term Residential care and (In)equities by Design” (2015) 95 Studies in Political Economy 59.

———, Prince Owusu, Anna Przednowek & Pat Armstrong. “We’re told, ‘Suck it up’: Long-Term Care Workers’ Psychological Health and Safety” (2018) 43:1 Ageing International 91.

Braithwaite, John. “The Essence of Responsive Regulation” (2011) 44 UBC L Rev 475.

——— & Valerie Braithwaite. “The Politics of Legalism: Rules Versus Standards in Nursing-Home Regulation” (1992) 4 Soc & Leg Stud 307.

Brickley, James A, Susan F Lu & Gerard J Wedig. “Malpractice Laws and Incentives to Shield Assets: Evidence from Nursing Homes” (2017) 14:2 Journal of Empirical Legal Studies 301.

Buhler, Sarah. Book Review of *Caring and the Law* by Jonathan Herring, (2015) 27 Can. J. Women & L. 336.

Campbell, Yolanda. “New Governance in Action: Community Health Centers and the Public Health Service Act” (2010-2011) 4 St Louis U J Health L & Pol'y 397.

Carey, Alison C, Liat Ben-Moshe, Chris Chapman. “Preface: An Overview of Disability Incarcerated.” In Liat Ben-Moshe, Chris Chapman, Alison C Carey, eds, *Disability Incarcerated: Imprisonment and Disability in the United States and Canada* (New York: Palgrave Mcmillian, 2014) IX.

Carter, Mark. “Fundamental Justice” (2017) 78 SCLR(2d) 259.

Chadha, Ena & C Tess Sheldon. “Promoting Equality: Economic and Social Rights for Persons with Disabilities Under Section 15” (2004) 16:1 NJCL 27.

Chivers, Sally. “Care, Culture and Creativity: A Disability Perspective on Long-Tem Residential Care” in Pat Armstrong & Susan Braedley, eds, *Troubling Care: Critical Perspectives on Research and Practices* (Toronto: Canadian Scholars’ Press Inc. 2013) 47.

———. “Cripping Care Advice: Austerity, Advice Literature, and the Troubled Link between Disability and Old Age” in Katie Aubrecht, Christine Kelly & Carla Rice eds, *Aging/Disability Nexus* (Vancouver: UBC Press, 2020).

———. & Ulla Kriebernegg. “Introduction” in Sally Chivers & Ulla Kriebernegg, eds, *Care Home Stories: Aging, Disability, and Long-Term Residential Care* (Transcript-Verlag, 2018) 17.

Choiniere, Jacqueline A., Malcolm Doupe, Monika Goldmann, Charlene Harrington, Frode F. Jacobsen, Liz Lloyd, Magali Rootham, & Marta Szebehely. “Mapping Nursing Home Inspections & Audits in Six Countries” (2016) 41 Ageing Int 40.

Clark, Phillip G. “Understanding Aging and Disability Perspectives on Home Care: Uncovering Facts and Values in Public- Policy Narratives and Discourse” (2007) 26 Canadian Journal on Aging 47.

Clement, Grace. *Care, Autonomy and Justice: Feminism and the Ethic of Care* (Boulder, CO: Westview Press, 1999).

Clough, Beverley & Jonathan Herring. *Ageing, gender and family law* (Abingdon, Oxon ; Routledge, 2018).

Cohen, Elias S. “Editorial: Law and Aging, Lawyers and Gerontologists” (1978) 18:3 Gerontologist 229.

———. “The Elderly Mystique: Constraints on the Autonomy of the Elderly with Disabilities.” (1988) *The Gerontologist* 28 (Suppl.) 24.

Cohen, Marjorie Griffin. “The Strange Career of Regulation in the Welfare State” (2015) Econ Journal Watch 12(1) 28.

Cohn, Margit. “Law and Regulation: the Role, Form and Choice of Legal Rules” in David Levi-Faur, ed. *Handbook on the Politics of Regulation* (Cheltenham, UK: Edward Elgar Publishing, 2011) 185.

Colker, Ruth. “Anti-Subordination above All: A Disability Perspective” (2006-2007) 82 Notre Dame L Rev 1415.

Comondore, Vikram R et al. “Quality of Care in for-Profit and Not-for-Profit Nursing Homes: Systematic Review and Meta-Analysis” (2009) 339 BMJ b2732.

Coughlan, Steve. “Arbitrary Detention: Whither -- or Wither? -- Section 9” (2008) 40 SCLR(2d) 147.

——— & Robert J Currie. “Sections 9, 10 and 11 of the Canadian Charter” (2013) 62 SCLR(2d) 143.

Creyke, Robin & John McMillan. “Soft Law v Hard Law” in Mark Aronson, Linda Pearson, Michael Taggart, Carol Harlow eds. Administrative Law in a Changing State (Hart Publishing, 2008) 377.

Cunliffe, Emma. “Ambiguities: Law, Morality and Legal Subjectivity in H.L.A. Hart’s The Concept of Law” in Maria Drakopoulous, ed. *Feminist Encounters with Legal Philosophy* (New York: Routlege, 2013) 185.

Daly, Tamara. “Out of Place: Mediating Health and Social Care in Ontario's Long-Term Care Sector” (2007) 26 Canadian Journal on Aging 63.

———. “The Politics of Women’s Health Equity: Through the Looking Glass” (2012) 28: 3 Canadian Woman Studies 84.

———. “Dancing the Two-Step in Ontario’s Long-Term Care Sector: Deterrent Regulation = Consolidation” (2015) 95 Studies in Political Economy 29.

———. “Chapter 5 The Quality Conundrum” in Pat Armstrong & Ruth Lowndes, eds, *Negotiating Tensions in Long-Term Residential Care: Ideas Worth Sharing* (Montreal: Canadian Centre for Policy Alternatives, 2018) 61.

——— & Marta Szebehely. “Unheard Voices, Unmapped Terrain: Comparing Care Work in Long-term Residential Care for Older People in Canada and Sweden” (2012) 21 International Journal of Social Welfare 139.

——— Jim Struthers, Beatrice Müller, Deanne Taylor, Monika Goldmann, Malcolm Doupe, & Frode F. Jacobsen. 2016. “Prescriptive or Interpretive Regulation at the Frontlines of Care Work in the ‘Three Worlds’ of Canada, Germany and Norway.” *Labour* 77 (Spring): 37–71.

——— & Pat Armstrong. “Liminal and Invisible Long-Term Care Labour: Precarity in the Face of Austerity” (2016) 58:4 Journal of Industrial Relations 473.

Dayton, AK. “Chapter 4 A Feminist Approach to Elder Law” in Israel Doron, ed, *Theories on Law and Aging: The Jurisprudence of Elder Law* (Berlin: Springer, 2009) 45.

Davis, Lennard J. *Bending Over Backwards: Disability, Dismodernism, and Other Difficult Positions* (New York: New York University Press, 2002).

———. Book Review of *Disability Rights and Wrongs Revisited* by Tom Shakespeare (2015) 17:1 Scandinavian Journal of Disability Research 95.

Davis, Mark A. "On Nursing Home Quality: A Review and Analysis" (1991) 48:2 Medical Care Review 129.

Dawson, Mark. "New Governance and the Displacement of Social Europe: the Case of the European Semester" (2018) 14:1 European Constitutional Law Review 191.

de Burca, Grainne. "New Governance and Experimentalism: An Introduction Symposium: New Governance and the Transformation of Law" (2010) 2010 Wis L Rev 227.

——— & Joanne Scott. "Introduction: New Governance, Law and Constitutionalism" in Gráinne de Burca & Joanne Scott, eds, *Law and New Governance in the EU and the US* (Oxford and Portland: Hart Publishing, 2006) 1.

Devlin, Richard & Diane Pothier. "Introduction: Toward a Critical Theory of Dis-Citizenship" in Critical Disability Theory: Essays in Philosophy, Politics, Policy, and Law (Vancouver: UBC Press, 2006) 1.

Dobinson, Ian & Francis Johns. "Qualitative Legal Research" in Mike McConville & Wing Hong Chui, eds, *Research Methods for Law* (Edinburgh: Edinburgh University Press, 2007) 16.

Doron, Israel. *From guardianship to long -term legal care: Law and caring for the elderly* (D.Jur., York University (Canada), 2000) [unpublished].

———, Nicola Rees & Helen Meenan. "Conclusion: from 'residential care' to 'ageing with dignity'" in Helen Meenan, Nicola Rees & Israel Doron, eds, *Towards human rights in residential care for older persons: international perspectives* (Abingdon, Oxon ; Routledge, 2016) 211.

Dosis, Olga. *Accessibility for Ontarians with Disabilities Act Implementation Guide – Integration Accessibility Standards: Information and Communications, Employment and Transportation* (Toronto: Carswell, 2013).

Dosman, Donna & Norah Keating. "Cheaper for Whom? Costs Experienced by Formal Caregivers in Adult Family Living Programs" (2005) *Journal of Aging & Social Policy* 17(2): 67.

Downie, Jocelyn & Jennifer J. Llewellyn. "Introduction" in Jocelyn Downie & Jennifer J. Llewellyn, eds, *Being Relational: Reflections on Relational Theory and Health Law* (Vancouver: University of British Columbia Press, 2012).

Drake, Robert F. "Welfare States and Disabled People" in Gary L. Albrecht, K.D. Seelman, & M. Bury, eds, *Handbook of Disability Studies* (Thousand Oaks, CA: Sage Publications Inc., 2001) 412.

Elliot, Robin & Michael Elliot. "Taking Rationales Seriously: Quality of the Legislative Process as a Factor in the Deference Analysis Under Section 1 of the Charter" (2017) 77 S.C.L.R.(2d) 255.

Fernandes, Natasha & Byron G. Spencer. "The Private Cost of Long-Term Care in Canada: Where You Live Matters" (2010) 29(3) Canadian Journal on Aging 307.

Fernández, José-Luis & Gori, Cristiano. "Introduction" in Gori, Cristiano, José-Luis Fernández and Raphael Wittenberg eds. *Long-Term Care Reforms in OECD Countries* (Bristol: Policy Press, 2016) 1.

Field, Sue. "Human Rights and Residential Care for Older Persons - an Australian Perspective" in *Towards Human Rights in Residential Care for Older Persons: International Perspectives* (Abingdon, Oxon: Routledge, 2016) 46.

Fineman, Martha Albertson. "The Vulnerable Subject: Anchoring Equality in the Human Condition" (2008) *Yale Journal of Law and Feminism* 20(1): 1.

———. "The Vulnerable Subject and the Responsive State" (2010) 60 Emory L.J. 251.

———."'Elderly' As Vulnerable: Rethinking the Nature of Individual and Societal Responsibility" (2012) 20 Elder L.J. 71.

Fish, Rebecca & Chris Hatton. "Gendered experiences of physical restraint on locked wards for women" (2017) 32:6 Disability & Society 790 DOI: 10.1080/09687599.2017.1329711.

Fletcher, Ruth. "Legal Form, Commodities, and Reproduction" in Maria Drakopoulou, ed, *Feminist Encounters with Legal Philosophy* (New York: Routledge, 2013) 138.

Flynn, Eilionóir. "Disability and Ageing: Bridging the divide? Social constructions and human rights" in Peter Blanck and Eilionoir Flynn eds, *Routlegde Handbook of Disability Law and Human Rights* (London and New York: Routlegde, 2017) 195.

——— et al. *Global Perspectives on Legal Capacity Reform: Our Voices, Our Stories*, (Abingdon, Oxon ; Routledge, 2019).

Fooks, Cathy, Genevieve Obarski & Lori Hale and Stephanie Hylmar. "The Patient Experience in Ontario 2020: What Is Possible?" (2015) 14:4 HealthcarePapers 8.

Ford, John A et al. "Access to Primary Care for Socio-Economically Disadvantaged Older People in Rural Areas: A Qualitative Study" (2018) 13:3 PLOS ONE e0193952.

Foster, Charles & Jonathan Herring. *Human Thriving and the Law* (Cham, Switzerland: Springer, 2018).

Frank, Jerome. "Realism in Jurisprudence" (1930-1934) 7 Am L Sch Rev 1063.

Fraser, Nancy. "Talking about Needs: Interpretive Contests as Political Conflicts in Welfare-State Societies" (1989) 99:2 Ethics 291.

———. "Struggle Over Needs: Outline of a Socialist-Feminist Critical Theory of Late-Capitalist Political Culture" in Linda Gordon, ed, *Women, the State and Welfare* (Madison: The University of Wisconsin Press, 1990) 199.

Frazee, Catherine, Joan Gilmour & Roxanne Mykitiuk. "Now You See Her, Now You Don't: How Law Shapes Disabled Women's Experience of Exposure, Surveillance, and Assessment in the Clinical Encounter" in Dianne Pothier & Richard Devlin, eds, *Critical Disability Theory: Essays in Philosophy, Politics, Policy and Law* (Vancouver: UBC Press, 2005) 223.

Friedman, Marilyn. "Relational Autonomy and Individuality" (2013) 63:2 UTLJ 327.

Garland-Thomson, Rosemarie. "Integrating Disability, Transforming Feminist Theory" (2002) 14:3 NWSA Journal 1.

———. "Feminist Disability Studies" (2005) 30:2 Signs 1557.

Gibbons, Hailee M. "Compulsory Youthfulness: Intersections of Ableism and Ageism in "Successful Aging" Discourses." (2016) 12(2-3) Review of Disability Studies: An International Journal 70.

Gilad, Sharon. "Beyond Endogeneity: How Firms and Regulators Co-Construct the Meaning of Regulation" (2014) 36 Law & Pol'y 135.

Gilchrist, Valerie J. & Robert L. Williams. "Key Informant Interviews" in Benjamin F. Crabtree & William L. Miller, eds, *Doing Qualitative Research* 2nd ed (Thousand Oaks, CA: Sage Publications Inc., 1999) 71.

Gilmour, Joan M. "Creeping Privatization in Health Care: Implications for Women as the State Redraws Its Role" in Brenda Cossman & Judy Fudge, eds, *Privatization, Law and the Challenge to Feminism* (Toronto: University of Toronto Press, 2002) 267.

———. "Legal Capacity and Decision Making" in Joanna N Erdman, Vanessa Gruben & Erin Nelson, eds, Canadian Health Law and Policy, fifth edition. ed (Toronto: LexisNexis Canada, 2017) 351.

Goffman, Erving. *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*. (Garden City, N.Y.: Anchor Books, 1961).

Gooberman-Hill, Rachael. Book Review of *Dependence and Autonomy in Old Age: An Ethical Framework for Long-Term Care* by George J Agich (2004) 33:2 International Journal of Epidemiology 435.

Gori, Cristiano, José-Luis Fernández & Raphael Wittenberg. "Conclusion: Looking ahead in Long-Term Care Policies" in Gori, Cristiano, José-Luis Fernández and Raphael Wittenberg eds. *Long-Term Care Reforms in OECD Countries* (Bristol: Policy Press, 2016) 293.

———, José-Luis Fernández & Raphael Wittenberg eds. *Long-Term Care Reforms in OECD Countries* (Bristol: Policy Press, 2016).

Grant, Isabel & Janine Benedet. "The Sexual Assault of Older Women: Criminal Justice Responses in Canada" (2016) 62:1 McGill LJ 41.

