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## Patient-centered Primary Care of Adults with Severe or Profound Developmental Disabilities: The Patient–Physician Relationship

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## Abstract

Adults with developmental disabilities receive most of their health care from family physicians, yet little is known of the development of the patient-physician relationship in this population. This qualitative study used a grounded theory approach to describe the development of this relationship between adult patients with severe or profound developmental disabilities and their family physicians. Semi-structured interviews were conducted with 13 caregivers and 15 family physicians of these patients. The recognition of the patient's vulnerabilities was a common starting point. Caregivers approached the patient-physician relationship as one unit with the person they cared for as part of the process of protecting them, before allowing the relationship to develop along different trajectories. Family physicians described a mutual process of acceptance—of the patient as a human being, and of the physician by the patient. Greater awareness of these processes of relationship development may improve health care delivery for patients with developmental disabilities.

## Keywords

Patient physician relationship, developmental disabilities, triadic relationship, primary care, vulnerable population.

## Co-Authorship Statement

The research for this thesis was conceived, planned, conducted and reported by the author.

The following contributions were made:

Drs. Amanda Terry and Bridget Ryan provided guidance and advice throughout the planning, execution, analysis, and reporting of the qualitative studies in this thesis. Both also contributed to the thematic analysis of the qualitative studies from both sets of semi-structured interviews.

So to become human implies two realities. It means to be someone, to have cultivated our gifts, and also to be open to others, to look at them not with a feeling of superiority but with eyes of respect.

—Jean Vanier, *Becoming Human*

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## Preface

While I am the principal researcher for this thesis, I am also an academic family physician whose clinical practice involves a special interest in caring for adult patients with severe or profound developmental disabilities. I have been involved in advocating for and starting a primary care referral clinic for adult patients with developmental disabilities in St. John's, Newfoundland and Labrador (NL) and received formal training in this regard. I also facilitate teaching sessions for the family medicine residents on caring for adults with developmental disabilities.

To appreciate the value of reflexivity, I must examine the biases I brought to this research as a family physician myself caring for my patients with severe and profound developmental disabilities. I have personally experienced both the challenges and immense fulfillment of developing these relationships, yet never stopped before this research project to question them. I feel strongly about the therapeutic power of the patient-physician relationship in family medicine and our responsibility to be able to provide this aspect of care to all our patients.

I realized once I began my data collection and analysis that my original research question did not sufficiently capture or acknowledge the intensity and closeness of the patient-primary caregiver relationship. This close bond, created through constant one-one caregiving is the central and original relationship. I have captured this impression by referring in Study One to the patient-caregiver-physician relationship.

Presently as a salaried academic family physician and having only practiced in St. John's, NL, the barriers and challenges I face may not always be the same as those of my colleagues in different clinical situations. I sought to expand my local experience and understanding of the research questions by including the perspectives of physicians from other provinces in Study Two.

I am confident that my experience of the patient-physician relationship both prior to and continuing throughout this study, my regular reflections on the effect of my clinical experiences, my knowledge of the physicians and the communities in which many of them

practice, and the ongoing data analysis together allowed for a rich and in depth co-construction of the theory grounded in the data produced together with the participants.

## Chapter 1

### 1 Introduction

People with developmental disabilities are living longer and are more likely to have multiple and complex medical problems (1–4). There is strong evidence of health disparities in this vulnerable population including inadequate attention to health care needs and health promotion and inadequate access to quality health care services (5). Family physicians are the most consistently available primary health care providers for adults with developmental disabilities (6). The enduring patient-physician relationship is a therapeutic hallmark of family medicine (7), yet research on the relationship in this population is scarce (2, 6).

This thesis seeks a deeper understanding of the development of this relationship and its influence on the provision of ongoing primary health care for adult patients with severe or profound developmental disabilities.

#### 1.1 The Purpose of the Introductory Chapter

This chapter will introduce the reader to the topic of this thesis by first explaining important terms and definitions. This is followed by an overview of the research purpose, research design and structure of the thesis.

#### 1.2 Terms and Definitions

A number of different terms are used around the world to describe developmental disabilities. In Canada, the terms developmental disabilities and intellectual disabilities are used interchangeably and are synonymous with the term learning disabilities in the United Kingdom. Some countries, including the United States, still use the term mental retardation. Other terms used to describe developmental disabilities include mental deficiency, handicap and sub-normality (1, 8). All these definitions have three criteria in common: significant limitations in intellectual functioning, significant limitations in adaptive functioning, and manifestations of these symptoms before the age of 18 years (9). This classification of developmental disabilities was developed within the broader

World Health Organization (WHO) framework for health and disability, the International Classification of Functioning, Disability and Health (ICF), which was created to provide a standard framework of language for the description of health and health-related states (10).

Developmental disabilities are further classified according to differing levels of intellectual and adaptive functioning (the collection of conceptual, social and practical skills that have been learned and are performed by people in their everyday lives) (10). These classifications include mild, moderate, severe, and profound developmental disabilities (11). Understanding the level of these skills in patients with developmental disabilities sets the stage for the development of a good patient-physician relationship and a productive clinical encounter. Physicians must learn to adapt their skills to accommodate the lower degree of adaptive functioning in these patients and this imbalance of adaptive functioning skills may impact relationship development. In order to understand this impact more deeply, the most severely affected patients were identified for this study.

Patients with severe developmental disabilities have an intelligence quotient (IQ) of 25-35, scores which fall within the first percentile. Their adaptive functioning skills are at the level of those of a three to six-year-old without developmental disabilities. Conceptual skills are limited to using simple one or two-word combinations in verbal communications and pointing to objects. Socially and practically, these patients can understand their immediate environment and one-step action words. They are considered not capable of making most medical decisions (8, 10).

Patients with profound developmental disabilities have an IQ of <20-25, scores which fall below the first percentile. Their adaptive functioning skills are similar to those of a newborn to three-year-old without developmental disabilities. Their conceptual skills are extremely limited and they may or may not be able to communicate verbally or by gesturing. Socially and practically these patients are also extremely limited in their abilities and are considered not capable of making medical decisions (8, 10).



The severity of the limitations in conceptual (including language), social (including interpersonal), and practical (including decision making) skills, make the active involvement of the caregiver in the patient-physician relationship a necessity. For the purpose of this thesis, the term “primary caregiver” will refer to the person primarily responsible for the health care of the person with disabilities. The term “paid caregiver” will refer to a paid primary caregiver who may be taking care of one or multiple clients with varying degrees of disability.

The term patient will be used when referring to an adult with developmental disabilities in the context of an interaction with a physician. When this same adult is being referred to exclusively in the context of their relationship with their caregiver, they will be referred to as a “family member/client”.

### 1.3 Thesis Purpose

There is strong evidence of health inequities and unmet health needs for people with developmental disabilities (2, 9, 12, 13). Primary health care, including the family physician and their relationship with their patients has an important role in addressing these inequities (12, 14). Research on this relationship in patients with developmental disabilities, particularly those with severe or profound developmental disabilities is scarce (2), leaving patients, caregivers and family physicians with little guidance on how to proceed. Given the lack of literature, an appropriate starting point is to explore this relationship. The purpose of this thesis therefore was to explore the processes of the development of the patient-physician relationship in adult patients with severe or profound developmental disabilities, first from the perspective of the patients and caregivers, and then from the perspective of family physicians.

### 1.4 Thesis Design

Research for this thesis was conducted in two phases consisting of two qualitative studies. Study One involved patients and their caregivers, while Study Two focused on family physicians. Constructivist grounded theory was chosen as the qualitative methodology for both studies. A relationship is a dynamic phenomenon; it is a process of

continued development. Knowledge of the theory behind this process is needed as a starting point to inform further research and potential interventions for those involved in such relationships. Grounded theory, therefore, was chosen to understand this process more deeply from the patient, caregiver, and physician perspective. To ensure the thesis author's experience with patient-physician relationships (particularly in patients with severe and profound developmental disabilities) was incorporated in a formal manner, constructivist grounded theory was chosen specifically for its foundations in relativism and its appreciation of the multiple realities of subjectivism (15). Constructivist grounded theory encourages a mutual construction of the truth with input from both the participants and the researcher. The focus of this study was patients with severe or profound developmental disabilities, who have significant limitations in their ability to represent themselves in an interview setting. Recognizing the strong bond between patients and their caregivers, and the limitations in verbal communication skills of the patients, caregivers were interviewed in Study One for their perspectives on this relationship rather than the patients themselves. This then informed Study Two: interviews with family physicians. Purposeful sampling was used in both studies to capture the appropriate subgroups of people involved in the relationship and facilitate comparisons thereof (16).

The data collection methods in qualitative inquiry are developed from the research question (17). In this study, a semi-structured interview guide was developed from research questions stemming from the research purpose and objectives as laid out in the thesis proposal (Appendix A). Semi-structured interview guides were regularly adjusted, informed by the data analysis that was occurring simultaneously with data collection. Open-ended questions and the semi-structured nature of the interviews encouraged information sharing by participants and avoided applying a preconceived structure to the interview (Appendix B).

Sample size, in keeping with qualitative methodology, was not guided by numerical calculations, but by the researcher's judgement on the sufficiency of information gathered. An adequate sample size is one that is not too small to support one's claims, yet small enough to permit deep, case-based data analysis (18). Data gathering in both

studies therefore continued until saturation was achieved, that is when no new themes were seen to emerge from the interviews (19).

This thesis was designed primarily to explore this unique patient-physician relationship within the context of Newfoundland and Labrador's primary health care system, drawing also on experience from other provinces in Canada.

## 1.5 Thesis Structure

This thesis explored the relationship between patients with severe or profound developmental disabilities and their family physicians. It aimed to understand and describe the process involved in forming these relationships, including the integral involvement of the primary caregiver.

The current chapter introduced the topics of developmental disability, related terms and definitions, and the thesis purpose and design.

Chapter two reviews the literature pertaining to the care of people with developmental disabilities including challenges in delivering quality healthcare and the role of primary health care and the family physician in meeting those challenges.

Chapter three details the methodology involved in the two constructivist grounded theory studies.

Chapter four reports on the findings of Study One, the purpose of which was to describe the process of development of the patient-physician relationship between adult patients with severe or profound disability and their family physician as perceived by the patient's primary caregiver. One main process, that of protection, is described including the requirements for that process to occur. This process resulted in a dynamic triangular interaction involving the patient, caregiver and family physician. This interaction then proceeded to develop along one of four different relationship development trajectories.

Chapter five reports on the findings of Study Two, the purpose of which was to describe the process of development of the patient-physician relationship between adult patients with severe or profound disability and their family physician as perceived by family

physicians. The main process identified here was that of mutual acceptance between the physician and patient. This process set the stage for a range of relationships to develop.

Chapter six integrates the findings from chapters four and five, and discusses shared themes and differences that emerged. Specific recommendations regarding the process of developing this relationship were then developed to inform those involved in the delivery of primary health care to patients with severe or profound developmental disabilities.

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## Chapter 2

### 2 Literature Review

#### 2.1 Prevalence of Developmental Disabilities

Individuals with developmental disabilities, estimated at approximately 60 million people worldwide, represent one of the largest population groups of those with lifelong disabilities (1). The prevalence of developmental disabilities in Canada is estimated at one to three percent of the population (2, 3). Recently, the Health Care Access Research and Developmental Disabilities (HCARDD) Program, a provincial program in the province of Ontario, identified a cohort of 66,864 adults with developmental disabilities representing a prevalence rate of 0.78% within adults in Ontario (4). Despite the large numbers, global data collection on this quietly vulnerable population has not occurred in a consistent manner. The World Health Organization (WHO), recognizing the lack of global information regarding this population, produced two recent publications on this topic (5, 6). Despite some good information regarding individual diagnoses of syndromes causing developmental disabilities or developmental disabilities in specific geographical areas, it is still difficult to find statistics that describe the impact of the full range of developmental disabilities at a national level in most countries, including Canada (5). In the USA, the Centers for Disease Control and Prevention developed a sophisticated tracking procedure to gain more accurate prevalence data (7). As such, we know that about one in six children in the USA were reported as having a developmental disability in 2006–2008, an increase of 17.8% from 1997–2008 (8). While the pediatric definition of developmental disability

In Newfoundland and Labrador (NL), a province of 530,000 people (9), there are no provincial statistics describing the prevalence of developmental disabilities in the population. The Autism Society of Newfoundland and Labrador represents people with Autism Spectrum Disorder (ASD), one diagnosis within the population of those with developmental disabilities. This organization collects data and in 2014 put the number of children from birth to school-leaving age with ASD in NL at more than 1,000. The

Autism Society still recognizes however, that the lack of epidemiological information in Canada and NL has led to great uncertainty regarding true prevalence rates of ASD (10). At present, we do not know the numbers of people with developmental disabilities living in NL, nor if their health care needs are being met or not. The development of an NL registry of individuals with ASD has been identified as a recommendation following the 2016 publication of the NL Autism Society's Needs Assessment (11).

## 2.2 Present Models of Care for Patients with Developmental Disabilities in Canada

Deinstitutionalization of people with developmental disabilities, beginning in the 1990s in Canada, resulted in a need to change the models of providing health care for these patients (12). Where these patients were once cared for behind the closed doors of institutions, they now live and access primary health care in the community as any other patient would expect to (12).

Despite the federal government's efforts to identify disability issues as a priority, much work remains to be done to ensure the full inclusion of people with disabilities in Canada (13, 14). An election platform promise of the previous government in 2004 to develop a national Canadians with Disabilities Act by 2010 was not kept (15). The recent change in the federal government has brought with it another such promise (16). At present, there is no national or Newfoundland and Labrador health policy specifically focused on approaches to the health care of people with developmental disabilities.

Most children, once diagnosed with development disabilities, are cared for within specialized multi-disciplinary teams within provincial paediatric health systems. Across NL, the only specialized centre providing care for these children is the Development and Rehabilitation Division of the Janeway Health Centre, St. John's, NL (17). At the age of 18 years, these young adults are required to transfer to the adult health care system. They may be referred to a number of specialists within this system, as well as to their family physician.



Within the Eastern Health Care Corporation in St. John's NL, services related to adults with developmental disabilities are delivered by the Rehabilitation and Continuing Care and the Community Services Programs (18). Neither of these programs provide services specifically for individuals with developmental disabilities, and each is large, representing many different patients. Transition planning from paediatric to adult health care services has only recently begun to be a focus on all areas of chronic disease management and disability and evidence of beneficial outcomes of specific programs is still mixed (19).

## 2.3 Transitions of Care

Children and adults in NL are traditionally serviced by two separate health care systems as in the case of St. John's, NL described above. Less than century ago, most people with developmental disabilities did not reach adulthood (12), hence the focus until quite recently on pediatric care. These same children however are now, thanks to medical and social advances, living longer (20–22). For example, in individuals with Down syndrome, the mean age of death increased from 26 years in 1983 to 49 years in 1997 (3). One unfortunate result of this increased longevity is that as compared to the population without developmental disabilities, this population is more likely to have multiple and complex comorbid medical conditions, rendering them vulnerable to further health disparities as they enter adult medical systems across the world with fewer accessible resources (3, 4, 22, 23). On average, adults with developmental disabilities have 5.2 conditions per person and half of these go unrecognized or are poorly managed (24).

People with developmental disabilities are especially vulnerable during transitions of care. Often, the first transition for people with developmental disabilities is the transition from a highly coordinated and specialized pediatric health care system to a more fragmented and less specialized adult system. Differences in these two systems are significant, particularly for patients with developmental disabilities as pediatric systems are largely family-focused, involving interprofessional teams, whereas adult systems are more focused on the individual patient and expect greater autonomy of the patient with respect to their health care decisions (25). Given the patient with developmental disabilities has varying abilities in this regard, their potential unmet needs may never be

adequately met (12). A recent study of 13 Dutch patients transferring from pediatric to adult care showed that parents of young people with profound intellectual and multiple disabilities valued the care provided by the pediatrician and wished to see it continued (26).

Rather than focusing on the transition from pediatric to adult health care, recent publications have highlighted the need for an early focus on lifelong functioning and transition for each individual and their family (27). Relationship building has been identified as one of the essential aspects of this patient-centred approach to care. A specific community “navigator”, a position created to support those with developmental disabilities by planning for their transitions and navigating all involved systems and resources, can be another important resource (27). While some provinces such as BC (28), Alberta (29), and Ontario (30) fund these types of positions, they are not universally established roles in Canada, and no such position exists in NL. Health care professionals can also facilitate the transition process; for example, by ensuring new health care professionals have all the information they need (31). An Australian study looking at plans for older adults with developmental disabilities highlighted the continuing nature of planning and the importance of the development of mechanisms to deal with changing circumstances throughout the lifecycle in order to avoid further vulnerability and health disparities (32).

The holistic approach to care throughout a patient’s life as a way to ensure smoother transitions relies on continuity of care and the providers of that care. Optimal care of a person with developmental disabilities is best provided by a specialized multidisciplinary team and a collaborating primary health care provider who together provide comprehensive and coordinated care and support to the patient and family (33, 34). Family physicians should either be involved prior to the birth of a child or immediately after the birth of a child, but involvement often begins at significant transitions such as transition to adult care (33). The Ontario-based Developmental Disabilities Primary Care Initiative recently developed a transitions toolkit in which they suggest that youth should, in addition to their paediatrician, connect with their primary health care provider at

minimum annually from at least age 12 years in preparation for transfer of care at age 18 years (35).

## 2.4 Addressing the Needs of Those with Developmental Disabilities within our Present Health Care System

The United Nations' Convention on the Rights of Persons with Disabilities states that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability (36). The World Health Organization (WHO) defines health as a state of complete physical, mental, and social well-being and not merely the absence of disease and infirmity (37). In its "Healthy Ageing—Adults with Intellectual Disabilities" report, the WHO states that while this description of health is equally applicable to people with developmental disabilities and without, those with developmental disabilities are still generally devalued and disadvantaged in regard to their health status (38). Key issues discussed in the Healthy Ageing report include: a lack of organized health care and supportive systems designed to address the needs of adults with developmental disabilities, the need for modification of public attitudes, and the failure of health practitioners to recognize the special problems experienced by this ageing population (38).

Hart's inverse care law states that "the availability of good medical care tends to vary inversely with the need for it in the population served" (39). Studies in Canada, the United Kingdom and Australia confirm that people with developmental disabilities are poorly supported by their health systems (3, 22, 23, 40). People with developmental disabilities have higher than average health care needs but generally access preventative primary health care services less (23, 24). Individuals with developmental disabilities are more likely than the general population to have physical disabilities, mental health problems, chronic diseases, hearing impairments, vision impairments, and communication disorders (4, 21, 23, 24). These combined disabilities, coupled with significant limitations in adaptive and intellectual functioning, make this population especially vulnerable to health disparities (3, 23, 41, 42). People with severe developmental disabilities are more severely affected and have even poorer health outcomes than those with mild disabilities (40). Research focusing on the experiences of

people with developmental disabilities and health care systems remains limited. However, recent studies are beginning to reveal that adult patients with mild developmental disabilities and their family physicians face challenges accessing and providing appropriate primary health care (4, 38, 43–45).

Provision of guidelines and training for those professionals dealing with people with developmental disabilities is important in order to recognize and understand the particular health care needs of people with developmental disabilities.

## 2.5 Primary Health Care Guidelines

The Developmental Disabilities Primary Care Initiative in Ontario recently brought together clinicians with expertise in the care of adults with developmental disabilities with a goal to improve primary health care and quality of life for these people. This resulted in the publication of the 2011 Canadian Consensus “Guidelines on the Primary Care of Adults with Developmental Disabilities” which gave practical recommendations, based on current knowledge to primary care providers throughout Canada (2). Similar guidelines have been produced in other countries including the USA and Australia (46, 47). These clinical guidelines emphasize involving caregivers, adapting procedures when appropriate, and seeking input from a range of health professionals when available.

The use of these guidelines, particularly when referring to providing regular preventative health care checks for patients with developmental disabilities has been associated with improved clinical outcomes such as increased immunization rates, cancer screening, increased detection of diseases and improved follow up (24, 47–49). It has also been shown to improve primary health care practitioners’ knowledge of the health needs of these patients, as well as ability to identify gaps in health care services (47, 49, 50).

Unfortunately, some of the recommended resources and specialized services, while generally available in most areas of Canada, may be lacking in some regional health service systems. This is the situation in most areas of NL. It was noted that people with disabling conditions, including those with developmental disabilities are a low priority for researchers, and as a result many of the recommendations are based on expert opinion

or published consensus statements rather than evidence (2). How widely these guidelines are actually used in clinical practice is variable and not sufficiently researched to date (50, 51).

Use of these guidelines does not come without significant challenges. For the patients, merely attending a physician's clinic was an anxiety provoking experience and they were reluctant to participate in preventative care visits (51). For the physician, challenges included limited experience working with people with developmental disabilities, lack of required information such as clinical and community resources, and an increase in time required to complete the assessment (24, 47–51).

## 2.6 The Role of the Family Physician in the Provision of Primary Health Care

The majority of all health and medical care services provided to the Canadian population occurs in primary care settings, most often by family physicians (52). As such the family physician plays a key role in primary health care of all Canadians, including those with developmental disabilities.

The specific role of family physicians in the primary health care of those with developmental disabilities is supported by the Developmental Disabilities program committee of the College of Family Physicians of Canada (CFPC) (53). This committee represents the interest of all CFPC members providing care to people with developmental disabilities. Its members were involved in the development of the Guidelines for the Primary Care of Adults with Developmental Disabilities (2) and provide resources such as teaching modules for family physicians who are training medical students and family medicine residents in this field (54).

Specific data detailing family physicians' involvement in the care of those with developmental disabilities in Canada is scant. Information from the College of Family Physicians of Canada's latest National Physician Survey does not include data on caring for people with developmental disabilities (55). In the USA, Australia and United Kingdom, community-based primary health care providers (including family physicians)

are the main providers of health care to people with developmental disabilities (56–58). One can only assume that family physicians, as the most common primary health care provider, are also the most consistently available health care provider for people with developmental disabilities across Canada, including Newfoundland and Labrador.

Research on the practice of family medicine for patients with developmental disabilities has been the focus of a very limited body of literature which has largely concentrated on the perspectives of, and challenges faced by, family physicians (44). Research including adults with developmental disabilities has relied primarily on secondary analysis of larger databases as opposed to direct accounts of individual and caregiver experiences (4, 44). Ten studies were identified that included the perspectives of patients and/or caregivers. Most studies focused on patients with mild developmental disabilities (43–45, 59–65). The results revealed that people with developmental disabilities face a series of barriers when trying to access primary health care, including physically accessing the clinics, communication issues, waiting for appointments and transitioning to adult care. The family physician's knowledge of the patient was an important enabling factor in addressing these barriers (43–45, 59). Studies focusing on physicians' perspectives of the primary health care of those with developmental disabilities have highlighted a lack of clinical knowledge since family physicians feel ill prepared for the task of providing health care to this population (3, 23, 45, 47, 49, 50, 58). One study involving nurse practitioners providing primary health care to patients with developmental disabilities in the United Kingdom highlighted the need for closer support and partnership with specialist developmental disability services (57). A study in which family physicians in the United States were interviewed found that although these practitioners tried to provide care for their patients with developmental disabilities, they did not believe they were knowledgeable about this population and lacked the resources and support they needed to provide good care (56). Without much evidence-based guidance or support, the family physician and caregiver are often left to adapt what knowledge they can access, to the people they are caring for—individuals with multiple, complex, and often unknown underlying conditions and needs.

## 2.7 Patient-Physician Relationship

As they deliver care to their patients, family physicians develop relationships with their patients. In one way or another, the construct of this patient-physician relationship and its effect on the medical encounter has been described throughout the history of medicine, beginning with the Greeks and continuing through to the 21st century in both medical and social science literature (66, 67). This relationship has had many different forms in different periods, reflecting the dominant medical paradigm at the time. The biomedical model, the dominant medical paradigm of the 19th and early 20th century, viewed the patient's disease independently from the person who was suffering from it and from the social context in which it occurred. More recently in the latter 20th and now 21st century, this model has been challenged by many, first a group of general practitioners led by psychoanalyst and physician Michael Balint (68) followed by others including psychoanalyst George Engel, neurologist Kurt Goldstein and family physician Ian McWhinney (69). The newer paradigm views the patient as whole, a dynamic integrated being ensconced in a context including, very importantly, the patient-physician relationship (69).

Bioethicists Emmanuel and Emmanuel suggested that power relations were the key construct of various elements of the patient-physician relationship (70). The balance of power between the patient and the physician formed the basis of their model of patient-physician relationship also described by Roter (66), ranging from mainly physician power (paternalism) to mainly patient power (consumerism) with the middle balance approach demonstrating mutuality of power and the dysfunctional relationship being a function of lack of power on either side. Roter described the optimal medical encounter as a mutual relationship-centred one, and then further characterized the patient-physician encounter as: medically functional, informative, facilitative, responsive, and participatory (66).