Gray, Julia et al. "Dementia (Re)performed Interrogating Tensions between Relational Engagement and Regulatory Policies in Care Homes through Theatre" in Sally Chivers & Ulla Kriebernegg, eds, *Care Home Stories: Aging, Disability, and Long-Term Residential Care* (Transcript-Verlag, 2018) 111.

Grenier, Amanda, Meredith Griffin & Colleen McGrath. "Aging and Disability: The Paradoxical Positions of the Chronological Life Course" (2016) 12 (2-3) *Review of Disability Studies: An International Journal* 11.

Griffin, Stephen. "Minding the Regulatory Gap" Book Review of *After the Rights Revolution: Reconceiving the Regulatory State* by Cass R. Sunstein (1993) 11:3 Law & Phil 291.

Griffiths, Dorothy M. *A Difficult Dream: Ending Institutionalization for Persons with Intellectual Disabilities with Complex Needs* (Kingston, New York: National Association for the Dually Diagnosed, 2016).

Grouchy, Michelle, Nancy Cooper & Tommy Wong. "Implementation of Behaviour Supports Ontario (BSO): An Evaluation of Three Models of Care" (2017) 19:4 Health Care Quarterly 69.

Hale, Robert. "Coercion and Distribution in a Supposedly Non-Coercive State" (1923) 38:3 Political Science Quarterly 470.

Hall, Margaret Isabel. "Old Age (or, Do We Need a Critical Theory of Law and Aging)" (2014) 35 Windsor Rev Legal & Soc Issues 1.

———. "Dementia, Decision-Making, and the Modern (Adult) Guardianship Paradigm: Bentley v. Maplewood Seniors Care Society" (2015) 1 Can J Comp & Contemp L 293.

———. “The Vulnerability Jurisdiction: Equity, Parens Patriae, and the Inherent Jurisdiction of the Court” (2016) 2 Can J Comp & Contemp L 185.

Haber, Hanan. “Regulating-for-Welfare: A Comparative Study of “Regulatory Welfare Regimes” in the Israeli, British, and Swedish Electricity Sectors” (2011) 33(1) *Law & Policy* 116.

———. “Regulation as Social Policy: Home Evictions and Repossessions in The UK and Sweden” (2015) Public Administration.

———. “Rise of the Regulatory Welfare State? Social Regulation in Utilities in Israel” (2017) 51:3 Social Policy & Administration 442.

Halsbury’s Laws of Canada (online). *Constitutional Law: Charter of Rights*, “IX. Legal Rights: Sections 8 to 14” at HCHR-73 "Purpose of s. 9 protection and general approach" (2014 Reissue).

Halsbury’s Laws of Canada (online). *Constitutional Law: Charter of Rights*, “IX. Legal Rights: Sections 8 to 14”, at HCHR-75 "Arbitrariness of detention or imprisonment" (2014 Reissue).

Halsbury’s Laws of Canada (online). *Constitutional Law: Charter of Rights*, “IX. Legal Rights: Sections 8 to 14”, at HCHR-76 "Required legal standards for non-arbitrariness in specific detention contexts" (2014 Reissue).

Halsbury’s Laws of Canada (online), *Mental Health*, “II. Consent and Capacity 1. Overview of Consent and Capacity” at “HMN-7 Consent to treatment and refusal" (2019 Reissue).

Hansen, Nancy & Lorna Turnbull, “Disability and Care: Still Not ‘Getting It’” (2013) 25 CJWL 111.

Harding, Rosie. *Duties to Care: Dementia, Relationality, and Law*, Cambridge studies in law and society (Cambridge, United Kingdom; Cambridge University Press, 2017).

Harrington, Charlene, Hugh Armstrong, Mark Halladay, Anders Kvale Havig, Frode F. Jacobsen, Martha MacDonald, Justin Panos, Kathy Pearsall, Allyson Pollock, & Leslie Ross. “Comparison of Nursing Home Financial Transparency and Accountability in Four Locations” (2016) 41 Ageing International 17.

Harris, Neville. *Law in a Complex State: Complexity in the Law and Structure of Welfare* (Oxford and Portland, Oregon: Hart Publishing 2013).

Hart, H.L.A. “Bentham and the Demystification of the Law” (1978) 36 Mod L R 2.

Hayter, Emily. “Sexual Expression in Long-Term Care Homes: Capacity & Consent” (2014) 35Windsor Rev Legal Soc Issues 54.

Herring, Jonathan. *Caring and the Law* (Oxford and Portland, Oregon: Hart Publishing 2013).

———. “The Disability Critique of Care” (2014) 8 Elder L Rev 1.

———. *Vulnerable Adults and the Law* (Oxford: Oxford University Press, 2016).

———. “Older People and Deficiencies in the Formal Care System: Equality and Rights” in Sue Westwood, ed, *Ageing, Diversity and Equality: Social Justice Perspectives* (Abingdon, Oxon; New York, NY: Routledge, 2019) 276.

Hillmer, Michael P et al. “Nursing Home Profit Status and Quality of Care: Is There Any Evidence of an Association?” (2005) 62:2 Med Care Res Rev 139.

Hiltz, D’Archy and Anita Szigeti. *A Guide to Consent & Capacity Law in Ontario* (Toronto: LexisNexis, 2017).

Hirdes, John P. “Long-Term Care Funding in Canada” (2002) 13:2-3 Journal of Aging & Social Policy 69 DOI: 10.1300/J031v13n02_06.

Hofland, Brian F. “Autonomy in Long Term Care: Background Issues and a Programmatic Response.” (1988) 28 (Suppl) The Gerontologist 3.

Holley, Cameron. “Linking Law and New Governance: Examining Gaps, Hybrids, and Integration in Water Policy” (2016) 38:1 Law & Policy 24.

Hood, Christopher, Henry Rothstein & Robert Baldwin. *The Government of Risk: Understanding Risk Regulation Regimes* (Oxford University Press, 2001).

Horowitz, Amy. “Aging and Disability in the New Millennium: Challenge for Social Work Research and Practice” in Sheila Neysmith, ed, *Critical Issues for Future Social Work Practice with Aging Persons* (New York: Columbia University Press, 1999) 97.

Howse, Robert. “Retrenechment, Reform or Revolution? The Shift to Incentives and the Future of the Regulatory State” (1993)31 Alta L Rev 455.

Hudson, Robert B ed. *The New Politics of Old Age Policy* (Baltimore: The John Hopkins University Press, 2005).

Hughes, Bill. “Disabled people as counterfeit citizens: the politics of resentment past and present” (2015) 30:7 Disability & Society 991 DOI: 10.1080/09687599.2015.1066664.

——— et al. “Love’s Labours Lost? Feminism, the Disabled People’s Movement and an Ethic of Care” (2005) 39:2 Sociology 259.

Hutter, Bridget M. “Negotiating Social, Economic and Political Environments: Compliance with Regulation within and beyond the State” in Christine Parker & Vibeke Lehamnn Nielsen eds, *Explaining Compliance: Business Responses to Regulation* (Cheltenham: Edward Elgar, 2011) 305.

Jackson, Beth. “Chapter 1: Theory and Methods for Thinking Women” in Pat Armstrong et al, eds, *Thinking Women and Health Care Reform in Canada* (Toronto: Canadian Scholars' Press and Women's Press, 2012) 15.

Jacobsen, Frode F, Suzanne Day, Katherine Laxer Liz Lloyd, Monika Goldmann, Marta Szhebehely, Jacqueline A. Choiniere, & Pauline Vaillancourt Rosenau. “Job Autonomy of Long-Term Residential Care Assistive Personnel: A Six Country Comparison” (2018) 43:1 Ageing International 4.

James, Grace. Book Review of *Caring and the Law* by Jonathan Herring, (2014) 22 Fem Leg Stud 331.

Jameton, Andrew. “In the Borderlands of Autonomy: Responsibility in Long Term Care Facilities ” (1988) 28 (Suppl.) The Gerontologist 18.

Jimenez, Rodrigo. “The Right to Live a Life Free of Violence for People with Disabilities” in Toba Bryant, Dennis Raphael & Marcia Rioux, eds, *Staying Alive: Critical Perspectives on Health, Illness, and Health Care*, 2nd ed. (Toronto: Canadian Scholars' Press and Women's Press, 2010) 397.

Johnson, Kelley & Rannveig Traustadóttir, ed. 2005. *Deinstitutionalization and People with Intellectual Disabilities: in and out of Institutions*. London and Philadelphia: Jessica Kingsley Publishers.

Jolls, Christine, Cass R. Sunstein & Richard Thaler. “A Behavioural Approach to Law and Economics” (1998) 50 Stanford Law Review 1471.

Jordana, Jacint & David Levi-Faur. “The Politics of Regulation in the Age of Governance” in Jacint Jordana & David Levi-Faur, eds, *The Politics of Regulation: Institutions and Regulatory Reforms for the Age of Governance* (Cheltenham: Edward Elgar, 2004) 1.

Jost, Timothy Stoltzfus. “The Necessary And Proper Role Of Regulation To Assure The Quality Of Health Care” (1988) 25 Hous L Rev 525.

Kaida, Lisa & Monica Boyd. “Poverty Variations among the Elderly: The Roles of Income Security Policies and Family Co-Residence” (2011) 30 (1) Canadian Journal on Aging 83 doi:10.1017/S0714980810000814.

Kane, Robert L. “A New Long-Term Care Manifesto” (2015) 55 (2) The Gerontologist 296.

Kang, Kiran & Sonia K Kang. “Interpreting Equality Rights under Sections 7 and 15 in New and Old Ways: An Empirical Analysis of the Concurrent Claims Approach” (2016) 35:2 NJCL 235.

Kanter, Arlene S. “The Americans With Disabilities Act At 25 Years: Lessons To Learn From The Convention On The Rights Of People With Disabilities” (2015) 63 Drake L. Rev. 819.

Kaplow, Louis. “Rules and Standards: An Economic Analysis” (1990) 42:3 Duke LJ 557.
———. “A Model of the Optimal Complexity of Legal Rules” (1995) 11 J L Econ & Org 150 – 163.

Karkkainen, Bradley C. "‘New Governance’ in Legal Thought and in the World: Some Splitting as Antidote to Overzealous Lumping” (2004) 89 Minn L Rev 471.

Kazin, Cathrael. "'Nowhere to Go and Choose to Stay': Using the Tort of False Imprisonment to Redress Involuntary Confinement of the Elderly in Nursing Homes and Hospitals" (1998/1999) 137 U. Pa. L. Rev. 903.

Kelly, Christine. “Making ‘care’ accessible: Personal assistance for disabled people and the politics of language” (2011) Critical Social Policy 31(4) 562.

———. *Disability Politics and Care: The Challenge of Direct Funding* (Vancouver: UBC Press, 2016).

———. “Care and Violence Through the Lens of Personal Support Workers” (2017) 1:1 International Journal of Care and Caring 97.

Kernaghan, Kenneth. “Serving Seniors: Innovation and Public Sector Service Delivery” (2015) 20(1) The Innovation Journal: The Public Sector Innovation Journal, article 3.

King, Jeff A. “The Pervasiveness of Polycentricity” (Spring 2008) Public Law 101.

Kittay, Eva Feder. “Getting from Here to There: Claiming Justice for the Severely Cognitively Disabled” in Rosamond Rhodes, Margaret P. Battin & Anita Silvers, eds., *Medicine and Social Justice: Essays on the Distribution of Health Care* 2nd ed. (New York: Oxford University Press, 2012) 313.

Klare, Karl. “Notes and Commentary: Law-Making as Praxis” (1979) Telos 123.

Klein, Daniel B. “Economists on the Welfare State and the Regulatory State: Why Don’t Any Argue in Favor of One and Against the Other? A Symposium Prologue” (2015) 12(1) Econ Journal Watch 2.

Klijn, Erik Hans. “New Public Management and Governance: A Comparison” David Levi-Faur, ed, *The Oxford Handbook of Governance* (Oxford: Oxford University Press, 2012) 201.

Kohn, Nina A, Maria Teresa Brown & Israel Doron. "Identifying Connections between Elder Law and Gerontology: Implications for Teaching, Research, and Practice" (2017) 25:1 The Elder Law Journal 69.

Kong, Camilla. *Mental Capacity in Relationship* (Cambridge: Cambridge University Press, 2017).

Koop, Christel & Martin Lodge. "What is Regulation? An Interdisciplinary Concept Analysis" (2017) 11:1 Regulation and Governance 95.

Koshan, Jennifer. "Redressing The Harms of Government (In)Action: A Section 7 Versus Section 15 Charter Showdown" (2013) 22: 1 Constitutional Forum 31.

——— & Jonnette Watson Hamilton. "The Supreme Court, Ameliorative Programs, and Disability: Not Getting It" (2013) 25 CJWL 56.

———. "Adverse Impact: The Supreme Court's Approach to Adverse Effects Discrimination under Section 15 of the Charter" (2015) 19: 2 Review of Constitutional Studies 191.

Kristof, Lorand, Richard H. Fortinsky, Kathy Kellett, Martha Porter, & Julie Robison. "Experiences of Informal Caregivers of Older Adults Transitioned From Nursing Homes to the Community Through the Money Follows the Person Demonstration" (2017) 29:1 Journal Of Aging & Social Policy 20.

Kröger, Teppo. "Care research and disability studies: Nothing in common?" (2009) 29(3) Critical Social Policy 398.

Krogh, Kari & Jon Johnson. "A Life without Living: Challenging Medical and Economic Reductionism in Home Support Policy for People with Disabilities" in Dianne Pothier & Richard Devlin, eds, *Critical Disability Theory: Essays in Philosophy, Politics, Policy and Law* (Vancouver: UBC Press, 2005) 151.

Kuluski, Kerry A., Paul Williams, Whitney Berta & Audrey Laporte. "Home care or long-term care? Setting the balance of care in urban and rural Northwestern Ontario, Canada" (2012) 20(4) Health and Social Care in the Community 438.

Lai, Poland. "How New Governance Shapes Changes in the Long-Term Care Sector in Ontario, Canada" online: (2015) *The Innovation Journal: The Public Sector Innovation Journal* 20(1), article 4.

———. "Regulation of 'Care' in Long-Term Care in Ontario, Canada" in Katie Aubrecht, Christine Kelly & Carla Rice eds, *Aging / Disability Nexus* (Vancouver: UBC Press, 2020) (Accepted).

Landis, James M. *The Administrative Process* (New Haven: Yale University Press, 1938).

Lawrence, Vanessa & Sube Banerjee. “Improving care in care homes: A qualitative evaluation of the Croydon care home support team” (2010) 14:4 Aging & Mental Health 416.

Laxer, Katherine *et al*. “Comparing Nursing Home Assistive Personnel in Five Countries” (2016) 41:1 Ageing International 62.

Leckey, Robert & Régine Tremblay. “Introduction: After Equality” (2015) 27:1 Can J Women & L i.

Lee, John David, C Tess Sheldon & Roberto Lattanzio. “Law and Ordered C.H.A.O.S.: Social Science Methodology, and the Charter Claims of Persons with Disabilities” (2013) 32:1 NJCL 61.

Leeuw, Frans L. *Empirical Legal Research: A Guidance Book for Lawyers, Legislators and Regulators* (Cheltenham: Edward Elgar, 2016).

Leisering, Lutz & Deborah Mabbett. “Introduction: Towards a new Regulatory State in Old Age Security? Exploring the Issues” in Lutz Leisering, ed, *The New Regulatory State: Regulating Pensions in Germany and the UK* (Basingstoke: Palgrave, 2011) 1.