Power in the patient-physician relationship, while often on the side of the health care provider, is also in the hands of the patient, especially when discussing his or her needs or when deciding whether or not to comply with a management plan, suggesting some codependence on each other in the relationship (71).

Various other models of patient-physician consultation and resultant relationship have been described. While they have a slightly different focus, these models all include aspects of understanding the patient, their behaviours, experiences, and context, as well as the importance of both the patient and the physician's input into the consultation experience itself (68, 72–76).

The success of relationship and patient-centred care has been linked to a variety of objective patient health outcomes. These positive health outcomes include emotional health, symptoms resolution, functional status, physiological measures (e.g., blood pressure and blood glucose levels), pain control, and chronic illness care (77–81). As an essential aspect of this care, the patient-physician relationship is an important therapeutic modality in itself.

Family medicine defines itself through the focus on the patient-physician encounter and resultant relationship (69, 72). The College of Family Physicians of Canada has developed four principles of family medicine, one of which focuses on the centrality of the patient-physician relationship in the role of the family physician. Described as having the qualities of a covenant, the description of this principle, includes elements of trust, privacy, a recognition of individual experience of suffering, an awareness of power differentials, and the development of this relationship over time (82). Longitudinal care and commitment across a wide range of concerns as well as the consultation experience itself, including valuing patients and the experience of interacting with them, are all important aspects of the patient-physician relationship in family medicine (56, 57, 83, 84).

The skills needed to form these positive professional patient-physician relationships are as important as any other clinical skill used in the encounter. These skills include the ability to communicate, to be compassionate, caring, and empathetic, and perhaps most importantly, the ability to inspire trust between both parties (85–87). Trust implies a transference of power to a person to act on one's behalf and in one's best interest (76). The balance of vulnerability and power in the patient-physician relationship is a well-studied phenomenon (70, 71, 83, 84, 87). Patients with severe or profound developmental



disabilities are considered a vulnerable group of people as a result of their limited cognitive and adaptive functioning abilities. This inherent vulnerability requires an appreciation of the power differential in the resulting relationship by the physician in order for it to be successful.

The development of this relationship, and the provision of continuous, coordinated care for people with severe or profound developmental disabilities does not come without its challenges. Recent research reflects concerns from patients with developmental disabilities regarding the ability of their family physicians to communicate appropriately with them (44). The level of developmental disability presents a unique challenge in communication which is a key component of relationship development. Patients with severe or profound developmental disabilities have very limited communication skills and require continuous support to optimize their communication opportunities (88, 89). This includes the caregiver's interpretation of behaviours which may indicate certain needs. These patients also often have physical and/or sensory impairments further impacting their ability to communicate which can then affect relationship development (90, 91). Receptive or understanding communication skills are often stronger than expressive ones, strengthening the argument for the physician to communicate directly with the patient, including them in the encounter even if the patient cannot be seen to be actively communicating in return (90). Family practitioners can optimize engagement and communication within a consultation by learning how an individual communicates (43, 65). They can also engage the caregivers in trying to interpret patients with profound developmental disabilities behaviours as forms of communication (60).

Patients with severe or profound developmental disabilities always present to their family physician with a caregiver. This results in the development of a triadic relationship. The third person speaks for the patient and as their interpreter and/or advocate, mediates the interaction between the patient and family physician. The caregiver's role in the medical encounter is essential to the patient's health outcomes (43, 58). The importance of involvement of caregivers is seen in the success of early intervention occupational therapy and physiotherapy programs which rely heavily on good interpersonal relationships between families and professionals (92). The physician is part of this triadic

interaction and as a result also has heightened communication needs as they interact with this patient population (58).

Research on the effect of a third person in the medical encounter in older patients with dementia reveals that the interactional dynamics change, and may influence the development of a trusting and effective patient-physician relationship (93). Some medical practitioners have been reported to ignore patients with communication difficulties, focusing solely on the caregiver (65). Effective and empathic management of this triad relationship requires specific communication skills (94, 95).

The patient-physician relationship has been researched quite extensively in other groups of people as described above. While some studies have included comments on issues related to relationship development such as communication issues (44, 45, 59, 95), only one study was found to report specifically on the patient-physician relationship in patients with mild developmental disabilities (43) and no studies were found focusing specifically on this relationship in adults with severe or profound developmental disabilities. Little is known of the process or outcomes of this interaction within different health care contexts, including those of Canada or NL.

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## Chapter 3

### 3 Methodology Study One and Study Two

#### 3.1 Purpose

The purpose of this study was to describe the development of the patient–physician relationship between adult patients with severe or profound developmental disabilities and their family physicians as perceived by:

Study One: the patients’ primary caregivers

Study Two: the patients’ family physicians

##### 3.1.1 Specific Objectives

1. To explore the process of how the patient-physician relationship develops in the context of adult patients with severe or profound developmental disabilities and their family physicians
2. To describe the trajectory of this relationship development
3. To use this knowledge to assist family physicians in caring for these patients.

#### 3.2 Methodology

##### 3.2.1 Study Design

This study used the qualitative methodology of constructivist grounded theory (1) to examine the specific processes of relationship development between patients with severe or profound developmental disabilities and their family physicians. Data were collected via in-depth interviews with primary caregivers and family physicians of adult patients with severe or profound developmental disabilities. As is appropriate in constructivist grounded theory methodology, the researcher adopted a reflective, non-judgemental stance during these interviews, thereby encouraging maximal participation. The sharing of personal details and asking and answering of questions from both parties was

encouraged. This allowed for the process of data generation rather than data collection (2). Analysis of these interviews allowed insight into the experiences of the participants. Using this insight, the researcher proposed themes and developed ideas about the process of developing the patient–physician relationship.

The stories of both sets of participants were reconstructed into a constructivist grounded theory model to understand the process of relationship development. Grounded theory goes beyond the “what and how” questions to those of “why” (3). Constructivist grounded theory requires that the answers to these questions are grounded in the experiences of both the participants and the researcher (2). The deeply personal experiences of the patients, caregivers, physicians and author of this thesis (a researcher and a family physician) in caring for this vulnerable and as yet relatively un-researched population, yield themselves to a constructivist grounded theory approach. By using this approach, this study attempts to understand why, how, and in what way the patient-physician relationship develops in this distinct population. When combined with insight and industry, grounded theory methods offer sharp tools for generating, mining and making sense of data (3). As a family physician deeply entrenched in the positive and therapeutic nature of the patient-physician relationship and involved clinically with the care of patients with severe or profound developmental disabilities, the author’s personal experience, insight and interpretive process were all an integral part of this research. The theory that was ultimately constructed is one that is grounded in the mutual experiences of both the participants and the researcher (2, 4).

Researchers using constructive grounded theory appreciate that they bring with them underlying assumptions that affect the collection and interpretation of the data (2). While some would argue that having a passion for an area of research can blind the researcher to a certain aspect of the data (2, 3), those using constructive grounded theory use this to their advantage. In this study, regular reflection by the researcher was therefore critical to ensure the necessary linkage of their personal and emotional experiences of their ongoing clinical work, the research interview, and the relationships they formed with the participants during those interviews, with the stringent intellectual methodology. In

addition to this, group analysis of the data with two non-clinical researchers in this study ensured regular evaluation of these assumptions.

### **3.2.2 Sampling and Recruitment**

#### **3.2.2.1 Study One – Caregiver Participants**

Participants were sampled purposefully. Potential participants were identified and recruited by family physicians at the Waterford Psychiatry Hospital and primary health care clinics in St. John's, NL. These physicians have experience caring for, and have developed relationships with, patients with developmental disabilities. The range of recruitment sources ensured a rich and varied sample which included family caregivers and paid caregivers of patients living in private homes or institutions. Family physicians recruited the caregiver participants who then responded back to the researcher if they were interested in participating. An invitational letter and information about the study were provided to the participants by the family physician (Appendix D). Further information and consent forms/information were provided by the researcher via email or telephone when the participants contacted her. Consent forms were provided for the caregiver as well as the substitute decision-maker for the patient if this was not the caregiver (Appendix E, Appendix F). Written consent from participants and substitute decision makers when appropriate, were obtained before data collection commenced. Sampling and data collection continued until the point of saturation, at which no additional concepts relevant to the central themes emerged from the data of new participants. To ensure maximum variation in the sample, a variety of participants in each study were recruited. This allowed participants with a range of ages, from a variety of locations, and with a variety of experiences in caring for adults with developmental disabilities to be included (5). This project was reviewed and approved by Newfoundland and Labrador's Health Research Ethics Board (Appendix G).

#### **3.2.2.2 Study Two – Family Physician Participants**

Potential participants were identified through purposeful sampling of family physicians with a variety of experience in developing enduring relationships with adults with severe or profound developmental disabilities. To ensure maximum variation of clinical

experience and practice type and location, participants were recruited from three groups of family physicians all of whom had some experience of enduring relationships with patients with severe or profound developmental disabilities:

1. Family physicians at the Waterford Hospital, St. John's, NL who saw a large number of outpatient and institutionalized patients with severe or profound developmental disabilities.
2. Community family physicians from St. John's and the Avalon Peninsula region of NL who had a minimum of two patients with severe or profound developmental disabilities in their practice and had some experience of forming relationships with such patients in this context.
3. Family physicians from the College of Family Physicians of Canada Special Interest Group on Developmental Disabilities who had specific expertise and/or experience in forming relationships with adults with severe or profound developmental disabilities.

Representation from local family physicians revealed specific knowledge of the local community context while physicians from other provinces in Canada gave a broad national level perspective. The range of recruitment sources ensured a rich and varied sample.

Invitations to participate, including information about the study, were provided to potential participants via email from the primary researcher (Appendix C). Further information and consent forms were then emailed to the participants after they identified that they would like to participate (Appendix D, Appendix H). Written consent was obtained before data collection commenced. Sampling and data collection continued until the point of saturation, at which no additional concepts relevant to the central themes emerged from the data of new participants. This project was reviewed and approved by Newfoundland and Labrador's Health Research Ethics Board (Appendix G).

### 3.2.3 Data Collection—Study One and Study Two

Data collection for Study One occurred from February 2015–May 2015. Data collection for Study Two occurred from June 2015–September 2015. Due to the relative lack of research in this area, the approach taken for this study was an open and exploratory one, with the researcher providing gentle guidance to the participants where appropriate. As is appropriate in constructivist grounded theory methodology, the researcher adopted a reflective, non-judgemental stance during these interviews, thereby encouraging maximal participation. Participants were asked to share their experiences and stories about interacting with their physicians or patients in the health care system. The sharing of personal details and asking and answering of questions from both parties was encouraged. This allowed for the process of data generation rather than data collection (2), resulting in a rich understanding of the process of developing the patient-physician relationship. A different semi-structured interview guide was used for each study which included open-ended questions and subsequent probes (Appendix B). The interview guide was regularly updated by simultaneously analyzing the data to identify emerging ideas, allowing the researcher to explore new avenues of inquiry in future interviews (Appendix I, Appendix J). Interviews occurred at a time and location most convenient for the participants and were conducted either in person or telephonically.

Interviews were audio-recorded and transcribed verbatim. Field notes describing the context of the interview and initial experience and impressions of the researcher in her role as the interviewer were documented immediately after each interview. These field notes allowed the author of this thesis to be cognizant of the wider context that influenced the participants telling of their stories (2) when analyzing the data. Memos in the form of notes taken both during and after review of the transcripts and iterative data analysis served as important source of data. These memos captured the researcher's reflections and insights informed by both the transcript data, as well as her personal experience of the interview process and of being a practising family physician caring for adults with severe and profound developmental disabilities.

### 3.2.4 Data Analysis Study One and Study Two

Data analysis has been described as an interpretive dance (5), being both iterative and responsive with multiple steps and changing rhythms. As a first step in this process, the three researchers involved in this study (Katherine Stringer, Bridget Ryan, Amanda Terry) independently read and coded the transcripts and field notes to identify key themes and concepts. These researchers then came together as a team in subsequent meetings to compare and discuss their independent coding. The lead researcher, Katherine Stringer, incorporated the information from these team discussions into both the data generation and data analysis processes to iteratively create the final coding templates used for Study One and Study Two. Data analysis meetings of the research team continued throughout both studies. Details of the analysis process, culminating in the development of the grounded theory are included below. The regular and ongoing meetings of the research team represented part of the interpretive dance, involving constant revision and development of the various levels of data analysis described below. Data collection and analysis occurred simultaneously to facilitate the development of a grounded theory (6).