———. “Transformations of the State: Comparing the New Regulatory State to the Post-War Provider State” in Lutz Leisering, ed, *The New Regulatory State: Regulating Pensions in Germany and the UK* (Basingstoke: Palgrave, 2011) 254.

Lepofsky, David. “Carter v. Canada (Attorney General), The Constitutional Attack on Canada's Ban on Assisted Dying: Missing an Obvious Chance to Rule on the Charter's Disability Equality Guarantee” (2016) 76 .S.C.L.R.(2d) 89.

——— & Randal N.M. Graham, “Universal Design in Legislation: Eliminating Barriers for People with Disabilities” (2009) 30 Stat L Rev 97.

Lessard, Hester A. "“Dollars Versus [Equality] Rights”: Money and the Limits on Distributive Justice." (2012) 58 SCLR (2d) 299.

Levi-Faur, David. “Regulation and regulatory governance” in David Levi-Faur, ed, *Handbook on the politics of regulation* (Cheltenham, UK: Edward Elgar, 2011) 3.

———. “From ‘Big Government’ to ‘Big Governance’?” in David Levi-Faur, ed, *The Oxford Handbook of Governance* (Oxford: Oxford University Press, 2012) 3.

———. “The Odyssey of the Regulatory State: From a “Thin” Monomorphic Concept to a “Thick” and Polymorphic Concept” (2013) 35(1–2) Law & Policy 29.

———. “The Welfare State: A Regulatory Perspective” (2014) 92 (3) Public Administration 599–614.

Lewis-Beck, Michael, Bryman Alan & Tim Futing Liao. "Coding Qualitative Data" in Lisa Given ed, *The SAGE Encyclopedia of Social Science Research Methods* (Thousand Oaks: Sage Publications, 2004).

Li, Kathy K et al. "Conceptualizing the use of public involvement in health policy decision-making" (2015) 138 Social Science & Medicine 14.

Lindsey, Jamie. "Book Review of *Vulnerable Adults and the Law* by Jonathan Herring" (2018) 27:2 Social & Legal Studies 273.

Lobel, Orly. "Setting the Agenda for New Governance Research" (2004) 89 Minn L Rev 498.

———. "The Renew Deal: The Fall of Regulation and the Rise of Governance in Contemporary Legal Thought" (2004) 89 Minn L Rev 262.

———. "The Paradox of Extralegal Activism: Critical Legal Consciousness and Transformative Politics" (2006-2007) 120 Harv L Rev 937.

———. "New Governance as Regulatory Governance" in David Levi-Faur, ed, *The Oxford Handbook of Governance* (Oxford: Oxford University Press, 2012) 65.

Lockyer, Sharon. "Coding Qualitative Data" in Michael Lewis-Beck, Alan Bryman & Tim Futing Liao, eds, *The SAGE Encyclopedia of Social Science Research Methods* (Thousand Oaks: California: Sage Publications, Inc., 2004) 138.

Lodge, Martin & Lindsay Stirton. "Accountability in the Regulatory State" in R. Baldwin, M. Cave & M. Lodge, eds., *Oxford Handbook of Regulation* (Oxford: Oxford Handbook of Regulation: 2010) 349.

Lord, Janet E. & Michael Ashley Stein. "Contingent Participation and Coercive Care" in Bernadette McSherry & Ian Freckelton, eds, *Coercive Care: Rights, Law and Policy* (New York: Routledge, 2013) 31.

Lowndes, Ruth, Pat Armstrong & Tamara Daly. 'The Meaning of Dining: The Social Organization of Food in Long-term Care" (2015) 4 Food Studies: An Interdisciplinary Journal 19.

Luxton, Meg. "Reclaiming Marxist Feminism: A response" (2015) 95 Studies in Political Economy 161.

Mabbett, Deborah. "The Regulatory Rescue of the Welfare State" in David Levi-Faur ed. *Handbook on the Politics of Regulation* (Cheltenham, UK: Edward Elgar Publishing, 2011).

———. "The Regulatory Politics of Private Pensions in the UK and Germany" in Lutz Leisering, ed, *The New Regulatory State: Regulating Pensions in Germany and the UK* (Basingstoke: Palgrave, 2011) 191.

Macdonald, Judy E. "Intersectionality and Disability" in Jeannette Robertson and Grant Larson eds, *Disability and Social Change: A Progressive Canadian Approach* (Halifax and Winnipeg: Fernwood Publishing, 2016) 136.

MacDonald, Martha. "Regulating Individual Charges for Long-Term Residential Care in Canada" (2015) 95 (Spring) Studies in Political Economy 83.

Majone, Giandomenico. "From the positive to the regulatory state: Causes and Consequences of changes in the mode of governance" (1997) 17: 2 Journal of Public Policy 139.

———. "The Transformations of the Regulatory State" in Lutz Leisering, ed, *The New Regulatory State: Regulating Pensions in Germany and the UK* (Basingstoke: Palgrave, 2011) 31.

Malhotra, Ravi. "Has the Charter Made a Difference for People with Disabilities? Reflections and Strategies for the 21st Century" (2012) 58 SCLR 273.

——— ed. *Disability Politics in a Global Economy: Essays in Honour of Marta Russell* (London and New York: Routledge, 2017).

——— & Morgan Rowe. *Exploring Disability Identity and Disability Rights through Narratives: Finding a Voice of Their Own* (New York: Routledge, 2014).

Manderson, Desmond & Richard Mohr. "From Oxymoron to Intersection: an Epidemiology of Legal Research" (2002) 6 Law Text Culture 159.

Marczak, Joanna & Gerald Wistow. "Commission Long Term Care Services" in Gori, Cristiano, José-Luis Fernández and Raphael Wittenberg eds. *Long-Term Care Reforms in OECD Countries* (Bristol: Policy Press, 2016).

Marks, Alexia Brunet. "A New Governance Recipe for Food Safety Regulation" (2015) 47 Loy U Chi LJ 907.

Marshall, Catherine & Gretchen B Rossman. *Designing Qualitative Research* (SAGE Publications, 2014).

Mathen, Carissima. "The Upside of Dissent in Equality Jurisprudence" (2013) 63 SCLR (2d) 111.

May, Peter J. "Regulatory Regimes and Accountability" (2007) 1 Regulation & Governance 8.

McColl, Mary Ann, Rebecca Bond, David W. Shannon & Charles Shortt. “People with Disabilities and the Charter: Disability rights at the Supreme Court of Canada under the Charter of Rights and Freedoms” (2016) 5.1 Canadian Journal of Disability Studies 183.

McConville, Mike & Wing Hong Chui, “Introduction and Overview” in Mike McConville & Wing Hong Chui eds, Research Methods for Law (Edinburgh: Edinburgh University Press, 2007) 1.

McDonald, Fiona. "To Become Old is to Become Institutionalized and Imprisoned”: Comparing Regulatory Frameworks for the Use of Restraints in Long-Term Care Facilities” (2003) 12:1 Health L Rev 22.

McGill, Jena & Daphne Gilbert. “Of Promise and Peril: The Court and Equality Rights” (2017) 78 .S.C.L.R.(2d) 235.

McGregor, Margaret & Pat Armstrong. “Chapter 8 Ownership Tensions” in Pat Armstrong & Ruth Lowndes, eds, *Negotiating Tensions in Long-Term Residential Care: Ideas Worth Sharing* (Montreal: Centre for Policy Alternatives, 2018) 83.

McLeod, Carolyn & Susan Sherwin. “Relational Autonomy, Self-Trust, and Health Care for Patients Who Are Oppressed” in Catriona Mackenzie & Natalie Stoljar, eds, *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self* (New York ; Oxford : Oxford University Press, 1999) 259.

McSherry, Bernadette & Ian Freckelton. “Coercive Care: Rights, Law and Policy” in Bernadette McSherry & Ian Freckelton, eds, *Coercive Care: Rights, Law and Policy* (New York: Rouledge, 2013) 3.

Meadus, Jane E. 2010. “Living in a Long-Term Care Home and Residents Rights.” Presentation made at Effective Legal Risk Management for Long-Term Care Homes (Osgoode Professional Development), Toronto.

Meenan, Helen. “The Residential Care of People in England and the Speical Relevance of Dignity and Human Rights” in Helen Meenan, Nicola Rees & Israel Doron, eds, *Towards human rights in residential care for older persons: international perspectives* (Abingdon, Oxon: Routledge, 2016) 85.

———, Nicola Rees & Israel Doron. “Introduction” in Helen Meenan, Nicola Rees & Israel Doron, eds, *Towards Human Rights in Residential Care for Older Persons: International Perspectives* (Abingdon, Oxon; Routledge, 2016) 1.

Milligan, Christine & Carol Thomas. “Dementia and the Social model of Disability: Does Responsibility to Adjust Lie with Society rather than People with Dementia?” (2016) 21:3 Signpost 5.

Mol, Annemarie. *The Logic of Care: Health and the Problem of Patient Choice* (London and New York: Routledge, 2008).

Mollot, Richard J. “Residential Care in the United States: a Persistent Struggle for Quality, Dignity and Independence” in Helen Meenan, Nicola Rees & Israel Doron, eds, *Towards Human Rights in Residential Care for Older Persons: International Perspectives* (Abingdon, Oxon ; Routledge, 2016) 167.

Moran, Michael. “Review Article: Understanding the Regulatory State” (2002) 32:02 British Journal of Political Science 391.

Morgan, Bronwen & Karen Yeung. *An Introduction to Law and Regulation: Text and Materials* (Cambridge: Cambridge University Press, 2007).

Morris, Jenny. “Feminism and Disability” (1993) 43 Feminist Review 57.

———. “Care or Empowerment? A Disability Rights Perspective” (1997) 31(1) Social Policy and Administration 54.

Mosoff, Judith. “Is the Human Rights Paradigm “Able” to Include Disability: Who’s In? Who Wins? What? Why?” (2000) 26 Queen’s L.J. 225.

Müller, Beatrice, Pat Armstrong & Ruth Lowndes. “Cleaning and Caring: Contributions in Long-term Residential Care” (2018) 43:1 Aging International 53.

Murphy, Susan. “Human Rights, Disability and the Law in Canada” in Jeannette Robertson and Grant Larson eds, *Disability and Social Change: A Progressive Canadian Approach* (Halifax and Winnipeg: Fernwood Publishing, 2016) 80.

Naffine, Ngaire. “Review Essay: The Liberal Legal Individual Accused: The Relational Case” (2014) 29 CJLS 123.

Nedelsky, Jennifer. *Law's Relations: a Relational Theory of Self, Autonomy, and Law* (New York: Oxford University Press, 2011).

NeJaime, Douglas. “When New Governance Fails” (2009) 70 Ohio St LJ 323.

Neysmith, Sheila. “A Failure of Vision and Political Will: The Reality of Long-Term Care in Ontario” in Pat Armstrong *et al.* ed. *A Place to Call Home: Long-term Care in Canada* (Balckpoint: Fernwood Publishing, 2009) 89.

Newman, JoNel. “Identity and Narrative: Turning Oppression into Client Empowerment in Social Security Disability Cases” (2015) 79 Alb L Rev 373.

Nourse, Victoria & Gregory Shaffert. “Varieties Of New Legal Realism: Can A New World Order Prompt A New Legal Theory?” (2009) 95 Cornell L Rev 61.

O’Neill, Laura. “Regulating Hospital Social Workers and Nurses: Propping Up An “Efficient” Lean Health Care System” (2015) 95 Studies in Political Economy 115.

Orloff, Ann Shola. “Gender” in Francis G. Castles, Stephan Leibfried, Jane Lewis, Herbert Obinger, and Christopher Pierson eds, *The Oxford Handbook of the Welfare State* (Oxford: Oxford University Press, 2010) 252.

Orsini, Michael. “Autism, Neurodiversity and the Welfare State: The Challenges of Accommodating Neurological Difference” (2012) 45 Canadian Journal of Political Science 805.

Österle, August & Heinz Rothgang. “Long-Term Care” in Francis G. Castles, Stephan Leibfried, Jane Lewis, Herbert Obinger, and Christopher Pierson eds, *The Oxford Handbook of the Welfare State* (Oxford: Oxford University Press, 2010) 518.

Overdevest, Christine & Jonathan Zeitlin. “Experimentalism in transnational forest governance: Implementing European Union Forest Law Enforcement, Governance and Trade (FLEGT) Voluntary Partnership Agreements in Indonesia and Ghana” (2018) 12:1 Regulation & Governance 64.

Parker, Christine. “Twenty years of responsive regulation: An appreciation and appraisal” (2013) 7:1 Regulation & Governance 2.

——— & John Braithwaite. “Regulation” in Mark Tushnet and Peter Cane eds, *The Oxford Handbook of Legal* Studies (Oxford: Oxford University Press, 2005) 120.

Peters, B. Guy. “Governance as a Political Theory” in David Levi-Faur, ed, *The Oxford Handbook of Governance* (Oxford: Oxford University Press, 2012) 19.

Perlin, Michael L. “Competency, Deinstitutionalization, And Homelessness: A Story Of Marginalization” 28 Hous. L. Rev. 63 1991.

Pfeiffer, David. “The Conceptualization of Disability” in Sharon N. Barnartt & Barbara M. Altman, eds, *Exploring Theories and Expanding Methodologies: Where We Are and Where We Need to Go* (Amsterdam, New York: Emerald Group Publishing Limited, 2001) 29.

Pflieger, Géraldine. “What “Regulatory State”? Explaining the Stability of Public Spending and Redistribution Functions after Regulatory Reforms of Electricity and Rail Services in the United Kingdom and Germany” (2014) 36: 2 Law & Policy 195.

Pollitt, Christopher & Geert Bouckaert. *Public Management Reform: A Comparative Analysis: New Public Management, Governance, and the Neo-Weberian State*, 3rd ed. (Oxford: Oxford University Press, 2011).

Pothier, Dianne. “Equality as a Comparative Concept: Mirror Mirror on the Wall, What’s the Fairest of Them All?’ (2006) 2 SCLR 135.

Potter, Kimberly. “The Role of Choice in Claims under Section 15 of the Charter: The Impact of Recent Developments in Section 7 Jurisprudence” (2016) 35 NJCL 181.

Pottie, Laura & Lorne Sossin, "Demystifying the Boundaries of Public Law: Policy, Discretion, and Social Welfare" (2005) UBC L Rev 147 (LegalTrac).

Priel, Dan. "In Defence of Quasi-Contract" (2012) 75:1 Mod L Rev 54.

Priestley, Mark. “Disability” in Francis G. Castles, Stephan Leibfried, Jane Lewis, Herbert Obinger, and Christopher Pierson eds, *The Oxford Handbook of the Welfare State* (Oxford: Oxford University Press, 2010) 406.

Prince, Michael J. “Canadian Disability Policy: Still a Hit-and-Miss Affair” (2004) 29 Canadian Journal of Sociology 59.

———. *Absent Citizens: Disability Politics and Policy in Canada* (Toronto: University of Toronto Press, 2009).

———. “Canadian Disability Activism and Political Ideas: In and Between Neo-Liberalism and Social Liberalism” (2012) 1:1 Canadian Journal of Disability Studies 1.

———. “The universal in the social: Universalism, universality, and universalization in Canadian political culture and public policy” (2014) 57: 3 Canadian Public Administration 344.

———. “Disability Policy in Canada: Fragments of Inclusion and Exclusion” in Jeannette Robertson & Grant Larson eds, *Disability and Social Change: A Progressive Canadian Approach* (Halifax and Winnipeg: Fernwood Publishing, 2016) 99.

Raymond, Émilie & Amanda Grenier. “Participation in Policy Discourse: New Form of Exclusion for Seniors with Disabilities?” (2013) 32 Canadian Journal on Aging 117.

———, Amanda Grenier & Jill Hainley. “Community Participation of Older Adults with Disabilities” (2014) 24:1 Journal of Community & Applied Social Psychology 50.

Reece, Helen. Book Review of *Caring and the Law* by Jonathan Herring (2014) 23(2) Social & Legal Studies 278.

Rhodes, R.A.W. “Waves of Governance” in David Levi-Faur, ed, *The Oxford Handbook of Governance* (Oxford: Oxford University Press, 2012) 32.

Richard, Michel P. “Goffman Revisited: Relatives vs. Administrators in Nursing Homes” (1986) 9(4) Qualitative Sociology 321.

Rioux, Marcia H. “Disability Rights and Change in a Global Perspective” (2011) 14 Sport in Society 1094.

——— & Christopher A. Riddle. “Values in Disability Policy and Law: Equality” in Marcia H Rioux, Lee Ann Basser Marks & Melinda Jones eds, *Critical Perspectives on Human Rights and Disability Law* (Leiden: Martinus Nijhoff Publishers, 2011) 37.

——— & Tamara Daly. “Constructing Disability and Illness” in Toba Bryant, Dennis Raphael & Marcia Rioux, eds, *Staying Alive: Critical Perspectives on Health, Illness, and Health Care*, Second Edition. (Toronto: Canadian Scholars' Press and Women's Press, 2010) 347.

———, Joan Gilmour & Natalia Angel-Cabo. “Negotiated Capacity: Legally Constructed Entitlement and Protection” in Bernadette McSherry & Ian Freckelton eds., *Coercive Care: Rights, Law and Policy* (New York: Rouledge, 2013) 51.

Ronald LA, McGregor MJ, Harrington C, Pollock A, Lexchin J. “Observational Evidence of For-Profit Delivery and Inferior Nursing Home Care: When Is There Enough Evidence for Policy Change?” (2016) 13(4) PLoS Med 1 doi:10.1371/ journal.pmed.1001995.

Roseman, Sharon, Pauline Gardiner Barber & Barbara Neis. “Towards a Feminist Political Economy Framework for Analyzing Employment-Related Geographical Mobility” (2015) 95 Studies in Political Economy 175.

Rosenblatt, Rand E. “The Four Ages of Health Law” (2004)14 Health Matrix 155.

Rothbauer, Paulette M. “Triangulation” in Lisa Given, ed, *The SAGE Encyclopedia of Qualitative Research Methods* (Thousand Oaks California: SAGE Publications, Inc., 2008) 893.

Rothstein, Henry. “The institutional origins of risk: A new agenda for risk research” (2006) 8:3 Health, Risk & Society 215.

———, Christopher Hood & Michael Huber. “Risk and the limits of governance: Exploring varied patterns of risk-based governance across Europe -” (2013) 7:2 Regulation & Governance 215.

Roulstone, Alan, Carol Thomas & Nick Watson, “The Changing Terrain of Disability Studies” in Nick Watson, Alan Roulstone & Carol Thomas, eds, *Routledge Handbook of Disability Studies* (New York: Routledge, 2012) 3.

Ryan, Gery & H Bernard. “Techniques to Identify Themes” (2003) 15:1 Field Methods 85.

Ryder, Bruce. "The Strange Double Life of Canadian Equality Rights" (2013) 63 SCLR (2d) 261.

Sampson, Fiona. “The Law Test for Discrimination and Gendered Disability Inequality” in Fay Farady, Margaret Denike & M. Kate Stephenson, eds, *Making Equality Rights Real: Securing Substantive Equality under the Charter* (Toronto: Irwin Law, 2006) 245.

———. “Beyond Compassion and Sympathy to Respect and Equality: Gendered Disability and Equality Rights Law” in Dianne Pothier & Richard Devlin, eds, *Critical Disability Theory: Essays in Philosophy, Politics, Policy and Law* (Vancouver: UBC Press, 2005) 267.

Sabel, Charles F & William H. Simon. “Epilogue: Accountability without Sovereignty” in Gráinne de Burca & Joanne Scott, eds, *Law and New Governance in the EU and the US* (Oxford and Portland: Hart Publishing, 2006) 395.

——— & William Simon. “Minimalism and Experimentalism in the Administrative State” (2011) 100 Georgetown Law Journal 53.

Salter, Liora. *Understanding Decisions that Matter* (unpublished manuscript).

Scambler, Sasha. “Long-Term Disabling Conditions and Disability Theories” in Nick Watson, Alan Roulstone & Carol Thomas, eds, *Routledge Handbook of Disability Studies* (New York: Routledge, 2012) 136.

Schneider, Ulrike, Gredt Sunström, Lennarth Johannson & Maria A. Tortosa. “Polices to Support Informal Care” in Gori, Cristiano, José-Luis Fernández & Raphael Wittenberg, eds, *Long-Term Care Reforms in OECD Countries* (Bristol: Policy Press, 2016) 219.

Schuck, Peter H. “Legal Complexity: Some Causes, Consequences, and Cures” (1992) 42 Duke L J 1.

Schur, Lisa, Douglas Kruse & Peter Blanck. *People with Disabilities: Sidelined or Mainstreamed?* (New York: Cambridge University Press, 2014).

Scott, Colin. “From Welfare State to Regulatory State: Meta-Regulation and Beyond” (2014) 11University of Tokyo Journal of Law and Politics 159.

Scott, Joanne & Susan Sturm. “Courts as Catalysts: Re-Thinking the Judicial Role in New Governance” (2006) 13 Colum J Eur L 565.

Seeley, Morgan. “Women, Aging and Residential Long-Term Care” in Pat Armstrong, Barbara Clow & Karen Grant, eds, *Thinking Women and Health Care Reform in Canada*. (Toronto: Canadian Scholars' Press and Women's Press, 2012) 107.

Shakespeare, Tom. “Review Article: Disability Studies Today and Tomorrow” (2005) 27 Sociology of Health & Illness 138.

———. *Disability Rights and Wrongs* (New York: Routlege, 2006).

———. “Still a Health Issue” (2012) 5 Disability and Health Journal 129.

———. *Disability Rights and Wrongs Revisited* (New York: Routledge, 2014).

———. *Disability: The Basics* (Abingdon, Oxon ; New York, NY : Routledge, 2018).

———. “Can Disabled People Be Healthy?” in Christopher Riddle, ed, *From Disability Theory to Practice: Essays in Honor of Jerome E Bickenbach* (Rowman and Littlefield, 2018) 61.

——— & Nick Watson. “Disability and Social Justice” in Gary Craig, ed, *Handbook on Global Social Justice* (Cheltenham, UK: Edward Elgar, 2018) 201.

———, Andrea Stöckl & Tom Porter. “Metaphors to work by: the meaning of personal assistance in England” (2018) 2:2 International Journal of Care and Caring 165.

———, Hannah Zeilig & Peter Mittler. “Rights in mind: Thinking differently about dementia and disability” (2019) 18:3 Dementia 1075.

Sheets, Debra et al. “Chapter 6: Caregiving and Care Receiving” in *The Canadian Longitudinal Study on Aging (CLSA) Report on Health and Aging in Canada: Findings from Baseline Data Collection 2010-2015* (Hamilton: Canadian Longitudinal Study on Aging, 2018) 74.

Sheldon, C Tess, Lorraine E Ferris & Carol Strike. “Hopeful Result, Unclear Implications: A Comment on Canada (Attorney General) v PHS Community Services Society” (2013) 21:2 Health Law Review 15.

———, Karen R Spector & Mercedes Perez. “Re-Centering Equality: The Interplay Between Sections 7 and 15 of the Charter in Challenges to Psychiatric Detention” (2016) 35 National Journal of Constitutional Law 193.

Sherwin, Susan. “Relational Autonomy and Global Threats” in Jocelyn Grant Downie & Jennifer J Llewellyn eds, *Being Relational: Reflections on Relational Theory and Health Law* (Vancouver, BC: UBC Press, 2012) 13.

——— & Katie Stockdale. “Whither Bioethics Now? The Promise of Relational Theory” (2017) 10:1 IJFAB: International Journal of Feminist Approaches to Bioethics 7.

Short, Jodi L. “The Paranoid Style in Regulatory Reform” (2011) 63 Hastings LJ 633.

Silvers, Anita. “Health Care Justice for the Chronically Ill and Disabled: A Deficiency in Justice Theory and How to Cure it” in Rosamond Rhodes, Margaret P. Battin & Anita Silvers, eds, *Medicine and Social Justice: Essays on the Distribution of Health Care* 2nd ed. (New York: Oxford University Press, 2012)

Simmons, Harvey G. *From Asylum to Welfare* (Toronto: National Institute on Mental Retardation, 1982).

Simon, William H. “Solving Problems vs. Claiming Rights: The Pragmatist Challenge To Legal Liberalism” (2004) 46 Wm & Mary L Rev 127.

Sinha, Vasuda, Lorne Sossin & Jenna Meguid. “Charter Litigation, Social and Economic Rights & Civil Procedure” (2017) 26 Journal of Law and Social Policy 43.

Sivananthan, Saskia N, Malcolm Doupe, and Margaret J. McGregor. “Exploring the Ecology of Canada’s Publicly Funded Residential Long-Term Care Bed Supply” (2015) 34 (1) Canadian Journal on Aging 60.

Smith, Gregory W H. *Erving Goffman* (Abingdon, Oxon: Routledge, 2006).

Smith, Lynn & William Black. “The Equality Rights” (2013) 62 SCLR(2d) 301.

Snellgrove, Susan, Cornelia Beck, Angela Green, and Jean C. McSweeney. “Putting Residents First: Strategies Developed by CNAs to Prevent and Manage Resident-to- Resident Violence in Nursing Homes” (2015) 55: 1The Gerontologist S99.

Söder, Mårten. “Tensions, perspectives and themes in disability studies” (2009) 11:2 Scandinavian Journal of Disability Research 67.

Soldatic, Karen. “The transnational sphere of justice: disability praxis and the politics of impairment” (2013) 28(6) Disability & Society 744 DOI:10.1080/09687599.2013.802218.

——— and Helen Meekosha. “Disability and Neoliberal State Formations” in Nick Watson, Alan Roulstone and Carol Thomas eds., *Routledge Handbook of Disability Studies* (New York: Routledge, 2012) 195.

Solomon, Jason M. “Law and Governance in the 21st Century Regulatory State” (2008) 86 Tex L Rev 819.

———. “New Governance, Preemptive Self-Regulation, and the Blurring of Boundaries in Regulatory Theory and Practice” (2010) Wis L Rev 591.

Sørensen, Eva. “Governance and Innovation in the Public Sector” in David Levi-Faur, ed, *The Oxford Handbook of Governance* (Oxford: Oxford University Press, 2012) 215.

——— & Jacob Torfing. “Introduction: Collaborative Innovation in the Public Sector” (2012) 17(1) The Innovation Journal: The Public Sector Innovation Journal 1. online: <www.innovation.cc/volumes-issues/intro_eva_sorensen_torfing_17v1i1.pdf>.

Spade, Dean. “Intersectional Resistance and Law Reform” (2013)8:4 Signs 1031.

Spencer, Charmaine & Ann Soden. “A Softly Greying Nation: Law, Ageing and Policy in Canada” (2007) 2 J Int’l Aging L & Pol’y 1.

Spilsbury, Karen et al. “The Relationship Between Nurse Staffing and Quality of Care in Nursing Homes: A Systematic Review” (2011) 48:6 International Journal of Nursing Studies 732.

Steele, Linda. “Policing Normalcy: Sexual Violence Against Women Offenders with Disability.” (2017) 31:3 *Continuum* 422.

———, Macarena Iribarne & Rachel Carr. “Medical Bodies: Gender, Justice and Medicine” (2016) 31:88 Australian Feminist Studies 117, DOI.

Stewart, Hamish. “Bedford and the Structure of Section 7” (2015) 60:3 McGill Law Journal 575.

Stewart, Richard B. “Regulation in the Liberal State: The Role of Non-Commodity Values” (1983) 92 Yale L J 1537.

Storm, Palle, Susan Braedley, & Sally Chivers. “Gender Regimes in Ontario Nursing Homes: Organization, Daily Work, and Bodies” (2017) 36 (2) Canadian Journal on Aging 196.

Streb, Christoph K. "Exploratory Case Study" in Albert J. Mills, Gabrielle Durepos & Elden Wiebe eds, *Encyclopedia of Case Study Research,* (Thousand Oaks: SAGE, 2010) 372.

Stribopoulos, James. “The Forgotten Right: Section 9 of the Charter, Its Purpose and Meaning” (2008) 40 SCLR(2d) 211.

Stroman, Duane F. *The Disability Rights Movement: from Deinstitutionalization to Self-determination*. (Lanham, Md.: University Press of America, 2003).

Struthers, James. “Reluctant Partners: State Regulation of Private Nursing Homes in Ontario, 1941-72” in R. B. Blake, P.E. Bryden & J.F. Strain eds, *The Welfare State in Canada: Past, Present and Future* (Concord: Irwin Publishing, 1997) 171.

———. “Home, Hotel, Hospital, Hospice Conflicting Images of Long-Term Residential Care in Ontario, Canada” in Sally Chivers & Ulla Kriebernegg, eds, *Care Home Stories: Aging, Disability, and Long-Term Residential Care* (Transcript-Verlag, 2018) 283.

Sturm, Susan. “The Architecture Of Inclusion: Advancing Workplace Equity in Higher Education” (2006) 29 Harv. J. L. & Gender 247.

———. “Gender Equity Regimes and the Architecture of Learning” in Grainne de Burca & Joanne Scott eds., *Law and New Governance in the EU and the US* (Oxford and Portland: Hart Publishing, 2006) 323.

Sullivan, Ruth. *Statutory Interpretation*, 2d ed. (Toronto: Irwin Law, 2007).

Sulmasy, Daniel P. "Dignity, Disability, Difference, and Rights" (2010) 104 Philosophy and Medicine 183.

Sunstein, Cass R. *After the Rights Revolution: Reconceiving the Regulatory State* (Cambridge: Harvard University Press, 1990).

———. "Paradoxes of the Regulatory State" (1990) 57 U Chicago L Rev 407.

———. *Simpler: The Future of Government* (New York: Simon & Schuster, 2013).

———. "Nonsectarian Welfare Statements" (2015) Regulation and Governance.

———. "Unhelpful Abstractions and the Standard View" (2015) 12(1) Econ Journal Watch 68.

Surtees, Doug. "Chapter 7 What can Elder Law Learn from Disability Law?" in Israel Doron, ed, *Theories on Law and Aging: The Jurisprudence of Elder Law* (Berlin: Springer, 2009) 93.

Taggart, Michael. "The Nature and Functions of the State" in Mark Tushnet and Peter Cane, eds, *The Oxford Handbook of Legal Studies* (Oxford: Oxford University Press, 2005) 101.

Thomas, Carol. "De-Constructing Concepts of Care" (1993) 27: 4 Sociology 649.