Data analysis of all interview transcripts, field notes and memos occurred through an interpretive and iterative approach based on that described by Charmaz (1). It involved:

1. Reading and becoming familiar with each transcript and field note.
2. Continued generation of memos.
3. Initial line by line focused coding.
4. Generating a thematic “coding template” which was continually revised during data collection.
5. Continual addition of research team insights, diagrams, reflections to the iterative process of theoretical coding.
6. Reviewing all the transcripts after completion of data collection.
7. Identifying theoretical codes grounded in the data and focused coding.

8. Identifying exemplar phrases that explained the theoretical codes and grounded them in the data.
9. Continuously referring back to the data and previous codes for verification and review of emerging theory.
10. Developing a coordinated constructive grounded theory.

Trustworthiness and credibility of the data was ensured through the following techniques (5):

1. Purposeful screening to ensure all participants had experience of the studied relationship
2. Audio-recording interviews, verbatim transcription, and detailed field notes to maintain methodological rigor.
3. Review of transcripts for accuracy
4. Group data analysis involving Katherine Stringer (MCISc student and family physician involved clinically in caring for those with developmental disabilities), Bridget Ryan, Phd, and Amanda Terry, Phd (thesis supervisors and non-clinicians). Regular questioning and challenging of all researchers' assumptions was encouraged.
5. Regular individual and group reflection on the part of all researchers including memo writing and journaling on the part of Katherine Stringer. This was done to maximize researcher transparency, grounding this transparency in the experience of those constructing the data—the participants and the researchers. It also helped Katherine Stringer to remember, question, analyze and make meaning of the time spent with the participants and the data generated together (1, 2)



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## Chapter 4

### 4 Study One Findings and Discussion

#### 4.1 Final Sample and Demographics

A total of thirteen individuals meeting the inclusion criteria of primary caregiver to one or more adults with severe or profound developmental disabilities participated in eleven interviews. Two of the participants were interviewed as couples. Eight of the participants were female and five were male with an age range of 49–82 years ( $M=61.3$ ,  $SD=11.7$ ). The patients they were caring for ranged in age from 24–67 years.

Six of the caregivers were parents (including one foster mother), four were other family members, and three were paid caregivers. The majority of the participants ( $n=9$ ) had no formal training in caring for patients with developmental disabilities, four caregivers did have formal training and worked for organizations caring for patients with developmental disabilities.

Six caregivers took care of these adults in their family home, one patient lived in her own home with full time care, five caregivers were involved in caring for patients in group homes or long term care facilities in the community.

Interviews ranged from 40 to 80 minutes and took place in patients' and caregivers' homes, a hospital room, or the primary researcher's office.

#### 4.2 Findings from Data Analysis

In Study One, to ensure that the importance of the integration of the caregiver into the patient-physician relationship is acknowledged, this relationship is referred to where appropriate, as the "patient-caregiver-physician relationship". Study findings revealed that the core process in the development of the patient-caregiver-physician relationship was that of protection. Caregivers needed to protect their family members/clients, and looked to the physician to be a part of this process. This process was necessary because

of the recognition of the vulnerability of their family member/client as a result of their developmental disability.

#### 4.2.1 Vulnerability

Caregivers described their family member/client as being vulnerable due to the fact that they could not take care of any of the basic activities of daily living independently or in many cases even communicate their needs. This lack of independence and the inability to communicate rendered them dependent on others for protection and assistance in every aspect of their life.

*“He is just difficult to look after because he is more or less like a baby. He is very limited. He can’t take care of himself on his own. He is like a baby only bigger, right?” (interview 1)*

The process of protection began from this starting point of the caregiver’s perception of the vulnerability of their family member/client. This process then proceeded through a number of stages resulting in the patient, caregiver and physician all interacting together in a medical encounter. This triadic interaction then followed four different relationship development trajectories.

Caregivers described this process of protection and the development of the four different relationship trajectories as occurring in numerous contexts specific to their family member/client’s life. While this study will report mainly on the impact of the health care context on the patient-physician relationship, it is worth noting that this process of protection continued in all contexts relating to the patient and caregiver, such as their homes and the broader community and social context.

The next section 4.2.2 describes the five stages in the process of protecting ending with the dynamic patient-caregiver-physician interaction. Section 4.2.3 describes the four different trajectories this interaction then followed as four different types of relationships developed. Finally, section 4.2.4 describes why this process of protection was necessitated by the health care and social contexts in which these relationships occurred.

## 4.2.2 Process of Protection

### 4.2.2.1 Extreme Nurturing

Nurturing developed from the dependence of the adult with severe or profound disabilities on those caring for them. More than simply caring for the adult, like the care given to a baby, it included the need to minimize vulnerability and protect, involving constant life-long vigilance, advocacy, and support. Nurturing included the act of promoting and sustaining development to maximize potential, no matter how limited this may have been.

*“But given that he is an adult now, he just looks like a little boy and that’s what he communicates to them. He communicates that I am very vulnerable right now and I’m only little so you got to do whatever it is you got to do to take care of me.” (interview 6)*

*“You have to be their advocate, you have to be their voice, you have no choice” (interview 8)*

The use of the word extreme describes the severity and intensity of the nurturing required to ensure a good quality of life. This population of people who had significant limitation in their adaptive functioning skills were unable to interact with their environment in the “usual” or accepted way, so protecting them involved adapting the environment to their needs. This included, for instance, providing assistance with all daily activities within the context of a normal busy family life.

*“We’d take him shopping, get what he needed, bath him, everything ...get his hair cut, do what he needed done.” (interview 3)*

Caregivers used words such as “fought” and “begging” to describe the extreme measures they had to use to ensure health care appropriate for this level of nurturing.

*“And it sometimes comes down to going to GPs that we know, basically begging. We know you are not taking new clients, but” (interview 4)*

*“...we (caregivers) had to push and scrape for every additional test”  
(interview 4)*

*“24 hours (home care). I fought for that like nothing else. And I got it”  
(interview 7)*

The term extreme also described the challenges associated with requests from physicians for seemingly small changes in routine care. Again, the patient’s limitations in adaptive functioning did not allow for the “usual” adaptations to “small” changes in routine.

*“‘Why won’t she let me take her blood pressure?’ Come in and see and you will see the anxiety and you will see the stuff being kicked across the floor and you will say, ‘Okay.’” (interview 4)*

While this nurturing process began in much the same way as for any parent on the arrival of a new baby or young child, it differed in that it was not preparing the person with developmental disabilities for a future life of independence but rather it continued for the entire life of the person with developmental disabilities.

*“But yeah, it is the responsibility that you take when you make that choice to keep your child and it is the responsibility forever or for however long you keep them” (interview 6)*

*“I go visit Patient 1 everyday” (81-year-old mother describing her continued involvement in her 62 years old son’s care). (interview 10)*

Extreme nurturing is the process by which the caregivers protected their family members/clients. This was what was required to care for these adults who were unable to interact with and adapt to their environment as a result of a severe or profound developmental disabilities. This process, likened to the constant level of care required for a baby was unique in that it was lifelong.

#### 4.2.2.2 Patient-Caregiver Bond

The constant and extreme level of nurturing led to the primary caregivers developing a close bond with their family member/client as part of the Protection Process. This bond

developed from time spent with each other and close observation of the family member/client during that time. It allowed for a safe place in which further familiarity developed, and as a result, the caregiver became better equipped than anyone else to understand their family member/clients attempts at communication.

*“I know him better than anybody else” (interview 6)*

*“the caregiver is the person that knows the patient best. We know the changes in their moods, we can usually tell...so we notice the changes in them, you have to be very, very familiar” (interview 5)*

This paid caregiver described how spending time with a client and the resulting deep level of knowledge developed into a deep relationship or “connection” with the client:

*“we all have an emotional connection to the client. Anybody in this field that has been in it for a long time and wants to stay in it, you do develop a relationship and it does become personal, even if you’re not family.”*  
(interview 4)

#### 4.2.2.3 Patient-Caregiver Encounter Family Physician Together

As a result of their many associated medical conditions, adults with severe or profound developmental disabilities all require a family physician for the coordination of their ongoing health care. To ensure continued protection when interacting with someone outside the patient-caregiver bond, the caregivers encountered the family physician together with the patient. They appreciated the physicians who recognized the importance of the patient-caregiver bond and its crucial role in developing their own relationship with the patient.

*“[the physicians] recognize that he [the patient] cannot communicate with us so you [the caregiver] communicate and tell us and teach us... they have been very good with me, they have been very good with understanding me and our relationship and knowing that, not that I have all the answers, but I got a lot more answers than most people do”*  
(interview 6)

After encountering the physician together, the patient and caregiver still had to decide whether they felt safe enough to let the physician into this bond.

#### 4.2.2.4 Decision is Made by the Patient and Caregiver Whether or not and How Much to Open the Patient-Caregiver Bond to the Physician

The degree to which the family physician was let into this very close patient-caregiver relationship and the resultant triad was related to how safe the caregiver felt both they and the patient were in the presence of the physician. The level of safety experienced was influenced by a number of factors related to each member in the relationship:

##### 4.2.2.4.1 Factors Related to the Physician

Caregivers allowed physicians who practiced empathetic, patient-centred care into this triad more than physicians who did not. This patient-centred care involved the skills of considering all issues related to the patient, listening, taking time, caring, and making the effort to create a safe and protective environment to which the caregiver felt they could bring the patient.

*“the doctor needs to see the person you know, as opposed to just seeing the, okay you’ve got a bruise on your knee” (interview 4)*

*“[the family physician was] always very relaxed with him” (interview 1)*

*“when you start to personally engage, you start to care. You know, on a personal level. I think when a doctor can do that, it’s really, really good” (interview 9)*

Caregivers also pointed out that being able to recognize the patients’ abilities and being interested enough to find alternate ways to connect and communicate with the patients was a very important factor in developing the relationship triad:

*“[a doctor who understands that] he can communicate, he just can’t speak” (interview 4)*

*“touching. Ah, not just taking a blood pressure, you know but like, putting a hand on the shoulder, ah, you know like letting the person know that they are comfortable with them” (interview 5)*

#### 4.2.2.4.2 Factors Related to the Patient

Caregivers described how the appearance, ability to communicate and sometimes unpredictable behaviours of the patient either helped:

*“People will look at him and go, oh my God he’s so good looking, those big brown eyes and stuff, and it draws people to him.” (interview 5)*

*“Well, my sister (the patient) is kind of a cuddly, she likes to hug and these sorts of things...she loves doctors. She doesn’t mind medical procedures at all.” (interview 2)*

or hindered:

*“And they’ve got behaviours that are unacceptable, you know like, if you have somebody in your office that’s screaming or attempting to bite you, you know like, all of the behaviours that the patient can have as an individual, can be offsetting to a doctor.” (interview 5)*

the creation of this safe environment in which the patient-caregiver-physician relationship could be allowed to develop.

#### 4.2.2.4.3 Factors Related to the Caregiver

Caregivers described themselves as individuals with their own physical and emotional needs and concerns that impacted their ability to protect the patient and be involved in the dynamic triangular relationship. These included health issues related to ageing, the stresses of work and caregivers’ personal fears around medical care.

*“the problem with us now is our (parents’) age and (patient’s) age, it is hard for us” (interview 3)*



*“I mean people, people forget staff are people you know. I [caregiver] have to bring a client to the doctor. I don’t like doctors, right.”*

*(interview 4)*

These factors also included the motivation and ability of families to be involved in their care.

*“I just think that probably she (patient) was fortunate in a lot of ways that she was born into a family that wanted to care for her and have enough education and what not to understand the needs and that sort of thing and work out a process that would work for her and the family.” (interview 2)*

All these factors were important in determining how safe the caregivers and patients felt and hence how much they were prepared to open the patient-caregiver bond. This then influenced the resultant patient-caregiver-physician dynamic triangular interaction.

#### **4.2.2.5 Creation of the Patient-Caregiver-Physician Dynamic Triangular Interaction**

As part of this process of protection, the caregiver realized the potential benefit of involving the family physician in the patient’s care. They also recognized the potential for increasing the patient’s vulnerability by exposing them to a system of health care delivery not designed for those with developmental disabilities. They therefore set out to create a dynamic triangular interaction where they expected the physician to be aware of this vulnerability and be actively involved with both the patient and the caregiver in the process of shared care and protection.

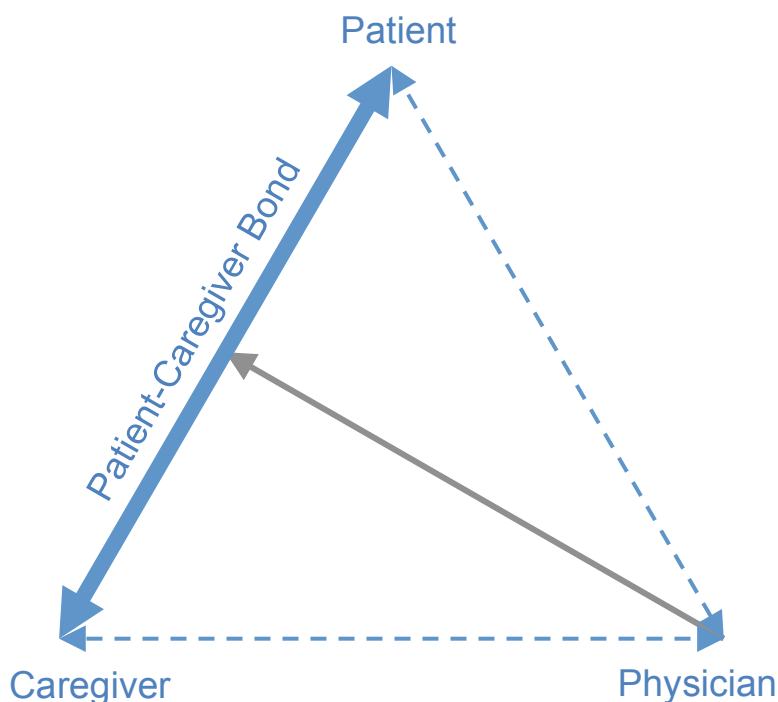
*“look into the whites of their eyes and say do you think you can take this on?” (interview 1)*

This interaction was one in which they all played a role and was expected by the caregiver to be dynamic, i.e. adjusting to the patient’s changing needs and circumstances.

*“Patients’ conditions are changing so you [caregiver] have to modify, so he [family physician] has to modify his behaviour to them ... so it’s continually changing” (interview 5)*

This dynamic interaction (Figure 1) formed the starting point from which different trajectories of relationship development were followed.

**Figure 1: Dynamic Triangular Interaction – Caregiver Perspective**



The bold line in Figure 1 depicting the dynamic triangular interaction reflects the primacy and importance of the patient-caregiver bond. The solid line through the middle of the triangle represents the caregivers’ view of the family physician interacting with the patient and caregiver as one unit. This was the primary interaction and more important than any interaction that either the patient or the caregiver may have had with the physician directly as depicted by the dotted lines.

### 4.2.3 Trajectories

The dynamic triangular interaction (Figure 2) described above then followed one of four different trajectories along which four different types of relationships developed. Which

trajectory was taken was determined by how the caregiver and patient experienced their interaction with the family physician.

#### 4.2.3.1 Upfront Knowledge Acquisition

This trajectory began instantly and actively and often involved both a family physician and caregiver with experience in dealing with patients with developmental disabilities or, at the very least, a family physician who was actively interested, patient-centred, and genuinely committed to getting to know the patient and building a relationship right from the start. This enabled the caregivers to give all the information they felt was pertinent “upfront.”

*“This gentleman [family physician] is very, very blunt, very to the point. Which we respect. He is not wishy washy. Asks questions, just appears to be engaged. Again interested.” (interview 4)*

*“[the family physician] allows you to give the information up front” (interview 9)*

The family physician incorporated the caregivers or the family into the relationship right from the beginning, asking relevant and probing questions with a goal of getting to know and understand the patient and their context as soon as possible.

*And you can tell from the type of questions that he asks. Because it’s not just about the specific problem that you’re here for, it’s ‘how’s she eating? How’s she sleeping? Is she getting out? How are things going? Is she happy? I mean what kind, what do you do at home?’ just interested” (interview 4)*

There was an understanding of the need for a certain level of commitment, interest and preparation for future times of need.

*“Yes, he [new family doctor] was thorough, he looked it [information on vaccination] up and talked with us, so he does have an interest” (interview 1)*

*“And you can tell, yeah, he’s building. This is a guy I’m going to be able to trust.” (interview 4)*

After an initial exponential rate of knowledge acquisition beyond the needs of the specific encounter, this process then slowed to a more usual rate, dictated by the needs of each encounter.

*“Ah, the last time we were here you said that, you know, just knowledge building and that really, really makes a difference” (interview 4)*

In summary, on this trajectory, the caregiver felt an instant “gut feeling” of trust and safety in the family physician, and a sense that the family physician could be depended on, by virtue of this obvious upfront commitment. This resulted in an early and wide opening of the patient-caregiver bond to enable an immediate trusting relationship.

#### 4.2.3.2 Familiarization with Time

On this trajectory, the key features were time and continuity of care with the same provider. Knowledge and familiarity developed at a fairly constant rate dictated by the overall time spent with the patient and caregiver during successive clinical encounters. Caregivers expressed the importance of the passage of time in order for the relationship to develop. This is in contrast to the previous description of upfront knowledge acquisition where caregivers described this knowledge acquisition process as being deliberately frontloaded. This trajectory could not be hurried because time itself, and the continuity of the family physician throughout this time, was the important characteristic.

*“I think a continuity of contact is the important part of it, that they get to understand the person, can communicate, because my sister doesn’t. Not everybody can understand my sister when she speaks but she and NP 1 get along good...because she knows her so well and the continuity is there so long that. So it is important to have continuity of service” (interview 2)*

*“The best doctors are the ones that can provide the background and continuity, that have the knowledge base over a long period of time...deep knowledge that goes back 5, 10, 15, 20, 25 years in some cases”*  
(interview 4)

Time, and the experiences during that time, allowed a very deep, stable, and dependable level of familiarization to occur. This familiarity and comfort drew the family physician into being a part of the patient’s family, the caregiver a part of the health care team’s “family” and the patient a part of the family physician’s clinic “family.” More than just being the whole family’s doctor (which these family physicians often were), the word “family” was used to portray a deeply personal level of this process of knowledge acquisition and acceptance of each other as individuals, each with their own role in the team over an extended period of time.

*“Well he [family physician] was more comfortable. He was relaxed, he was part of the family you know.”* (interview 1)

*“I think really she [patient with developmental disabilities] was just comfortable with the [clinic] set up as it is and she knew pretty much everybody down there and all the receptionists and everybody else knows her. So, I think it starts way back before I [brother caregiver] started providing any kind of care and it’s just that she has confidence in the process...I just think that they [clinic staff] look at her as being part of the family too at the centre, so.”* (interview 2)

In summary, on this trajectory, the passage of time and the shared experiences during that time facilitated the acquisition of a deeper level of knowledge, familiarity and safety resulting in the caregiver-patient bond ultimately being opened completely to allow for a deep personal relationship and a sense of belonging to a “family”.

#### **4.2.3.3 Stable and Functional Resource**

On this trajectory, the caregiver took the lead active role, involving the family physician as a passive but stable and supportive resource when required. The caregiver took control

using their knowledge of the needs of the patient to direct the family physician in their joint management of the patient. This included letting physicians know when and why they felt medications were too strong, not sufficient or needed repeating, or contacting physicians when they felt the patient was ill and required further medical care. There was no need expressed to build an ongoing relationship between times of need or beyond the functional requirement of medical care for the patient when the caregiver deemed it necessary. Naturally, knowledge acquisition in the form of the family physician getting to know the patient and caregiver did occur with time, but it was fairly superficial and experiences were too infrequent to build on each other or include the patient getting to know the family physician.

*“she [family physician] is very accessible to me, but it goes on what I [mother caregiver] ask her to do. Because I guess I know him [son with developmental disabilities] better than anybody else so I am the only one who can speak for him...she will just say what do you need, how’s he doing, what can I do, makes sure he gets his flu shot, make sure all those things happen for him, but other than that it’s kind of like it’s only at my discretion we will get anything done for him...She will, whatever I want she will take care of.” (interview 6)*

*“Well I don’t think it [previous experience] affects his [son with developmental disabilities] relationship [with his family physician] because there really isn’t a big relationship. He is just my prescription writer.” (interview 8)*

In summary, the caregiver took control on this trajectory, keeping the physician at arms-length as an informational and technical resource. The patient-caregiver bond was controlled by the caregiver who opened and closed it according to their perceptions of the needs of the patient. The caregiver did not require the physician to really get to know the patient, rather they relied fully on their own deep knowledge of the patient. The resultant relationship was a functional one that did not develop further with time.

#### 4.2.3.4 Assumption of Physician's Authority/Physician-Centered Care

This trajectory was followed when the caregiver's expectation of patient-centred collaborative care within the dynamic patient-caregiver-physician interaction was not met. The physician assumed the authority as the best one to make decisions affecting the patient's care, without overtly respecting the patient and caregivers' perspectives. The resultant tension that developed, especially if the physician and caregiver perspectives differed or the caregiver's participation remained ignored, damaged the balanced, interaction and resultant relationship.

*"A doctor just totally threw me under the bus and totally ignored everything I had to say" (interview 6)*

Caregivers described a lack of empathy for those with developmental disabilities and felt both they and the patient were "disrespected" and "dismissed."

*"But you know my analysis in the end of the story is just that he just don't want to be told because he's the doctor...I didn't have respect for the doctor anymore" (interview 8)*

Caregivers reacted by trying to turn this process around through gathering and conveying accurate information from their constant observations of the patient. Occasionally, through repeated experience, the process changed into a learning experience for all involved as physicians eventually realized the value of the caregiver's and patient's input.

*“And that’s what I [caregiver] did and basically, I refused, not that I refused to leave, I said I really need you [family physician] to see this information. So I had it all done. Every [patient] behaviour was correlated with the sleep data, with the spoken things that the guy [patient] was saying ...That convinced him [family physician]. So that’s what it took. But to the man’s [family physician’s] credit, it was almost like a light went on, right? ‘Oh wait, maybe he [the patient] really has not been giving me [family physician] the true picture?’ and we [caregivers] say, ‘no he [patient] has not.’” (interview 4)*

They also gave up, feeling helpless and totally dependent on this frustrating process in a medical system with minimal options for the care their children/family members/clients required.

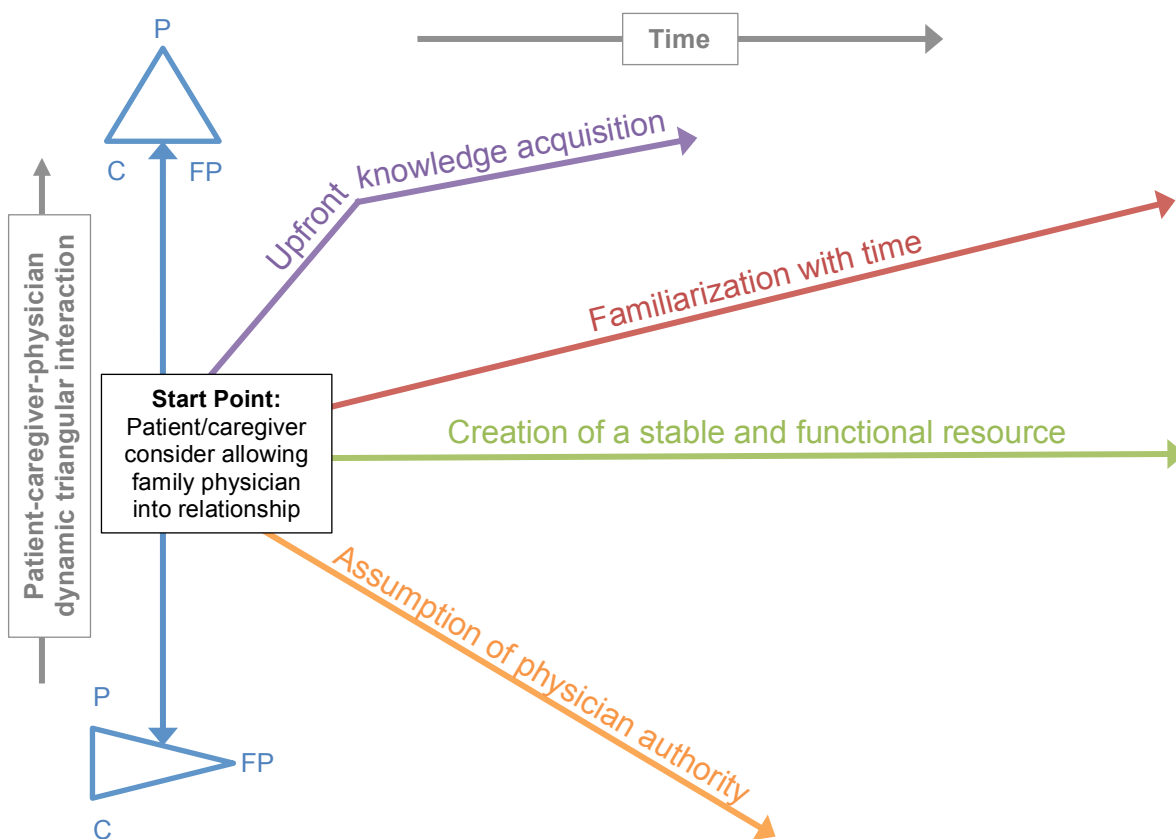
*“You know the [group home] staff are saying, you know, dump this guy [family physician]. Can’t, we need someone to prescribe the friggin medication. That’s what it comes down to.” (interview 9)*

In summary, on this trajectory, the imbalance of power was evident with the powerful physician assuming total control of healthcare decisions. This lack of respect of patient autonomy and the importance of the patient-caregiver bond caused tension and a perception of an unsafe environment. As a result, the patient-caregiver bond remained closed, only opening to allow the physician in when absolutely necessary.