———. *Female Forms: Experiencing and Understanding Disability* (Philadelphia: Open University Press, 1999).

———. "Disability and Gender: Reflections on Theory and Research" (2006) 8:2-3 Scandinavian Journal of Disability Research 177.

———. *Sociologies of Disabilities and Illness: Contested Ideas in Disability Studies and Medical Sociology* (Hampshire: Palgrave McMillian, 2007).

———. "Disability and Diversity" in Steven Vertovec ed, *Routledge International Handbook of Diversity Studies* (New York: Rouledge, 2015) 43.

——— & Christine Milligan. "Dementia, Disability Rights and Disablism: Understanding the Social Position of People Living with Dementia" (2018) 33:1 Disability & Society 115.

Traustadóttir, Rannveig. "Disability and Gender: Introduction to the Special Issue" (2006) 8:2-3 Scandinavian Journal of Disability Research 81.

Troyer, Jennifer L & Herbert G Thompson. "The Impact of Litigation on Nursing Home Quality" (2004) 29:1 Journal of Health Politics, Policy and Law 11.

Trubek, David M. & Louise G. Trubek, "New Governance & Legal Regulation: Complementarity, Rivalry, and Transformation" (2006) 13 Colum J Eur L 539.

Trubek, David & Louise Trubek. "The World Turned upside Down: Reflections on New Governance and the Transformation of Law Symposium: New Governance and the Transformation of Law - Wisconsin Law Review Symposium Afterword: Part I" (2010) 2010 Wis L Rev 719.

Trubek, Louise G. "Public Interest Lawyers and New Governance: Advocating for Healthcare" (2002) Wis L Rev 575.

———. "New Governance and Soft Law in Health Care Reform" (2006) 3 Ind Health L Rev 139.

———. "New Governance Practices in US Health Care" in Gráinne de Burca & Joanne Scott, eds, *Law and New Governance in the EU and the US* (Oxford and Portland: Hart Publishing, 2006) 245.

——— et al. "New Governance and Effective Health Care Regulation" (2008) 2 Regulation and Governance 1.

Tufford, Frances, Ruth Lowndes, James Struthers & Sally Chivers. "'Call Security': Locks, Risk, Privacy and Autonomy in Long-term Residential Care" (2017) Ageing Int DOI 10.1007/s12126-017-9289-3.

Ursin, G. & Lotherington, T. A. "Citizenship as Distributed Achievement: Shaping New Conditions for an Everyday Life with Dementia." (2018) 20(1) Scandinavian Journal of Disability Research 71.

Vanhala, Lisa. "Disability Rights Activists in the Supreme Court of Canada: Legal Mobilization Theory and Accommodating Social Movements" (2009) 42:4 Canadian Journal of Political Science 981.

———. *Making Rights a Reality? Disability Rights Activists and Legal Mobilization* (Cambridge: Cambridge University Press, 2011).

Vehmas, Simo. "What Can Philosophy Tell Us about Disability?" in Nick Watson, Alan Roulstone & Carol Thomas, eds, *Routledge Handbook of Disability Studies* (New York: Routledge, 2012) 298.

——— & Tom Shakespeare. "Disability, Harm, and the Origins of Limited Opportunities" (2014) 23 Cambridge Quarterly of Healthcare Ethics 41.

Vincent, John. "Age, Ageism and Social Identity in Later Years" in Steven Vertovec ed, *Routledge International Handbook of Diversity Studies* (New York: Rouledge, 2015) 33.

Vogiatzis, Nikos. “The Ombudsman and Open Meetings: Lessons from the Canadian and the European Experience” (March 2014) Paper Presented at Osgoode Hall Law School, Toronto.

Wahl, Judith A. 2010. “Long-Term Care Homes Act: Hearings – Review of a Determination of Ineligibility for Admission and Review of Capacity to Consent for Admission to Secure Units and Elder Policies and Regulated Documents.” Paper Presented at How Legislative Changes Will Affect your Litigation and Corporate Practices (Ontario Bar Association, Institute 2010 of Continuing Legal Education), Toronto.

Walker, Neil & Gráinne de Búrca. “Reconceiving Law & New Governance” (2007) 13 Colum J Eur L 519.

Walsh, Christine A. & Yongjie Yon. “Developing an Empirical Profile for Elder Abuse Research in Canada” (2012) 24:2 Journal of Elder Abuse & Neglect 104 DOI: 10.1080/08946566.2011.644088.

Ward, Stephanie Francis. "The human cost of doing business: fines against nursing homes are routinely reduced and considered a slap on the wrist rather than incentives to provide better care." ABA Journal, Aug. 2016, p. 52.

Ward, Tony & Claire Stewart. “Putting Human Rights into Practice with People with an Intellectual Disability” (2008) 20 Journal of Developmental and Physical Disabilities 297.

Watchman, Karen. “The Intersectionality of Intellectual Disability and Ageing” in Sue Westwood, ed, *Ageing, Diversity and Equality: Social Justice Perspectives* (Abingdon, Oxon; New York, NY: Routledge, 2019) 245.

Waterstone, Michael. “A New Vision of Public Enforcement” (2007) 92 Minn L Rev 434.

Watson, Nick et al. “(Inter)Dependence, Needs and Care: The Potential for Disability and Feminist Theorists to Develop an Emancipatory Model” (2004) 38:2 Sociology 331.

Weber, Mark C. “Law and the Contradictions of the Disability Rights Movement Book Review Essay” (2010) 31 J Legal Med 241.

——— “Disability Rights, Welfare Law” (2011) 32 Cardozo L. Rev. 2483.

Weicht, Bernhard. “Embracing Dependency: rethinking (in)dependence in the discourse of care” (2011) The Sociological Review 205.

Wikeley, Nick. “The Welfare State” in Mark Tushnet & Peter Cane eds, *The Oxford Handbook of Legal Studies* (Oxford: Oxford University Press, 2005) 397.

Windholz, Eric L. *Governing through Regulation: Public Policy, Regulation and the Law* (New York and London: Routledge, 2018).

——— & Graeme A Hodge. “Conceptualising Social and Economic Regulation: Implications For Modern Regulators And Regulatory Activity” (2012) 38 Monash UL Rev 212.

Wiseman, David. "The Past and Future of Constitutional Law and Social Justice: Majestic or Substantive Equality?" (2015) 71 SCLR(2d) 563.

Wittenberg, Raphael. “Demand for Care and Support for Older People.” in Gori, Cristiano, José-Luis Fernández and Raphael Wittenberg eds. *Long-Term Care Reforms in OECD Countries* (Bristol: Policy Press, 2016) 9.

Yeandle, Sue, Teppo Kröger & Bettina Cass. “Voice and choice for users and carers? Developments in patterns of care for older people in Australia, England and Finland” (2012) 22(4) Journal of European Social Policy 432.

Yeung, Karen. “The Regulatory State” in Robert Baldwin, Martin Cave & Martin Lodge eds., *The Oxford Handbook of Regulation* (Oxford: Oxford University Press, 2010) 64.

Yin, Robert K. *Case Study Research: Design and Methods*. 5th. (Los Angeles: CA: Sage Publications, 2014).

Yishai, Yael. “Participatory Governance in Public Health: Choice, but not Voice” in David Levi-Faur, ed, *The Oxford Handbook of Governance* (Oxford: Oxford University Press, 2012) 527.

Young, Margot. "Social Justice and the Charter: Comparison and Choice" (2013) 50.3 Osgoode Hall L J 669.

Zumbansen, Peer. “Governance: An Interdisciplinary Perspective” in David Levi-Faur, ed, *The Oxford Handbook of Governance* (Oxford: Oxford University Press, 2012) 83.

GOVERNMENT DOCUMENTS

Ontario

Reports, websites and other documents

Accessibility Directorate. “Accessibility: legislative reviews, committees and councils”, (2 June 2015), online: <https://www.ontario.ca/page/accessibility-legislative-reviews-committees-and-councils>.

———. “The Path to 2025: Ontario’s Accessibility Action Plan”, (1 June 2015), online: <https://www.ontario.ca/page/path-2025-ontarios-accessibility-action-plan>.

Auditor General of Ontario. *2004 Annual Report of the Office of the Auditor General of Ontario* (Toronto: Auditor General of Ontario, 2004).

———. *2007 Annual Report of the Office of the Auditor General of Ontario* (Toronto: Auditor General of Ontario, 2007).

———. *2009 Annual Report of the Office of the Auditor General of Ontario* (Toronto: Auditor General of Ontario, 2009).

———. *2011 Annual Report of the Office of the Auditor General of Ontario* (Toronto: Auditor General of Ontario, 2011).

———. *2012 Annual Report of the Office of the Auditor General of Ontario* (Toronto: Auditor General of Ontario, 2012).

———. 2015 *Annual Report of the Office of the Auditor General of Ontario* (Toronto: Auditor General of Ontario, 2015).

Behavioural Supports Ontario. "Background", online: <http://www.behaviouralsupportsontario.ca/29/Background/>.

———. *Behavioural Supports Ontario: Final Implementation Report* (Toronto: Behavioural Supports Ontario, 2013).

———. *Behavioural Supports Ontario Annual Report 2015-16* (North Bay: Behavioural Supports Ontario, 2016).

———. *Behavioural Supports Ontario Annual Report 2016-17* (North Bay: Behavioural Supports Ontario, 2017).

Capacity Assessment Office. *Guidelines for Conducting Assessments of Capacity* (Toronto: Ministry of the Attorney General, 2005).

Geriatric and Long-Term Care Review Committee. *Annual Report of the Geriatric and Long-Term Care Review Committee* (Toronto: Office of the Chief Coroner, 2016).

Gillese, Honourable Eileen E. *Report of the Public Inquiry into the Safety and Security of Residents in the Long-Term Care Homes System* (Toronto: Long-Term Care Homes Public Inquiry, 2019).

Government of Ontario. *September 2016 Mandate letter: Health and Long-Term Care* (Toronto: Government of Ontario, 2016).

———. *Statement from Attorney General and Minister of Health and Long-Term Care on a Public Inquiry into the Circumstances of the Elizabeth Wettlaufer Case* (Toronto: Government of Ontario, 2017).

———. *Aging with Confidence: Ontario's Action Plan for Seniors* (Toronto: Government of Ontario, 2017).

Health Quality Ontario. *Strategic Plan 2012* (Toronto: Health Quality Ontario, 2012).

———. *Annual Report 2011-12* (Toronto: Health Quality Ontario, 2012).

———. *Quality Improvement Guide Long-term Care* (Toronto: Health Quality Ontario, 2012).

———. *Better Has No Limit: Partnering for a Quality Health System (a Three-Year Strategic Plan 2016-2019)* (Toronto: Health Quality Ontario, 2015).

———. *Long-Term Care: Advanced Training for Quality Improvement Planning, 2016/17 QIPs* (Toronto: Health Quality Ontario, 2015).

———. *Long-Term Care Impressions and Observations 2015/16 Quality Improvement Plans* (Toronto: Health Quality Ontario, 2016).

———. The *Reality of Caring: Distress among the Caregivers of Home Care patients* (Toronto: Health Quality Ontario, 2016)

———. *Measuring Up: A Yearly Report on how Ontario's Health System is Performing* (Toronto: Health Quality Ontario, 2016).

———. *Insights into Quality Improvement: Long-Term Care: Impressions and Observations – 2016/17 Quality Improvement Plans. (*Toronto: Health Quality Ontario, 2017).

———. *Income and Health: Opportunities to Achieve Health Equity in Ontario* (Toronto: Health Quality Ontario, 2016).

———. *Behavioural Symptoms of Dementia Care for Patients in Hospitals and Residents in Long-Term Care Homes* (Toronto: Health Quality Ontario, 2016).

———. *Engaging with Patients and Caregivers about Quality Improvement A Guide for Health Care Providers* (Toronto: Health Quality Ontario, 2016).

———. *Quality Matters: Realizing Excellent Care for All* (Toronto: Health Quality Ontario, 2017).

———. *Creating and Sustaining Patient and Family Advisory Councils – Recruiting for Diversity* (Toronto: Health Quality Ontario, 2017).

———. *Ontario's Patient Engagement Framework: Creating a Strong Culture of Patient Engagement to Support High Quality Health Care* (Toronto: Health Quality Ontario, 2017).

———. *Quality Standards: Process and Methods Guide* (Toronto: Health Quality Ontario, 2017).

———. *Quality Improvement Plan Guidance: Workplace Violence Prevention* (Toronto: Health Quality Ontario, 2017).

———. *Quality Improvement Plan (QIP) Guidance Document for Ontario's Health Care Organizations* (Toronto: Health Quality Ontario, 2017).

———. *Looking Back and Looking Forward: A sneak peek for the 2018/19 long-term care quality improvement plans (QIPs)* (Toronto: Health Quality Ontario, 2017).

———. "Measuring Long-Term Care Homes", (2017), online: <http://www.hqontario.ca/System-Performance/Measuring-System-Performance/Measuring-Long-Term-Care-Homes>.

———. "Wait Times for Long-Term Care Homes", (2019), online: <https://www.hqontario.ca/System-Performance/Long-Term-Care-Home-Performance/Wait-Times>.

Legal Aid Ontario. "Will legal aid pay for my lawyer?", (2019), online: *Getting legal help* <https://www.legalaid.on.ca/en/getting/eligibility.asp>.

Moran, Mayo. *Second Legislative Review of the Accessibility for Ontarians with Disabilities Act, 2005* (Toronto: Ministry of Economic Development, Employment and Infrastructure: 2014).

Ministry of Community and Social Services. *Guidelines For Supporting Adults With A Developmental Disability When Applying To, Moving Into And Residing In A Long-Term Care Home* (Toronto: Ministry of Community and Social Services, 2017).

Ministry of Finance. 2014 Budget. (Toronto: Ministry of Finance, 2014).

Ministry of Health and Long-Term Care. *Commitment to Care: A Plan for Long-Term Care in Ontario* by Monique Smith, Parliamentary Assistant, Ministry of Health and Long-Term Care (Toronto: Ministry of Health and Long-Term Care, Spring 2004).

———. *Future Directions for Legislation Governing Long-Term Care Homes* (Toronto: Ministry of Health and Long-Term Care, November 2004).

———. *Mcguinty Government Launches Comprehensive Strategy to Protect Seniors in Long-Term Care (May 11 News Release)* (Toronto: Ministry of Health and Long-Term Care, 2004).

———. *McGuinty Government Gives Long- Term Care Residents and Their Families Greater Say in Decisions" (August 26 News release)* (Toronto: Ministry of Health and Long-Term Care, 2004).

———. Response to the Inquest into the death of El-Roubi & Lopez (Toronto: Ministry of Health and Long-Term Care, November 2005).

———. *Alternative Levels Of Care Strategy Will See Patients Discharged From Hospitals Sooner (February 10 News release)* (Toronto: Ministry of Health and Long-Term Care, 2005).

———. *Mcguinty Government Investing in Better Patient Care (February 9 News Release)* (Toronto: Ministry of Health and Long-Term Care, 2005).

———. 2006-07 Results-Based Plan Briefing Book (Toronto: Ministry of Health and Long-Term Care, 2006).

———. Response to the Standing Committee on Public Accounts dated January 3, 2006 (Toronto: Ministry of Health and Long-Term Care, 2006) (RG49-190)

———. Response to the Standing Committee on Public Accounts dated April 5, 2006 (Toronto: Ministry of Health and Long-Term Care, 2006) (RG49-190)

———. *Compendium to Bill 140, Long-Term Care Homes Act, 2007* (Toronto: Ministry of Health and Long-Term Care, 2006).

———. 2007-08 Results-Based Plan Briefing Book (Toronto: Ministry of Health and Long-Term Care, 2006).

———. *Long-Term Care Homes Manual* (Toronto: Ministry of Health and Long-Term Care, 2007).

———. *CCAC Client Services Policy Manual* (Toronto: Ministry of Health and Long-Term Care, 2007).

———. *RAI-MDS 2.0 LTC Homes – Practice Requirements* (Ministry of Health and Long-Term Care, 2007).

———. 2007-08 Results-Based Plan Briefing Book (Toronto: Ministry of Health and Long-Term Care, 2007).

———. 2008-09 Results-Based Plan Briefing Book (Toronto: Ministry of Health and Long-Term Care, 2008).

———. *What We Heard: Long-Term Care Quality Consultation 2008 - A Common Vision of Quality in Ontario Long-Term Care Homes* (Toronto: Ministry of Health and Long-Term

Care, 2008).

———. 2009-10 Results-Based Plan Briefing Book (Toronto: Ministry of Health and Long-Term Care, 2009).

———. 2010-11 Results-Based Plan Briefing Book (Toronto: Ministry of Health and Long-Term Care, 2010).

———. *A Guide to the Long-Term Care Homes Act, 2007 and Regulation 79/10* (Toronto: Ministry of Health and Long-Term Care, 2010).

———. 2011-12 Results-Based Plan Briefing Book (Toronto: Ministry of Health and Long-Term Care, 2011).

———. *Caring For Our Aging Population and Addressing Alternate Level of Care: Report Submitted to the Minister of Health and Long-Term Care* by Dr. David Walker (Toronto: Ministry of Health and Long-Term Care, June 30, 2011).

———. 2012-13 Results-Based Plan Briefing Book (Toronto: Ministry of Health and Long-Term Care, 2006).

———. *Living Longer, Living Well: Report Submitted to the Minister of Health and Long-Term Care and the Minister Responsible for Seniors on Recommendations to Inform a Seniors Strategy for Ontario* by Dr. Samir K. Sinha (Toronto: Ministry of Health and Long-Term Care, December 20, 2012).

———. *Ontario's Action Plan for Health Care* (Toronto: Ministry of Health and Long-Term Care, 2012).

———. 2013-14 Results-Based Plan Briefing Book (Toronto: Ministry of Health and Long-Term Care, 2013).

———. *Inspection Protocol - Resident Council Interview* (Toronto: Ministry of Health and Long-Term Care, 2013).

———. *Inspection Protocol - Family Council Interview* (Toronto: Ministry of Health and Long-Term Care, 2013).

———. 2014-15 Results-Based Plan Briefing Book (Toronto: Ministry of Health and Long-Term Care, 2014).

———. 2015-16 Published Plans and 2014-2015 Annual Reports (Toronto: Ministry of Health and Long-Term Care, 2015).

———. *Mandate Letter from the Minister of Health and Long-Term Care to the Health Quality Ontario* (2015).

———. *Ministry-LHIN Accountability Agreement (2015-16-2017-18).*

———. *Patients First: Action Plan for Health Care* (Toronto: Ministry of Health and Long-Term Care, 2015).

———. *Construction Funding Subsidy Policy for Long -Term Care Homes, 2015* (Toronto: Ministry of Health and Long-Term Care, 2015).

———. *Long-Term Care Home Design Manual 2015* (Toronto: Ministry of Health and Long-Term Care, 2015).

———. *Long-Term Care Homes Licensing Overview: Prepared for the Ministry-LHIN-LTC Operator Education Sessions March-April 2015* (Toronto: Ministry of Health an Long-Term Care, 2015).

———. 2016-17 Published Plans and 2015-2016 Annual Reports (Toronto: Ministry of Health and Long-Term Care, 2016).

———. *Response from the Ministry of Health and Long-Term Care to the Standing Committee on Public Account's report on Long-Term Care Home Quality Inspection Program (Section 3.09 of the 2015 Annual Report of the Office of the Auditor General of Ontario)* (Toronto: Ministry of Health and Long-Term Care, 2017).

———. *LTCH Level-of-Care Per Diem Funding Policy* (Toronto: Ministry of Health and Long-Term Care, 2017).

———. *Policy: LTCH Level-of-Care Per Diem Funding Summary* (Toronto: Ministry of Health and Long-Term Care, 2017).

———. *2017- 2018 Published Plan and 2016-2017 Annual Report* (Toronto: Ministry of Health and Long-Term Care, 2017).

———. *Ontario Boosting Nursing, Personal Support in Major Expansion of Home Care* (October 5 News Release) (Toronto: Ministry of Health and Long-Term Care, 2017).

———. *Backgrounder "Strengthening Quality and Accountability for Patients Act, 2017" (September 27, 2017)* (Toronto: Ministry of Health and Long-Term Care, 2017).

———. *Ontario Passes Legislation to Strengthen Transparency in Health Care* (News release: 12 December) (Toronto: Ministry of Health and Long-Term Care, 2017).

———. *Compendium to Bill 160, Strengthening Quality and Accountability for Patients Act, 2017* (Toronto: Ministry of Health and Long-Term Care, 2017).

———. “Long-term care accommodation costs and subsidy”, (2019), online: <https://www.ontario.ca/page/get-help-paying-long-term-care>.

———. “Reports on Long-Term Care Homes: Search Selections for Long-Term Care homes”, online: <http://publicreporting.ltchomes.net/en-ca/default.aspx>.

———. *Building a Connected Public Health Care System for the Patient* (Toronto: Ministry of Health and Long-Term Care, 2019).

Local Health Integration Networks. *Long-Term Care Service Accountability Agreements* (L-SAA) (2016-2019).

Ministry of Labour. *Preventing Workplace Violence in the Health Care Sector: Progress Report* (Toronto: Ontario, 2017).

———. *Keeping Health Care Professionals Safe on the Job Ontario Moving Forward with Recommendations to Prevent Workplace Violence (*May 15 News release*)* (Toronto: Ministry of Labour, 2017).

Moran, Mayo. *Second Legislative Review of the Accessibility for Ontarians with Disabilities Act, 2005* (Toronto: Ministry of Economic Development, Employment and Infrastructure, 2014).

Ontario Human Rights Commission. “Policy on preventing discrimination because of gender identity and gender expression”, online: <http://www.ohrc.on.ca/en/policy-preventing-discrimination-because-gender-identity-and-gender-expression/1-introduction>.

———. “Cole v Ontario (Health and Long-Term Care) : Challenging the funding limits to live in community settings”, online: <http://www.ohrc.on.ca/en/cole-v-ontario-health-and-long-term-care-challenging-funding-limits-live-community-settings>.

Office of the Chief Coroner for Ontario. *Ezz-El-Dine El-Roubi and Pedro Lopez Inquest Jury Recommendations* (Toronto: Office of the Chief Coroner for Ontario, 2005).

Ontario Ombudsman. *Findings relating to the Ombudsman’s Investigation of the Ministry of Health and Long-Term Care’s Monitoring of Long-Term Care Homes* (Toronto: Ontario Ombudsman, December 21, 2010).

———. *Case update - Annual Report* (Toronto: Ontario Ombudsman, 2011 and 2012).

———. *Nowhere to Turn: Investigation into the Ministry of Community and Social Services’ response to situations of crisis involving adults with developmental disabilities* (Toronto: Ontario Ombudsman, 2016).

———. “Ontario Ombudsman - Adults with developmental disabilities in crisis”, online: <https://www.ombudsman.on.ca/Investigations/SORT-Investigations/Completed/Adults-with-developmental-disabilities-in-crisis.aspx>.

———. “Ontario Ombudsman - Adults with developmental disabilities in crisis”, online: <https://www.ombudsman.on.ca/Investigations/SORT-Investigations/Completed/Adults-with-developmental-disabilities-in-crisis.aspx>.

ServiceOntario. “Ontario’s Regulatory Registry” (2018), online: http://www.ontariocanada.com/registry/

———. “Amendments to Ontario Regulation 79/10 under the Long-Term Care Homes Act, 2007”, online: <http://www.ontariocanada.com/registry/view.do?postingId=26226&language=en>.

Parliamentary documents

Legislative Library and Research Services. *Long Term Care Facilities Activity: s. 4.04, Auditor General’s 2004 Annual Report Briefing Materials* (Prepared for: Standing Committee on Social Policy) (Toronto: Legislative Assembly. Legislative Library and Research Services. 2005).

———. *Second Interim Summary of Recommendations: Bill 140, Long- Term Care Homes Act, 2006* (Prepared for: Standing Committee on Social Policy). (Toronto: Legislative Assembly. Legislative Library and Research Services: November 2007).

———. *Bill 41, The Patients First Act, 2016 Summary of Recommendations* (Prepared for: Standing Committee on the Legislative Assembly) (Toronto: Legislative Assembly. Legislative Library and Research Services: November 2016).

Standing Committee on Public Accounts. *Long-Term Care Facilities Activity* (Toronto: Legislative Assembly. Standing Committee on Public Accounts: November 2005).

———. *Long-term-care Homes—Medication Management* (Toronto: Legislative Assembly. Standing Committee on Public Accounts: November 2009).

———. *Long-Term Care Home Quality Inspection Program (Section 3.09 of the Auditor General’s 2015 Annual Report)* (Toronto: Legislative Assembly. Standing Committee on Public Accounts: 2017)

Debates

Ontario, Legislative Assembly, Official Report of Debates (Hansard), 35th Parl, 2nd Sess (26 November 1992).

Ontario, Legislative Assembly, Official Report of Debates (Hansard), 35th Parl, 2nd Sess (1 February 1993).

Ontario, Legislative Assembly (Standing Committee on Public Accounts), Official Report Journal of Debates (Hansard), 38th Parl, 1st Sess, (May 5, 2005).

Ontario, Legislative Assembly (Standing Committee on Social Policy), Official Report of Debates (Hansard), 38th Parl, 2nd session, (30 January 30 2007).

Ontario, Legislative Assembly (Standing Committee on Public Accounts), Official Report of Debates (Hansard), 39th Parl, 2nd session, (12 May 2010).

Ontario, Legislative Assembly (Standing Committee on Public Accounts), Official Report of Debates (Hansard), 41st Parl, 2nd session, (26 October 2016).

Canada

Reports, websites and other documents

Canada, Department of Finance. *Economic and Fiscal Implications of Canada's Aging Population* (Ottawa: Department of Finance, 2012).

Employment and Social Development Canada. *Government of Canada — Action for Seniors report* (Ottawa: Employment and Social Development Canada, 2014).

Employment and Social Development Canada. *The Government of Canada tables the Optional Protocol to the United Nations Convention on the Rights of Persons with Disabilities (News Release November 30, 2017)* (Ottawa: Employment and Social Development Canada, 2017).

Human Resources and Skills Development Canada. *2011 Federal Disability Report - Seniors with Disabilities in Canada* (Ottawa: Human Resources and Skills Development Canada, 2011).

Statistics Canada. *Residential Care Facilities 2009/2010* (Ottawa: Statistics Canada, 2011).

———. *Low Income in Canada - A Multi-line and Multi-index Perspective* (Ottawa: Statistics Canada, 2012).

———. *Women in Canada: A Gender-based Statistical Report (Senior Women)* (Ottawa: Statistics Canada, 2016).

———. Table 18-10-0005-01 Consumer Price Index, annual average, not seasonally adjusted (Ottawa: Statistics Canada, 2019).

Veterans Affairs Canada. "Long Term Care - Health and well being - Services - Veterans Affairs Canada", (15 December 2014), online: <http://www.veterans.gc.ca/eng/services/health/long-term-care>.

Parliamentary documents

Library of Parliament. *The United Nations Convention on the Rights of Persons with Disabilities: An Overview (Publication No. 2013-09-E) by Julian Walker* (Ottawa: Library of Parliament, 2013).

———. *Statistical Profile of Poverty in Canada*. (Ottawa: Library of Parliament of Canada) online: <http://www.lop.parl.gc.ca/content/lop/ResearchPublications/prb0917e.htm.>

Special Senate Committee on Aging. *Canada's Aging Population: Seizing the Opportunity* (Ottawa: Senate of Canada, 2009).

Standing Senate Committee on National Finance. *Getting Ready: For a New Generation of Active Seniors* (Ottawa: Senate of Canada, 2017).

United Kingdom

United Kingdom. *When Laws Become Too Complex A review into the causes of complex legislation* (London: Office of the Parliamentary Counsel, 2013).

OTHER DOCUMENTS

Accreditation Canada. *Helping you deliver quality residential care for seniors* (Ottawa: Accreditation Canada, 2015

———. *Standards: Long-Term Care Services (Ver. 11)* (Ottawa: Accreditation Canada, 2016).

———. *Accreditation Basics* (Ottawa: Accreditation Canada).

AdvantAGE, *Advancing Senior Care Recommendations to Change the LTCHA and Its Regulation (February 2017)* (Toronto: AdvantAGE, 2017).

Advocacy Centre for the Elderly. *Submission to the Standing Committee on General Government: Bill 160 Strengthening Quality and Accountability for Patients Act* (Toronto: Advocacy Centre for the Elderly, 2017).

———. Newsletter (Spring/Summer 2018) Vol. 15, No. 1 (Toronto: Advocacy Centre for the Elderly, 2018).

Armstrong, Pat, Hugh Armstrong, Jacqueline Choiniere & Ruth Lowndes. *RNs in Long-Term Care: A Portrait* (Toronto: Ontario Nurses' Association, 2019).

Association of Municipalities of Ontario. *Coming to a Crossroad: The Future of Long Term Care in Ontario* (Toronto: Association of Municipalities of Ontario, 2009).

———. *Coming of Age: The Municipal Role in Caring for Ontario's Seniors* (Toronto: Association of Municipalities of Ontario, 2011).

———. *Strengthening Age-Friendly Communities and Seniors' Services for 21st Century Ontario* (Toronto: Association of Municipalities of Ontario, 2016).

———. *A Compendium of Municipal Health Activities and Recommendations* (Toronto: Association of Municipalities of Ontario, 2019).

———. *Long-Term Care: Municipal Challenges in Ontario* (Toronto: Association of Municipalities of Ontario, 2019).

Canadian Centre for Policy Alternatives. "Freeing our people: Updates from the long road to deinstitutionalization", online: <https://www.policyalternatives.ca/publications/monitor/freeing-our-people-updates-long-road-deinstitutionalization>.

Canadian Union of Public Employees. "Stop the violence against us", (5 October 2017), online: <https://cupe.ca/stop-violence-against-us>.

Canadian Institute for Health Information (CIHI). *When a Nursing Home is Home: How do Canadian Nursing Homes Measure Up on Quality?* (Ottawa: Canadian Institute for Health Information, 2013).

———. *Health Spending - Nursing Homes* (Ottawa: Canadian Institute for Health Information, 2014).

———. *CCRS Quick Stats, 2016–2017* (Canadian Institute for Health Information, 2017).

———. *Patient-Reported Experience Measures: Long-Term Care* (Ottawa: Canadian Institute for Health Information).