In summary, these four distinct trajectories of developing relationships identified as Upfront Knowledge Acquisition, Familiarization with Time, Creation of a Stable and Functional Resource, and Assumption of Physician Authority, were determined by the caregiver’s perception of how their expectations of care were met and hence, how safe they felt to allow the physician into the patient-caregiver bond (Figure 2).



**Figure 2: Patient-Caregiver-Physician Relationship Trajectories over Time**



#### 4.2.4 Context

This process of protecting and resultant relationship development occurred within a particular healthcare context and a broader social context. Neither of these have been designed primarily with people with severe or profound developmental disabilities in mind and hence made the need for protection even more evident.

##### 4.2.4.1 Health Care Context

Adjusting health care delivery methods to allow for a person with severe or profound developmental disabilities and hence severe limitations in adaptive functioning was challenging. The patient's vulnerability, and therefore the enhanced the need for protection, was highlighted in this context.

*“I guess, I mean there’s problems with the broader system for everybody. But I think they’re multiplied, if you like, for our client base.”*

*(interview 4)*

*“Adults with profound disabilities and high anxiety, ah, are individuals who do not react well to change. Who do not do well in areas that they have no control over what is occurring” (interview 9)*

Where these challenges were met, relationship building was fostered, but negative experiences did not foster a good environment for the patient-caregiver-physician relationship to develop. These experiences may not have involved the family physician directly, but affected the caregiver’s perception of the health care system in which the family physician worked.

*“it just doesn’t fit—the service model or whatever you call it.”*

*(interview 1)*

Challenges of the health care system included the following:

#### **4.2.4.1.1 Accessibility**

Physical and behavioural barriers made accessing clinic or hospital-based care difficult for many patients with severe or profound developmental disabilities. Home visits or clinics that were accessible in physical layout and flexible appointment structures reduced the stressors related to seeking medical care and positively impacted the relationship.

*“Well, he [patient] is happier and contented because she [family physician] makes house calls. She comes to my [caregiver] house. And like I said, I don’t know if I could get anyone else to do that. So she is making [patient] happy and she is making, you know, myself more contented because I don’t have to take [patient] out into a crowded waiting room and have him to sit there and wait patiently to go in to see a doctor”. (interview 7)*

*“A GP able to recognize that this individual has the potential to get out of control, we are going to fast track. Or we are going to make the appointment for 9 AM because he is a morning person and I know if I make the first appointment, it is not crowded. I know that this young man needs a waiting area, or a side room or an examination room, even though he may be in there for half an hour waiting, its better in there than on the outside.” (interview 9)*

#### 4.2.4.1.2 Provision of a Safe Environment

Whether at home or at a clinic, the provision of a safe environment was key to protecting the patient and encouraging development of the patient-caregiver-physician relationship. One caregiver described how a physician continued to adapt and provide care at his clinic despite the patient’s initial anxious and aggressive behaviour until the patient finally relaxed, knowing that:

*“this is a safe place for me.” (interview 4)*

Another caregiver described how she felt arriving at her family physician’s clinic with her patient:

*“The security I feel” (interview 3)*

Caregivers understood the challenges associated with seeking medical attention in places where this safe environment could not be assured and only undertook this measure if absolutely necessary. This placed extra pressure on caregivers when deciding whether or not to bring their child/client in to the hospital. This meant their family member/client could be quite ill by the time they arrived.

*“We [parent caregivers] found the emergency room an extremely intimidating place to be. I wouldn’t go there myself unless I was looking down the barrel of a gun, not in a million years, but that is for me. I’ll wait at home. But it was horrible to see him with difficulty breathing.” (interview 1)*

#### 4.2.4.1.3 Provision of Equal and Ethical Standard of Care

Caregivers felt that lack of exposure to patients with developmental disabilities resulted in physicians displaying “fear”, “anxiety”, and a lack of “empathy” and “understanding.” More recently, increased exposure to patients with developmental disabilities during training and in the health care system has positively impacted the ability of all involved to develop a relationship appropriate to the provision of an equal and ethical standard of care.

*“Because 30 years ago, because I can think of one incident when I had a patient that had his arm broken and he came back from the emergency department out here and I phoned the physician on call to see about pain medication and he said to me: ‘Why? Do they have pain?’ And that is not there anymore now. The physicians that we have now are very, very caring, very aware of patients with developmental disabilities. They are seeing them come in through the acute care services now, so I think that they are having more exposure and so, ah, there seems to be a higher level of understanding of the type of clients that they are dealing with.”*  
(interview 5)

#### 4.2.4.1.4 Transitions of Care

The patient-caregiver-physician relationship had to withstand transitions within the context of the health care system. These focused mainly on the transition from pediatric to adult care but also included transitions such as the retirement of a family physician, aging or death of a caregiver, or the placement of the patient in a long-term care institution. Caregivers expressed concern around the need to prepare for these changes as well as the sadness and sense of loss associated with them.

*“Moving your child and I still will call him a child because he is my child, from the children’s system to the adult is the most painful, excruciating thing that anybody would ever have to do in their entire life.” (8)*

*“we are getting older and he is getting harder to look after and we don’t know what to do for the longer term. These are big issues.” (interview 1)*

#### 4.2.4.2 Broader Social Context

In recent years, increased integration and exposure of patients with developmental disabilities in the community had led to greater acceptance of these people into the community. This increased acceptance and understanding positively impacted the patient-caregiver-physician relationship.

*“if the community values the person with a developmental delay and even not an individual, they may not know an individual with a developmental delay, but if they have a broader understanding and accepting, then the relationship is going to be easier” (interview 5)*

Family support, when present either as a result of a general acceptance and sense of responsibility or a deeper sense of guilty/blame or sadness as to the reasons for their family member’s developmental disability, positively impacted relationship development.

*“we always said look you [Mother] don’t ever have to worry about him [brother with developmental disabilities], you know he’ll be fine as long as we [sister and brother-in-law] are alive.” (interview 3)*

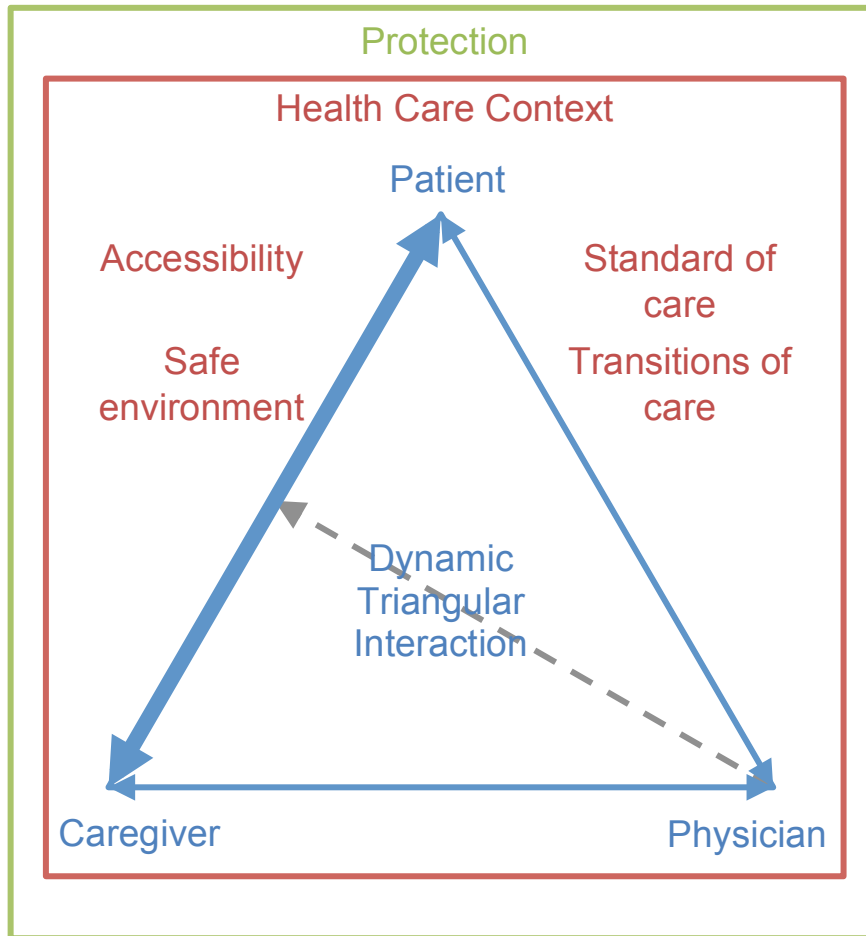
*“my parents took a long time to adjust to the fact that they had to deal with the situation and then when they finally did come to grips with it, I mean there was the obvious: ‘my side of the family has never had any of this kind of thing.’ So, it was a little contentious, but we all came to understand that, you know, she [sister with developmental disabilities] was going to live better and longer and she was with us and what not.” (interview 2)*

One mother cried quietly as she told her story of learning of her now 35-year-old son’s disability after his birth and the reasons for it:

*“well his problem started off to be, I was in contact with German measles.” (interview 7)*

These patient-caregiver-physician relationships developed within health care and social contexts that were not primarily designed with those with developmental disabilities in mind. How these contexts could be safely adapted to meet the patient’s and caregiver’s needs affected further relationship development (Figure 3).

In summary, the core process of protection drove caregivers to form strong bonds with their family members/clients. How much these bonds were then opened to allow for the patient-caregiver-physician interaction and what trajectory they then followed to foster further relationship development was influenced by a number of factors, all related to the ongoing protection of the patient.

**Figure 3: Process of Protection in Context**

## 4.3 Discussion

The main finding in Study One was that caregivers recognized the vulnerability of their family members/clients and engaged in a resultant process of protecting them. This process led to the creation of a dynamic patient-caregiver-physician interaction which could then travel along four different relationship development trajectories.

The patients in this study had severe or profound developmental disabilities. This meant that they had significant limitations in cognition and adaptive functioning, described as conceptual (including language), social (including interpersonal), and practical (including decision making) skills (1). Our healthcare systems are not designed to accommodate these significant limitations, making this population especially vulnerable to health disparities (2, 3).

This sense of vulnerability was exacerbated by the inability on the part of both patient and caregiver to be able to address their needs in the present health care system within which the patient-physician relationship existed. The balance of power in patient physician relationships ranges from mainly physician power (paternalism) to mainly patient power (consumerism) with the middle approach demonstrating mutuality of power (4). Caregivers in this study recognized that a potential lack of power could increase their family member/client's vulnerability.

They reacted to this vulnerability by protecting their family member/client and valuing patient-caregiver-physician relationships with a mutuality of power.

### 4.3.1 Protection

This process of protection included a number of steps described below:

#### 4.3.1.1 Extreme Nurturing

The definition of nurturing includes caring and protecting for and promoting the development of someone or something. When referring to a person, it is usually used when referring to a child (5). Caregivers in this study described how they nurtured their patients in caring for their every need on a daily basis. The difference in the nurturing in



this study, versus the care giving of infants, young children, the acutely ill or the frail elderly is that these patients were often otherwise healthy young adults. Caregivers committed to the lifelong nurturing of their patients with severe or profound developmental disabilities. Daniela Stehlik refers to this process as “life-long caring” in her study on aging mothers and aging daughters with intellectual disabilities (6).

People with developmental disabilities have higher health care needs yet, due to numerous barriers, access health care services, particularly preventative services less (2, 7, 8). Caregivers in this study described the extreme measures they had to go to ensure their patients were able to access and receive what they felt was the appropriate level of health care in order for them to adequately protect their patients. Stehlik also describes the struggles mothers faced and tensions they felt between their own notions of caring for their children and the state policies on providing care for these same children (6).