Canadian Patient Safety Institute. *Medication Reconciliation in Long-Term Care Getting Started Kit (version 3)* (Ottawa: Canadian Patient Safety Institute, 2015).

———. *Reducing Falls and Injuries from Falls Getting Started Kit* (Ottawa: Canadian Patient Safety Institute, 2015).

Champlain Region Family Council Network. "About the CRFCN", online: <https://www.champlainfamilycouncils.ca/about>.

Change Foundation, *Enhancing Care, Enhancing Life: Spotlight on Residents' Councils and Family Councils in Five Long-Term Care Homes in Ontario* (Toronto: Change Foundation, 2017).

College of Dietitians of Ontario. *The Jurisprudence Handbook for Dietitians in Ontario* (Toronto: College of Dietitians of Ontario, 2015).

College of Nurses of Ontario. *Practice Standard: Ethics (Pub. No. 41034)* (Toronto: College of Nurses of Ontario, 2009).

———. *Practice Standard: Infection Prevention and Control (Pub. No. 41002)* (Toronto: College of Nurses of Ontario, 2009).

———. *Practice Guideline: Complementary Therapies (Pub. No. 41021)* (Toronto: College of Nurses of Ontario, 2014).

———. *Practice Standard: Restraints (Pub. No. 41043)* (Toronto: College of Nurses of Ontario, 2017).

———. *Practice Guideline: Consent (Pub. No. 41020)* (Toronto: College of Nurses of Ontario, 2017).

College of Physicians and Surgeons of Ontario. *Policy Statement # 6-12: Mandatory and Permissive Reporting* (Toronto: College of Physicians and Surgeons of Ontario, 2012).

———. *Policy Statement #2-15: Professional Obligations and Human Rights* (Toronto: College of Physicians and Surgeons of Ontario, 2015).

———. *Policy Number #3-15: Consent to Treatment* (Toronto: College of Physicians and Surgeons of Ontario, 2015).

———. *Policy Statement #4-08 - Maintaining Appropriate Boundaries and Preventing Sexual Abuse* (Toronto: College of Physicians and Surgeons of Ontario, 2017).

Concerned Friends of Ontario Citizens in Care Facilities. "Inspection Results", online: <http://www.concernedfriends.ca/look-long-term-care-homes/inspection-results>.

———. "The Work We Do", online: <http://www.concernedfriends.ca/our-work>.

Council of Canadians with Disabilities. "Monitoring of the CRPD", online: <http://www.ccdonline.ca/en/international/un/canada/monitoring-of-the-crpd>

Family Councils Ontario. "Education and Networking", online: <https://fco.ngo/education-and-networking/family-council-networking>.

———. "Resources", online: <https://www.fco.ngo/resources>.

———. *Supporting Families in Long Term Care Results from a Research Project* (Toronto: Family Councils Ontario, 2018).

———. “Supporting Families Research”, (2018), online: *Updates and Events* <https://www.fco.ngo/updates-and-events/updates/supporting-families-research-project>.

Hall, Margaret. *Developing an Anti-Ageist Approach Within Law* (Toronto: Law Commission of Ontario, 2009).

Institute of Public Administration of Canada. *Healthcare Governance Models in Canada A Provincial Perspective* (Toronto: Institute of Public Administration of Canada, 2013).

Joffe, Kerri. *Enforcing the Rights of People with Disabilities in Ontario’s Developmental Services System* (Toronto: Law Commission of Ontario, 2010).

Law Commission of Ontario. *The Law as it Affects Persons with Disabilities: Consultation Paper.* (Toronto: Law Commission of Ontario, 2011).

———. *Discussion Paper: Legal Capacity, Decision Making and Guardianship* (Toronto: Law Commission of Ontario, 2014).

Long-Term Care Medical Directors Association of Canada. *Long Term Care: Six Things Physicians and Patients Should Question* (Toronto: Choose Wisely Canada, 2017).

Long Term Care Innovation Expert Panel. *Why Not Now? A Bold, Five-Year Strategy for Innovating Ontario’s System of Care for Older Adults*. (Toronto: Ontario Long-Term Care Association, 2012).

Long Term Care Task Force on Resident Care and Safety. *An Action Plan to Address Abuse and Neglect in Long-Term Care Homes* (Toronto: Ministry of Health and Long Term Care, 2012).

———. *Third Progress Report on An Action Plan to Address Abuse and Neglect in Long-Term Care Homes (October 2013 – October 2014)* (Toronto: Long Term Care Task Force on Resident Care and Safety, 2014)

Manitoba Law Reform Commission. *Substitute consent to health care (Report #110)* (Winnipeg: Manitoba Law Reform Commission, 2004).

Meadus, Jane. *ACE Newsletter Special Insert “A Brand New World: Ontario’s New Long-Term Care Homes Act”* (Toronto: Advocacy Centre for the Elderly, 2010).

Muir, Tim. *Measuring Social Protection for Long-Term Care* (OECD Health Working Papers, No. 93) (Paris: OECD Publishing, 2017) http://dx.doi.org/10.1787/a411500a-en

Multiple Sclerosis Society of Canada (Ontario Division). *Finding My Place: Age-appropriate housing for younger adults with multiple sclerosis* (Toronto: Multiple Sclerosis Society of Canada (Ontario Division), 2006).

———. *The Need for Age-Appropriate Long-Term Care: MS Society of Canada Views on Bill 140, Long-Term Care Homes Act, 2006* (Toronto: Multiple Sclerosis Society of Canada (Ontario Division), 2007).

Murakami, Yuki & Francesca Colombo. "Regulation to improve quality in long-term care", in Organization for Economic Cooperation and Development, *A Good Life in Old Age?: Monitoring and Improving Quality in Long-term Care* (Paris: OECD Publishing, 2013). http://dx.doi.org/10.1787/9789264194564-8-en

———. "Why the Quality of Long-Term Care Matters" in *A Good Life in Old Age? - Monitoring and Improving Quality in Long-term Care* (Paris: OECD / EU, 2013) 37.

OECD. OECD Health Policy Overview: Health Policies in Canada (Paris: OECD Publishing, 2016).

Ontario Association of Residents' Councils. "Through Our Eyes: Ontario Association of Residents' Councils", online: <http://www.ontarc.com/through-our-eyes.html>.

———. *2014-15 Annual Report* (Toronto: Ontario Association of Residents' Councils, 2015).

———. *2015-16 Annual Report* (Toronto: Ontario Association of Residents' Councils, 2016).

———. *Seasons (Spring)* (Toronto: Ontario Association of Residents' Councils, 2017).

Ontario Long-Term Care Association. "About Long-Term Care in Ontario: Facts and Figures", (2018), online: <https://www.oltca.com/oltca/OLTCA/Public/LongTermCare/FactsFigures.aspx#Ontario's%20long-term%20care%20homes%20(June%202017)>.

———. *Seniors in Need of Long-Term Care to Benefit from Landmark 2018 Budget* (Toronto: Ontario Long-Term Care Association, 2018).

Ontario Nurses' Association. "ONA – Workplace Violence | Recognize Violence. Report It.", online: <http://violence.ona.org/>.

OPSEU. *End Workplace Violence By making safety a priority in mental health* (OPSEU, 2016).

Public Services Health & Safety Association. "Workplace Violence Prevention Resources – Hospital, Community Care and Long Term Care", online: <https://www.pshsa.ca/workplace-violence-leadership-table-4/>.

Registered Nurses' Association of Ontario. *Prevention of Falls and Fall Injuries in the Older Adult* (Registered Nurses of Ontario, 2005).

———. *Oral Health: Nursing Assessment and Intervention* (Toronto: Registered Nurses' Association of Ontario, 2008).

———. *Promoting Continence Using Prompted Voiding* (Toronto: Registered Nurses' Association of Ontario, 2011).

———. *Promoting Safety: Alternative Approaches to the Use of Restraints* (Toronto: Registered Nurses' Association of Ontario, 2012).

———. *Assessment and Management of Pain (Third Edition)* (Toronto: Registered Nurses' Association of Ontario, 2013).

———. *Preventing and Addressing Abuse and Neglect of Older Adults: Person-Centred, Collaborative, System-Wide Approaches* (Toronto: Registered Nurses' Association of Ontario, 2014).

———. *Long-Term Care Best Practices Program Newsletter (Summer 2015)* (Toronto: Registered Nurses Association of Ontario, 2015).

———. *Delirium, Dementia, and Depression in Older Adults: Assessment and Care Second Edition* (Toronto: Registered Nurses' Association of Ontario, 2016).

———. *Financial Statements for the year ending October 2017* (Toronto: Registered Nurses' Association of Ontario, 2017).

———. "Clinical Best Practice Guidelines | Long-Term Care Best Practices Toolkit, 2nd edition", online: <http://ltctoolkit.rnao.ca/clinical-topics>.

Romano, Lisa and Jane Meadus. *Congregate Living and the Law as it Affects Older Adults* (Toronto: Law Commission of Ontario, 2009).

SEIU. "'Break the Silence': Workplace Violence Survey (Anonymous)", online: <https://www.surveymonkey.com/r/breakthesilenceonworkplaceviolence?sm=RiOpAicD7V0uDpGMjEzqDYZZiJm1d%2bdglkawhZtV4kE%3d>.

Sheldon, Tess & Ivana Petricone. *Addressing the Capacity of Parties before Ontario's Administrative Tribunals: Promoting Autonomy and Preserving Fairness* (Toronto: Law Commission of Ontario, 2009).

Unifor. *The Unifor Healthcare Council Action Plan 2016* (Ottawa: Unifor, 2016).

United Nations Office of the High Commissioner for Human Rights. "Questions and Answers" online: <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/QuestionsAnswers.aspx>.

Wahl, Judith, Mary Jane Dykeman, & Brendan Gray. *Health Care Consent and Advance Care Planning in Ontario*. (Toronto: Law Commission of Ontario, 2014).

NEWS SOURCES

McKie, David. "Advocates demand inquiry into Ontario's costly handling of Royal Crest nursing-home failure", *CBC News*, (March 23, 2009) online: <http://www.cbc.ca/news/canada/advocates-demand-inquiry-into-ontario-s-costly-handling-of-royal-crest-nursing-home-failure-1.791359>.

Fox, Bailey. "You Are Not Alone: Ontario and British Columbia Invalidate Solitary Confinement", (6 February 2018), online: *TheCourt.ca* <http://www.thecourt.ca/not-alone-ontario-british-columbia-invalidate-solitary-confinement/>.

Goffin, Peter. "Thousands of Under-65 Adults with Physical Disabilities Are Being Forced into Ontario Nursing Homes: Ministry Data", *Toronto Star (*July 9, 2017*); Toronto, Ont*, online: <https://www.thestar.com/news/gta/2017/07/09/thousands-of-under-65-adults-with-physical-disabilities-are-being-forced-into-ontario-nursing-homes-ministry-data.html>.

Gordon, Andrea & Laurie Monsebraaten. "A Promise to Fix Disability Crisis: Ombudsman's Scathing Report on Disabled Adults Sparks Minister's Apology and Vow to Make It Right", *Toronto Star* (25 August 2016) A.1.

Priest, Lisa. "Nursing Homes No Answer for the Young", *The Globe and Mail* (18 December 2004), online: <https://beta.theglobeandmail.com/news/national/nursing-homes-no-answer-for-the-young/article1008752/?ref=http://www.theglobeandmail.com&>.

Puxley, Chinta. "McGuinty vows to do more to care for elderly; Ombudsman to probe long-term home system" *The Toronto Star* (9 July 2008) A.15 (Proquest).

Quesnel, Jennifer. "Active man with Down syndrome being diapered and spoon-fed in long-term care but needs group home, sister says", *CBC* (11 January 2018), online: <http://www.cbc.ca/news/canada/saskatoon/he-needs-a-home-sister-of-man-with-down-syndrome-says-long-term-care-is-wrong-place-for-him-1.4482193>.

Welsh, Moira. "Health minister vows 'revolution' in care; Smitherman has personal reason for taking action; Promises to bring 'missionary zeal' to troubled system" *The Toronto Star* (8 December 2003) A01 (Proquest).

Appendix A: Detailed Comparison of the Current and Previous Frameworks

Legal Instruments	**Current Legal Regime Since 2010**	**Previous Legal Regime (up to 2010)**
Hard Law (statutes and LGIC regulations)	*Long-Term Care Homes Act, 2007*, SO 2007, c8. O Reg 79/10. *Excellent Care for All Act 2010*, SO 2010, c 14. O. Reg. 187/15: Annual Quality Improvement Plan. Local Health System Integration Act, 2006, S.O. 2006, c.4. O Reg. 264/07 O Reg. 279/07 O Reg. 456/16	*Nursing Homes Act*, RSO 1990, c N.7 RRO 1990, Reg 832: GENERAL. *Homes for the Aged and Rest Homes Act*, RSO 1990, c H.13 (excluded from the review – substantially the same as the Nursing Homes Act) RRO 1990, Reg 637: GENERAL *Charitable Institutions Act*, RSO 1990, c C.9 (excluded from the review– substantially the same as the Nursing Homes Act) RRO 1990, Reg 69: GENERAL
Soft Law (Guidelines with various degree of legal formality and agreements made under specific statutory authority)	A Guide to the Long-Term Care Homes Act, 2007 and Regulation 79/10 – Note: The Guide covers parts of the LTCHA and its regulation MOHLTC Inspection Protocols (31) LHIN-Ministry Memorandum of Understanding LHIN-Ministry Accountability Agreement Long-Term Care Home Service Accountability Agreement (L-SAA)	Long Term Care Home Manual – Note: The Manual repeats the requirements in statutes and adds more requirements MOHLTC-CCAC Client Services Policy Manual (chapters relevant to admission) Ministry's agreements with individual homes (excluded from the review – not publicly available)

Appendix B: Interviewees and topics

Note: Not all topics were addressed in-depth by interviewees. Interviewees may decide not to address particular topics.