#### **4.3.1.2 Patient-Caregiver Bond**

Studies involving triadic relationships, not specific to patients with developmental disabilities, reveal that the companion or caregiver often knows the patient very well and is involved in communication and decision making discussions both in and outside the medical encounter (9, 10). This was consistent with findings in this study, where the caregivers bonded closely with their patients through time spent caring for their patients before encountering the family physician. This set the scene for the patient and the caregiver to then encounter the family physician together as one united entity.

#### **4.3.1.3 Patient-Caregiver Encounter the Family Physician Together**

The medical community in general appreciates the value of patient-caregiver-physician medical encounters (11). In this study, caregivers described how they decided whether or not they were going to open their protective bond with their patient to let the physician in during an encounter. How much this occurred depended on a number of factors related to the physician, patient and caregiver. Physicians who were more patient-centred were more likely to be included. This is in keeping with previous research on the perspectives of patients with mild developmental disabilities on interacting with their family physicians (7, 12–14). The impact of both patient and caregiver characteristics have been

noted previously on the well-being of caregivers of patients with developmental disabilities (15). This study extends this finding to include the impact of the patient and caregiver characteristics on physician behaviour. The impact of patient appearance, communication abilities and behaviours as well as caregiver age and emotional wellbeing impacted on the physician's responses to the patient and caregiver and the patient and caregiver's decision on whether or not to allow the physician to enter into this patient-caregiver-physician triadic interaction.

#### 4.3.1.4 Creation of the Patient-Caregiver-Physician Dynamic Triangular Interaction

The importance of patient-centred care in family medicine (16, 17), specifically in patients with developmental disabilities, has been noted (18). Physicians' active attempts to involve the caregiver are extremely important when caring for adults with developmental disabilities (1). In this study, caregivers expected a genuine commitment to a triadic relationship with the patient and caregiver from the family physician. This involved the physician being able to adapt to the patient's changing needs, usually as interpreted by the caregiver, when required.

The caregiver's perception of how committed the physician was to involving everyone in this dynamic relationship and of how the needs of the patient-caregiver unit were being met, determined the trajectory that the relationship then followed. The above interpretation and the consideration of the balance of power in patient-physician relationships (4, 19, 20) provide further insight into the following described trajectories:

### 4.3.2 Trajectories

#### 4.3.2.1 Upfront Knowledge Acquisition

In his description of patient-centred care, Ian McWhinney described a new paradigm of viewing the patients as whole, a dynamic integrated being set in a context (16).

Caregivers have reported the positive influence of the health care provider knowing their patients with developmental disabilities, knowing their context and valuing the input from the caregiver. Specifically, caregivers felt the quality of care they received and the

length of wait times were both improved (7). Patients and caregivers have also reported relying on their physicians knowing information such as the nature of their medical benefits to ensure they accessed care they could afford (12).

In this study, the Upfront Knowledge Acquisition trajectory described the physician who was experienced, or at least interested and actively committed to acquiring knowledge from both the patient and the caregiver as a base for the development of a trusting relationship right from the start. The balance of power was essentially equal with the physician receiving and recognizing the importance of the initial information brought to the physician by the patient and caregiver. The physician also recognized the importance of further specific information gathering targeted to inform ongoing patient care. Caregivers felt included and valued and recognized the expertise of the physician. As a result, a trusting dynamic relationship was established earlier than any other trajectory.

#### 4.3.2.2 Familiarization with Time

The importance of the passage of time and continuity of care with one family physician and related improved health outcomes, has been well documented (16, 21–23).

In this study, the key features of this Familiarization with Time trajectory were time and continuity of care with the same provider. Knowledge and familiarity grew at a fairly constant rate determined by the overall time spent with the patient and caregiver. The power balance was equal between all parties because with time, they learned and shared more about each other and the decision-making around the medical care of the patient with severe or profound developmental disabilities.

The importance of the role of any patient's family in the provision of medical care has been documented (24, 25). The view of the family as the fundamental unit of medical care delivery was described some time ago, yet numerous barriers to this approach still exist in our present medical systems (26).

In this trajectory, the passage of time and resultant growing familiarity, knowledge and trust, drew the physician into the patient's family and the patient into the healthcare provider "family" resulting in a deep personal experience of this relationship. Previous

studies of caregivers of youth with developmental disabilities have reported the importance of placing the entire family at the centre of care (27). Other studies have documented the importance of family and social supports on quality of life in patients with multimorbidity (28, 29).

This trajectory extends these concepts by recognizing the family physician as an integral part of the patient's family.

One other study found, described the inclusion by patients and families of other health care professionals as part of an "extended family" on a hospital ward, but this did not include the attending physician. (30).

This deep personal and familial relationship trajectory reflects the importance of the personal aspect of the patient-physician relationship in family medicine extending beyond the purely medical, functional relationship (16, 19).

#### **4.3.2.3 Stable and Functional Resource**

Various models of patient-physician relationships have been described. These models are usually based on constructs such as power, control and responsibility (4, 19, 20).

In the Stable and Functional Resource trajectory illuminated by this study, the caregiver, as part of their interpretation of the necessary protective process, assumed power, control and ultimate responsibility, involving the family physician as a passive but supportive resource to this end. Roter described one of the characteristics of the patient-physician relationships as "medically functional". In this trajectory, this characteristic dominated the patient-physician relationship entirely, excluding all the other described characteristics namely informative, facilitative, responsive, and participatory (20).

This trajectory was in contrast to the previous trajectories where the balance of power was equal and flow of information and control was dynamic resulting in equal participation and responsiveness by both the caregiver and the physician according to the patient's needs.

Naturally, knowledge acquisition in the form of the family physician getting to know the patient and caregiver did occur with time, but it was fairly superficial and experiences were too infrequent to build on each other or include the patient getting to know the family physician. One could speculate that the potential benefits of the growing familiarity and expertise of the family physician were therefore not realized. This is in contrast to the previous two trajectories where maximal input from all parties ensured that the potential of the dynamic relationship was met.

The beneficial outcomes of the patient-physician relationship in the delivery of patient-centred care have been established (31, 32). Adults with developmental disabilities are more likely to suffer health care disparities in the form of multimorbidity and decreased access to appropriate health care than adults without developmental disabilities (8). The caregiver's lack of interest in the patient-physician relationship as a resource to maximize health care delivery to this population could further widen the gaps in appropriate health care utilization and resultant health care disparities.

The main focus in this relationship was the patient-caregiver unit. The caregiver reacted to a perception of their patient's vulnerability by attempting to protect their patient using their deep knowledge of the patient to assume power and control whilst unilaterally directing the physician in the management of the patient.

#### **4.3.2.4 Assumption of Physicians Authority/Physician-Centred Care**

Approaches to the care of patients in family medicine have changed over the years from a more paternalist/physician-centred approach to more of a balanced patient and relationship-centred approach (4, 16, 17, 19, 20). The patient-centred approach has been linked to improvement in objective patient outcomes (31, 32). Previous studies have highlighted the many barriers to appropriate health care experienced by patients with developmental disabilities including feeling that physicians did not adequately attempt to communicate or understand their illness experience (12, 13, 18).

The Assumption of Physician Authority Trajectory described the caregiver's perception of the relationship when the physician assumed total power and control, choosing to

ignore the patient and caregiver roles. Caregivers were left feeling that their input was not valued and their patients did not receive appropriate care, but they were often powerless to change this, trapped in a resource deficient system with no accessible alternate form of care. This finding can be understood in relation to findings in other populations with complex needs, where it has been suggested that well-designed systems are as essential aspect of meeting the health care needs of the population (32).

This trajectory provides an understanding of how this type of dysfunctional patient-physician relationship set within a poorly designed health care system can negatively impact on patient care and contribute to the ongoing health care disparities evident in the population of patients with severe or profound developmental disabilities.

#### 4.4 Conclusion

The findings in Study One described the caregiver's perception of their family member/client's vulnerability and their resultant reaction to protect them. This process of protection led to a creation of a dynamic triangular patient-caregiver-physician interaction, which then travelled along four different relationship development trajectories.

The discussion highlighted the importance of the lifelong extreme commitment of the caregivers to this process of protection as well as the impact of patient, caregiver and physician characteristics on this process. The discussion of each relationship development trajectory highlighted the patient's and caregiver's experience of the presence or lack of mutuality of involvement, power and control in this interaction and their reaction to this experience.

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## Chapter 5

### 5 Study Two Findings and Discussion

#### 5.1 Final Sample and Demographics

A total of fifteen family physicians meeting the criteria of one the three groups described below participated in fifteen interviews.

Group 1: family physicians with local experience of outpatient and inpatient care of adults with severe or profound developmental disabilities: 3

Group 2: local community family physicians: 7

Group 3: family physicians with a special interest in the primary health care of adults with developmental disabilities from across Canada: 5

Years in practice ranged from 3–48 ( $M=25.9$ ,  $SD=11.7$ ), and years caring for patients with severe and profound disabilities ranged from 1–47 ( $M=21.3$ ,  $SD=11.7$ )

Four family physicians out of the fifteen had received some sort of formal specialized medical training in caring for patients with developmental disabilities. All of these physicians were in Group 3.

Interviews ranged from 45–60 minutes and took place in a variety of locations in person or over the telephone.

#### 5.2 Findings from Data Analysis

##### 5.2.1 Process of Acceptance

Analysis of Study Two data revealed that the core process in the development of the patient-physician relationship was that of acceptance. Family physicians had to accept and respect their patients as equals and as individuals with their own specific goals and potential in order to consider the possibility of a relationship.

*“part of that relationship is an attitude toward what I would call just human vulnerability and that, that’s okay” (interview 15)*

In addition, they sought signs of acceptance from the patient in order to fully appreciate and develop a trusting relationship. This required family physicians to accept different and varied amounts of feedback according to the level of ability of their patients.

*“you don’t always get instant gratification, but at some point in time you get the gratification” (interview 6)*

*“it’s been harder to get to know these people because you don’t have some of the normal cues that you do, I guess, in other doctor patient relationships in the sense of easy communication, and sort of characteristics of people you pick up from them by talking to them and having them respond. (interview 11)*

This process of acceptance required commitment from the family physician to adapt to the patient’s level of functioning or ability. It also required that the family physician define their role specifically within this unique relationship given the very different role patients with severe or profound developmental disabilities were able to play as compared to patients without this level of disability (Figure 5).

This chapter describes how the family physicians went through the process of acceptance, the process of committing to adapt, and the definition of their roles in the relationship, as well as their perspectives of the resultant relationships and the contexts within which they occurred.

### **5.2.1.1 Committing to Adapt**

Patients with severe or profound developmental disabilities have significant limitations in adaptive functioning. This decreased ability of the patient to adapt meant that the family physician needed to be the one to adapt. Physicians needed to be aware of the magnified effect of any changes, whether they related to a medical condition or the management suggested by the physician.

*“but he won’t come into the room, because he’ll feel you know, threatened by that. So you adapt.” (interview 13)*

To mitigate this effect, the family physician needed to be really invested in the process of forming a relationship and adapting accordingly.

*“it is sometimes a process and it does require patience, and ah, patience, commitment, creativity and you know, real desire to get to that point.” (interview 15)*

This level of commitment was something that family physicians had to become aware of, as most had not been prepared for this through appropriate training or previous exposure to this population in their practices.

*“It’s [medical training] not set up to train our future, or our current learners for the future” (interview 1)*

Family physicians also had to commit to adapt despite most of the healthcare systems in which they were practicing not having adapted to provide the appropriate resources or adjust their processes to meet the needs of their patients with severe or profound developmental disabilities. This included committing to working with limited interprofessional resources; accepting adult patients without any transition from the pediatric system; and not being remunerated sufficiently for the extra time it took to provide the appropriate level of primary health care to these patients. This commitment therefore required the family physician to think out of the box and commit to make the best out of what they had.

*“think outside the box, and think what else can we do here, maybe get on the computer and look for some tools” (interview 12)*

The family physicians committed to adapt the way they interacted with their patients to foster relationship development in the following ways:

### 5.2.1.1.1 They Dedicated More Time to their Patients

Realizing that for patients with severe or profound developmental disabilities, an encounter with a new health care provider in a new place was inherently a traumatic experience, family physicians had to allow more time, particularly in the beginning of the relationship to see these patients.

*“so you are very tentative you know, so you’re sort of trying to do trust building things, so you know initially it’s that being very tentative, and taking time to find ways that you can help that person relate to you”  
(interview 10)*

The process of respecting these patients as any others, getting familiar with each other and ultimately gaining their personal trust was one that took more time, not only initially, but during subsequent encounters as well. This process could not be rushed.