Interviewee	Description	Topics
1	Health law lawyer (anonymous)	Consent to admission, consent to treatment, secure unit provisions in the Long-Term Care Home Act
2	Lorraine Purdon, Executive Director, Family Councils of Ontario	Family Council provisions in the LTCHA, implementation of the new inspection program, FCO's current initiatives to support family councils such as the 60-minute consultations, the Change Foundation's report family councils and residents' councils
3	Samantha Peck, Director, Communications and Education, Family Councils of Ontario	Family Council provisions in the LTCHA, implementation of the new inspection program, FCO's current initiatives to support family councils such as the 60-minute consultations, the Change Foundation's report family councils and residents' councils
4	Dr. Fred Mathers, President, Ontario Long Term Care Clinicians	Documentation requirements, treating incapable residents, zero tolerance of abuse and neglect of residents policy, safety of staff, discharge of residents, Resident Quality Inspections, resources for homes (soft law)
5	Lois Dent, Board Member, Concerned Friends of Ontario Citizens in Care Facilities	Implementation of the Long-term Care Task Force on Care and Safety Action Plan, Concerned Friends' on-going review of inspection results and compliance order, residents and families asserting choices and preferences and wait times
6	Jordanne Holland, Board Member, Concerned Friends of Ontario Citizens in Care Facilities	Implementation of the Long-term Care Task Force on Care and Safety Action Plan, Concerned Friends' on-going review of inspection results and compliance order, residents and families asserting choices and preferences and wait times
7	Keith Dee, Director of Membership, Community Living Ontario	Younger residents in LTC homes, alternatives for people with disabilities who are at risk of institutionalization, Cole v Ontario (Health and Long-Term Care) updates
8	Gord Kyle, Director of Policy, Community Living Ontario	Younger residents in LTC homes, alternatives for people with disabilities who are at risk of institutionalization, Cole v Ontario (Health and Long-Term Care) updates
9	Union representative (anonymous)	Health and safety of frontline workers in LTC homes, legal protections for front-line workers such

Note: Not all topics were addressed in-depth by interviewees. Interviewees may decide not to address particular topics.		
Interviewee	**Description**	**Topics**
		as whistleblower protections in LTC homes, implementation of the new Inspection Program
10	Industry association representative (anonymous)	Implementation of the Long-term Care Task Force on Care and Safety Action Plan, Auditor General's report on the Inspection Program, responsive behaviour provisions in the LTCHA and Behavioural Support Ontario, Homes' relationships with the Family Councils and Residents' Councils such as involvement of the Councils' in quality improvement plans and satisfaction surveys, Guidelines or check lists developed by organizations such as the Accreditation Canada, Canadian Patient Safety Institute (CPSI), Choosing Wisely Canada, and the Registered Nurses Association of Ontario (RNAO) for topics such as fall prevention, infectious diseases etc.
11	Beverly Mathers, Chief Executive Officer, Ontario Nurses' Association	ONA's Workplace Violence Prevention campaign and what homes do if a resident engages in behavior (including responsive behaviour) that harms another resident or a staff member, Implementation of the Long-term Care Task Force on Care and Safety Action Plan (2012), Legal protections for front-line workers such as whistleblower protections in long-term care homes, Resources available to nurses such as CNO's practice guidelines and RNAO's Long-Term Care Best Practices Program.
12	Judith Wahl, Elder law lawyer	Challenging finding of incapacity and access to the Consent and Capacity Board, Eligibility requirements and admission wait times, Residents' Bill of Rights, Responsive behaviour provisions (s.53 to s.55) and discharge (s.145) in Regulation 79/10
13	Disability rights lawyer (anonymous)	Challenging finding of incapacity, access to the Consent and Capacity Board, Power of attorney and People with disabilities who are at risk of institutionalization (or re-institutionalization)
14	Dee Lender, Executive Director, Ontario Association of Residents' Councils	implementation of the Long-Term Care Home Quality Inspection Program, Quality Improvement Plans and annual satisfaction surveys, OARC's Through Our Eyes: Bringing the Residents' Bill of Rights Alive, Residents asserting choices and preferences, The Change Foundation's Report entitled "Enhancing Care, Enhancing Life:

Note: Not all topics were addressed in-depth by interviewees. Interviewees may decide not to address particular topics.		
Interviewee	**Description**	**Topics**
		Spotlight on Residents' Councils and Family Councils in Five Long-Term Care Homes in Ontario"
15	Andy Savela, Director of Health Care, Unifor	Unifor's Dignity 4.0 Time to Care campaign, Health and safety of frontline workers in long-term care homes, Legal protections for front-line workers such as whistleblower protections in long-term care homes, Implementation of the Long-Term Care Home Quality Inspection Program (LQIP).
16	Industry association representative (anonymous)	Recommendations to Change the LTCHA and Its Regulation, Homes' relationships with the Family Councils and Residents' Councils such as involvement of the Councils' in quality improvement plans and satisfaction surveys , Guidelines or check lists developed by organizations such as the Accreditation Canada, Canadian Patient Safety Institute (CPSI), Choosing Wisely Canada, and the Registered Nurses Association of Ontario for topics such as fall prevention, infectious diseases etc.
17	Michael Jacek, Senior Advisor, Association of Municipalities of Ontario	Follow-up questions to Strengthening Age-Friendly Communities and Seniors' Services for 21st Century Ontario (recommendations specific to long-term care), Service Accountability Agreements, Issues with the implementation of Long-Term Care Homes Act, 2007 in municipal homes, Follow-up questions to AMO's submission on Bill 160 Strengthening Quality and Accountability for Patients Act, 2017 and Long Term Care Home Quality Inspection Program
18	Lisa Corrente, Partner, Torkin Manes LLP	Intensive Risk-Focused and Risk-focused Resident Quality Inspections (RQIs), Reporting of critical incidents and complaints, Additional enforcement tools provided by Bill 160 (An Act to amend, repeal and enact various Acts in the interest of strengthening quality and accountability for patients), Interpretation of the Residents' Bill of Rights, Admission to "locked units" or "dementia units" and the common law duty to restrain

Appendix C: Codes used in NVivio

Node and child nodes	**Description**
Caring Conditions	Includes a number of child codes. This code is intended to include working conditions of health care workers. But not just about caregivers. This is supposed to illustrate the interdependencies of workers and care recipients.
Legal protections for caregivers	whistleblower protection, union's role, why these protections effective or not effective
Responsive behaviour	what this terms means, why it is used in the LTC context, why it is contested, what this term means for different people
Violence and safety	how workers get assaulted, why, employer's response, how LTC is different than other settings, how long term care is compared
Workload and demands	how many residents a caregiver has to take care, how pressed of time the caregiver feels
Public Inquiry	Public Inquiry into the Safety and Security of Residents in the Long-Term Care Homes System
Residents' rights and entitlements	Includes a number of child codes. Rights and entitlements in the LTCHA and other legal instruments
Access to justice	how do residents assert their rights when they are infringed, pros and cons of different forums, how do they get information about their rights, who can help them to assert their rights, what are the barriers to access to justice

Node and child nodes	Description
Accommodation of disability and differences in care	Whether disabilities are being accommodated in the delivery of care.
Autonomy	Whether residents being able to make decisions. Choice: where to live, whether to live in LTC, treatment decisions, choices of homes, lack of housing options
Informal caregivers and families	Support for informal caregivers to participate in different aspects of the home. Relationship between home and informal caregivers. The proper role of the informal caregivers and families in the lives of applicants and residents. Family dynamics that affect the well-being of applicants / residents.
Mismatch of environment and resources and needs of residents	Balancing the needs of different residents: residents may have different triggers, there are different types of residents (e.g. aggressive, frail etc) Mix of residents not suited for LTC: long term care residents with mental health issues, developmental issues, MS etc all mixed up in LTC Lack of alternatives for those who exhibit violent and difficult behaviour
Participation of residents	what the law means when residents have to be engaged, consulted or informed, what kind of support required, how participation looks like
State responsibilities	Include responsibilities of the state towards the sector, caregivers, residents, and others in the health care system
Collaboration	Any discussion about working with stakeholders etc
Enforcement and	including different understanding of the priority of enforcement

Node and child nodes	**Description**
compliance	in LTC policy, the purpose, shortcomings, achievements to date, what this means for homes, what enforcement means for residents and families and friends, what it cannot accomplish, what enforcement is not
Funding of the sector and setting priorities	what the government should be doing about funding the sector, what other levels of government should be doing, what is the province’s duty to maintain the health care system. what is the government's role in co-ordinating the different pieces in the health system and the social services system.
Law as a tool	what are the options offered by law, why do we use law, why is it limited, why law and why not

Appendix D: Detailed Comparison of the Compliance Regime under the Nursing Homes Act and the Long-Term Care Homes Act

The table below summarizes the key aspects of the previous and current regime:

	Nursing Homes Act	**LTCHA**
Powers of Inspectors	• May inspect premise or records, demand the production for records or other things, question persons (subject to the person's right to have counsel or some other representative), conduct examination or tests[3]	Similar scope of powers with the following exceptions: • Power to exclude any person when questioning a person (new) • Power to question a person not subject to the person's right to have counsel • What constitutes as obstruction is broadened to include destruction of records and failure to produce and assist[4]
Inspection process	• The review of resident care, programs, and services included: Programs and Services Review, Indicator Identification and Analysis, including focused audits, In-Depth Review of Resident Care and Review of Staffing[5]	• The procedures are included in each of the inspection protocols

---

[3] *Nursing Homes Act,* RSO 1990, c N.7, s 24(2) - (12).

[4] *Long-Term Care Homes Act, 2007,* SO 2007, c 8, s 147, 151.

[5] Ministry of Health and Long-Term Care, *Long-Term Care Homes Program Manual* (Toronto: Ministry of Health and Long-Term Care, 2007) at Tab 1101-01, page 4.

	Nursing Homes Act	**LTCHA**
Inspector's obligation to meet with Residents' Council and Family Council	• None • But the Program Manual refers to interviews with residents and families	• Yes – during annual inspection if requested or permitted to do so by the Council[6]
Reporting (during and after inspection)	• Interim Summary Report • Final Summary Report[7] • Posting of inspection report and making it available to residents and others[8]	• All inspection reports and summary of the annual inspection must be provided to the Residents' Council and Family Council[9] • Additional posting requirements[10] • More reports and information that the director is required to publish, such as direction regarding suspension of admission, a licensee's written plan of compliance, administrative monetary penalties, convictions and fines[11]
Informal actions to address non-	• Statement of Unmet Standards or Criteria (which lists the standard	• All non-compliance must be documented[14]

---

[6] *Long-Term Care Homes Act, 2007, supra* note 4, s 145.

[7] Ministry of Health and Long-Term Care, *supra* note 5 at Tab 1101-02, pages 1-6. This is not referenced in the *Nursing Homes Act.*

[8] *Nursing Homes Act, supra* note 3, s 24(13); RRO 1990, Reg. 832: General, s 98(2) [Reg. 832].

[9] *Long-Term Care Homes Act, supra* note 4, s 149.

[10] *Ibid*, ss 79(3)(k) – (m).

[11] *Ibid*, s 173.

	Nursing Homes Act	LTCHA
compliance	or criteria number, content, and examples observed)[12] - Corrective Action Plan[13]	
Stopping non-compliant activities, remedying any damages created and addressing harm / risk	- Written notice of non-compliance[15] - Suspension of admission of residents[16] - Revocation or suspension of licence[17] - Interim management[18] - Ministry may take over the home operation under the *Health Facilities Special Orders Act*[19]	- Written notification - Written request to prepare a written plan for correction to be implemented voluntarily - Referral from inspector to the director for further actions - Compliance orders - Work and activity orders - Recovery of costs - Money withheld or to be paid back to the government - MOHLTC / home entering into agreements (instead of an order) - Mandatory Management Order[20]

---

[14] *Long-Term Care Homes Act, 2007, supra* note 4, s 149(3).

[12] Ministry of Health and Long-Term Care, *supra* note 5 at Tab 1101-02, page 1. This is not referenced in the *Nursing Homes Act.*

[13] *Ibid* at Tab 1101-02, page 1–2. This is not referenced in the *Nursing Homes Act*.

[15] Reg. 832, *supra* note 8, s 97; Ministry of Health and Long-Term Care, *supra* note 5 at Tab 1103-01, page 1.

[16] *Nursing Homes Act, supra* note 3, s 20.1(17); Ministry of Health and Long-Term Care, *supra* note 5 at Tab 1103-01, page 4–6.

[17] *Nursing Homes Act, supra* note 3, s 15; Ministry of Health and Long-Term Care, *supra* note 5 at Tab 110301, page 1. It should be noted that the *Nursing Homes Act* did not refer to suspension of licence, only revocation or refusal of issuance of licence.

[18] *Nursing Homes Act, supra* note 3, s 19(2).

[19] Ministry of Health and Long-Term Care, *supra* note 5 at Tab 1103-01, page 2. Before 2010, in the *Health Facilities Special Orders Act* the definition of “health facility” included a nursing home.

[20] *Long-Term Care Homes Act, 2007, supra* note 4, ss 152–156, 176.

	Nursing Homes Act	**LTCHA**
Sanctions	• Prosecution • Individual: first offense with maximum fine of $25,000 or imprisonment of maximum of 12 months or both and subsequent offence with maximum fine of $50,000 or imprisonment of maximum of 12 months or both[21] • Corporation: first offense with maximum fine of $50,000 and subsequent offence with maximum fine of $200,000[22]	• Administrative monetary penalty (less than $100,000)[23]. For example, the administrative penalty for a second failure to comply with the Residents' Bill of Rights is $5,000 and for a third failure the amount is increased to $10,000[24] • Prosecution • A new offence for failing to comply with an order but this new offence may not result in imprisonment or probation[25] • Higher fines: Individual: first offense with maximum fine of $100,000 and subsequent offence with maximum fine of $200,000 (certain exceptions apply)[26] • Re-inspection fee for each subsequent inspection to determine compliance of an order: $500 (the first one is free)[27]

---

[21] *Nursing Homes Act, supra* note 3, s 36(1).
[22] *Ibid*, s 36(2).
[23] *Long-Term Care Homes Act, 2007, supra* note 4, s 156.1.
[24] O Reg 79/10, s 292.2.
[25] *Long-Term Care Homes Act, 2007, supra* note 4, s 162.2(1)-(2).
[26] *Ibid*, s 182(1).
[27] O Reg 79/10, *supra* note 24, s 299.1.

	Nursing Homes Act	LTCHA
		• Corporation: first offense with maximum fine of $200,000 and subsequent offence with maximum fine of $500,000[28] • Same prison terms • Revocation of licence[29] • Suspension of licence (by director or Minister)[30] • Interim management[31]
Guidance or considerations about imposing sanctions	• Criteria for issuing written notice (e.g. risk to health, safety, welfare, security, or rights of residents and corrective actions not taken) and grounds for suspension of admission in the Program Manual[32]	• Factors to be taken into account when deciding actions to be taken: severity of non-compliance including severity of the harm or risk of harm, scope of non-compliance and history of compliance or any factors that the director considered relevant[33]
What cannot be used as defence	• None	• Due diligence, honest and reasonable belief not a defence[34] • Sufficiency of the funding provided to a home from any

---

[28] *Long-Term Care Homes Act, 2007, supra* note 4, s 182(4).
[29] *Ibid*, s 157.
[30] *Ibid*, s 157 and 158.1.
[31] *Ibid*, s 157(4) to (8).
[32] Ministry of Health and Long-Term Care, *supra* note 5 at Tab 1103-01, page 1–5.
[33] O Reg 79/10, *supra* note 24, s 299.
[34] *Long-Term Care Homes Act, 2007, supra* note 4, s 159(1), 162.2(3).

	Nursing Homes Act	LTCHA
		source must not be considered in any review or appeal[35]
Review and appeal	• Licensing decisions could be appealed to the Health Services Appeal and Reveal Board and then division court • Rules about who can participate at hearings (e.g. residents and employees who request party status) • Hearing may be delayed if the home satisfies the Appeal Board that the licensee has not been given a reasonable opportunity to comply and health, safety or welfare of the residents would not be adversely affected[36]	• Orders and notices - Review by director and then appeal to the Health Services Appeal and Review Board and then divisional court[37] • No reference to participation of residents or employees at hearings[38] • Specific timelines for notices and beginning of hearing unless parties agree to a postponement[39] • Evidentiary rules[40] • Crown has the option to elect to have a prosecution heard by a judge rather than a justice of the peace[41]

---

[35] *Ibid*, s 171.
[36] *Nursing Homes Act, supra* note 3, s 15.
[37] *Long-Term Care Homes Act, 2007, supra* note 4, ss 163–170.
[38] *Ibid*, s 167.
[39] *Ibid*, ss 168(1) – (3).
[40] *Ibid*, s 173.1.
[41] *Ibid*, s 182(5.2).