*“sometimes we just need to give them more time so that they can answer in the way they know how”. (interview 2)*

Time also included a commitment to continuity of care over a long period of time. With these repeated interactions came an increase in familiarity, comfort and confidence for patients, physicians and caregivers.

*“you might meet a new patient in your practice and have the meet and greet appointment and spend half an hour or sixty minutes with them and there’s been a lot of relationship building in that time. We know that that changes and grows with continuity of care over time, but with the patient with severe profound disability, it may be the actual repetitiveness of the visits themselves that is contributing quite a bit more so than you know the initial interaction. “(interview 15)*

Challenges occurred when paid caregivers could not give that same commitment to continuity. The repeated involvement of new caregivers in the relationship hampered the development of the patient-physician relationship.

*“when it’s a family caregiver you can build that relationship over time and they get to trust you and those sorts of things. It is a lot more difficult when it’s a group home situation because they come and go. The care workers do.” (interview 4)*

This adaptation of dedicating more time occurred within the different practice settings and health care systems that the physicians in this study were working.

Most health care systems including the one in NL are not set up to remunerate family physicians for the extra time they spend with these patients. This posed a potential challenge for family physicians, the vast majority of whom were in fee-for-service practices. This dedication to extra time also meant a commitment to lack of financial compensation for that extra time.

*“he had dedicated time for this patient population and he could take an hour with each patient, that’s something I may not be able to do in a fee for service model ... that time pressure can significantly influence your interaction” (interview 14)*

*“another challenge is time and funding” (interview 15)*

Accepting the fact that they had to dedicate more time, whether in the moment of the encounter, or in the context of continuity of care, was an adaptation family physicians made.

#### **5.2.1.1.2 They Adapted to the Presence of the Caregiver in the Relationship**

The family physicians realized the importance of including the caregiver as more than a source of information. The caregiver knew the patient best and had been through the process of developing their own bond with the patient. Family physicians therefore valued caregivers as essential role models and teachers in developing rapport with their patients.

*“the mother knew more what to do with her, obviously, than anybody else did.” (interview 6)*

Recognizing the important role of the caregiver without ignoring the patient as an individual was a potential challenge.

*“one of the risks perhaps is to direct all one’s attention to them [caregivers] and forget about, kind of bypass [the patient] because they’re such good spokespeople. (interview 13)*

Inclusion of the caregiver allowed the family physician to understand and get to know the patient better facilitating the practice of patient-centred care.

#### **5.2.1.1.3 They Practised a Mandatory Higher Level of Patient-Centred Care**

Adapting to the inclusion of the caregiver and the vulnerability of these patients demanded that the physicians perform at what one physician described as a “higher level” of exceptional patient-centred care. This required adapting how they showed their patient that they were respected and worthy of their attention and empathy. It was also described as “being present to that individual”. Practically, it required respecting the patient’s age and individual worth, whilst simultaneously adjusting their communication style according to their level of comprehension.

*“so you have to use language that they comprehend, but you still have to have an approach that gives them the respect of being an adult” (interview 10)*

Physicians were challenged to find new ways to connect and communicate with their patients whom one physician described as “non-traditional communicators”.

One family physician described how she used scented body cream which the caregivers knew the patient liked, so that the patient would let her examine her abdomen:

*“that was just so very powerful because it was all about the scent and connecting with her and having her trust me even though it was a little disguised, to examine her and what I remember was the calmness of it”*  
(interview 12)

Practising excellent patient-centred care required physicians to become more observant as they searched to empathize with and understand their patient’s illness experience through alternate routes, particularly where usual verbal communication was not possible. This meant considering that some extreme behaviours were perhaps attempts by the patient to communicate distress.

One family physician spoke of a profound learning moment when he realized the cause of a patient’s severe behavioural disturbance was something as simple as the sound of the metal tray on which his meals were being placed:

*“I spoke with them and they said every time around lunch hour he would start hitting himself, so the squeaking of the tray, for dinner. Because their other senses become very hyper acute. He would hear that coming and then when the door would open, he would hear the metal tray on the floor and he would start hitting himself. So he was kind of self-fulfilling, he’d hit himself which would then be the pain, he would be afraid of that, that’s all he remembered when he’d hear that sound.”* (interview 1)

Patient-centred care also involves understanding the context in which a patient’s symptoms occur. In these patients, adaptation to what others without developmental disability might deem innocuous was not always possible. Therefore, understanding the effect of the context on that patient’s illness experience and adapting accordingly was vital. Family physicians described stimuli from surrounding contexts including visual, sensory and olfactory cues that had significant consequences on their interactions with their patients. When the family physician recognized this, and adjusted accordingly, both the symptoms and the interaction between the patient and the physician improved.



*“She would cry, she’d scream, she’d kick, she’d spit, she’d throw feces at you, she’d you know, whatever. So I said to the family one day, ‘Why don’t I see her in your home?’ So I asked them to see if there’s a difference, because I think what we’ve done is we’re taking her out of her comfort zone, and we are bringing her into an environment that stinks, right of alcohol and that would be the thing that would get me most. So they agreed and I went to their home. I was amazed at how everything was set up for her.” (interview 2)*

Through communicating in alternate ways and understanding the context in which they lived, family physicians practiced a high level of patient-centred care and got to know their patients really well.

#### **5.2.1.1.4 They got to Know their Patients Personally**

Adapting to the unique requirements of these patients meant that family physicians had to do more than solve their patients’ medical problems, they had to get to know them personally. This deep knowledge, for example of the patient’s idiosyncratic likes or dislikes, allowed the family physician to adapt the way they delivered healthcare in order to maximize success in a potentially challenging relationship or encounter. Getting to know these patients was also the family physician’s way of showing that they respected these patients as individuals worthy of being known, even if that process was not as easy as it was with some of their patients without severe or profound developmental disabilities.

*“Connect with the person beyond their disability” (interview 13)*

*“it is not so much what you can do for them, it’s how well you can get to know them.” (interview 12)*

Through this process, family physicians gained deep knowledge of their patients and demonstrated respect for their patients’ humanity.

### 5.2.1.1.5 They Adopted a Parental Role

Realizing the vulnerability, lack of independence and more child-like role of these adult patients, family physicians had to adapt to being more involved, like a parent would be, advising on their patient's behalf, while still appreciating as much autonomy as the patient was capable of.

*“I would say the relationship is more like a parental relationship, like, I’m the parent...it’s very innocent in that way” (interview 6)*

As part of this parental role, family physicians accepted the responsibility of planning ahead and preparing their patients and their caregivers for potential future problems.

*“it’s you know, along those plans, and preparations, preparing families for what’s to come” (interview 10)*

This added commitment of adapting to a parental role in this relationship did not come without its challenges and family physicians felt the need for support from their colleagues as they faced these.

### 5.2.1.1.6 They Reached out to Create their Own Informal Community of Health Care Professionals

Family physicians cared for their patients in health care systems that were not designed for patients with severe or profound developmental disabilities. A formal interprofessional team approach to care did not occur for majority of family physicians interviewed. Family physicians had to adapt on their own to managing the challenging problems associated with the ongoing primary health care of their patients with severe or profound developmental disabilities in these resource-deficient health care contexts. Family physicians realized that the only way to cope, without feeling “alone”, “frustrated” and “hopeless”, was to actively seek out and create supportive networks within the medical community themselves.

*“align yourself with key individuals who can help you” (interview 1)*

These networks were informal, sometimes stumbled upon by chance, desperation, or by concerted effort on the part of the family physician calling specialists and interprofessional colleagues.

*“I suppose I mucked along for a long time, but when it finally came to the crunch, I got to the stage where I exhausted every alternative. She had seen everybody I could send her to, the psychiatrist didn’t know what to do with her because they had never seen it. So except that I managed to stumble on, but I knew [specialist physician]” (interview 6)*

These challenges, requiring the support of colleagues, were usually related to the complexity of the problems the family physician encountered as well as the relationship itself.

#### 5.2.1.1.7 They Adapted to the Complexity of the Relationship

These patient-physician relationships were complex for a number of reasons. The developmental disability itself posed challenges when adapting various chronic disease guidelines developed without these patients, their vulnerability and their fragile existence in mind. This physician described having to consider managing a patient who was profoundly developmentally disabled, as well as blind and deaf who did not react well to any change in routine or any medical interventions, who now by standard guidelines required regular insulin injections:

*“the diabetes, how interesting it was for that to hit me out of the blue, like oh, he’s got diabetes, how are we going to swing this? So your goals for him are so different.” (interview 7)*

In addition to the developmental disability itself, these patients had many medical comorbidities, making their medical management more complex. Family physicians had to be aware of and adapt to this level of medical complexity.

*“these are complex people. And you know, it’s one thing to be renewing medications, but it’s not so simple” (interview 13)*

In addition to the patient themselves, the number of additional people involved, always a minimum of one, but often more when considering all caregivers and family members, also added to this complex relationship. The relationship was described as a “spider web” by one physician.

*“you’re trying to figure out what the patient needs and you’re listening to the caregiver and just because it’s more, it’s from multiple sources, it’s just a little bit more complicated to figure out what their needs are”*  
(interview 12)

This complexity, by virtue of the patient, their disability, their multiple medical conditions and the involvement of caregivers meant that the family physician had to adapt to simultaneously considering a number of variables and to customize their suggested health care management appropriately.

As the family physician adapted to this complexity, their role as what one physician described as a “fixer” was not always attainable.

*“I’m really having trouble calling her [caregiver] because I can’t fix what she has. And I said I can’t relate to that. Like I’m used to being able to fix people or at least help them or move them from point A to point B.”*  
(interview 6)

This adaptation to complexity required the family physician to define their role within this complex relationship.

### 5.2.1.2 The Struggle to Define the Relationship and the Family Physician’s Role in it

Family physicians struggled to characterize their relationships with their patients with severe or profound developmental disabilities. This struggle related primarily to each physician’s philosophical outlook on how much reciprocity was needed to establish a mutual level of acceptance in a relationship. This lack of interpretable feedback or sign of mutual acceptance was a challenge for some family physicians who doubted if a relationship even existed.

*“it has been difficult for me to develop relationship or feel like I had a really knowledgeable close relationship with patients in this particular group”. (interview 11)*

*“I don’t know if truly know how much they [the relationships] develop because, you know, the cues we get from people who are not severely delayed are different. You know, you get acknowledgement and feedback and things and you can’t get those things from patients with severe developmental disabilities in the same way” (interview 5)*

Other family physicians accepted what they described as limited or technical relationships but were content to continue providing care to their patients. They continued to interact with their patients in a respectful way without expecting anything in return.

*“I find directly, with the patient who doesn’t communicate, I really don’t have much of a relationship but I don’t mind doing it...I don’t lose sleep over it. “(interview7)*

Other family physicians had similar experiences of patients who could either not provide feedback at all, or whose attempts at feedback they could not interpret, yet they accepted the mutuality of these relationships independent of the feedback they could not interpret. They recognized that these relationships looked different as compared to the relationships they had with their patients without severe or profound developmental disabilities, but still described them as extremely “rewarding or “enriched”

*“the relationship is different, it’s off the bell curve” (interview 1)*

*“there’s this kind of sense of mutuality and so on. You know. I guess it does depend on how severe the disability is, but I would say as long as people are conscious, there’s a connection.” (interview 13)*

Sometimes family physicians looked to the caregivers to give them feedback and hence feel they were developing a patient-physician relationship when they could not appreciate it directly from their patients.

*“I feel I’ve seen some strong relationships develop between myself and some of my patients and I guess you could walk in the door though and think that patient has no idea who this is, but I think their caregiver would feel differently”. (interview 15)*

Characterizing their relationships with their patients required family physicians to define their role in these complex and varied relationships.

*“part of the difficulty in looking after this group of people for me is figuring out what the role is” (interview 11)*

This struggle with the family physician’s role definition required the consideration of a number of other roles within this complex relationship (Figure 5).

#### 5.2.1.2.1 The Role of the Family Physician in Relation to the Patient and the Caregiver

These relationships always involved a third party: the caregiver. The family physician appreciated the significant role the caregiver played, often communicating on behalf of the patient and interpreting their symptoms for the physician. More than a voice, they valued the strong bond the caregiver had formed with the patient and saw them as inspiring role models for the family physician on how to form their own connections with their patients

*“the fact that they [patient and caregiver] do have such strong relationships reminds me of the fact that the patients are worthy of being in an intimate relationship with the people around them” (interview 11)*

While the family physicians valued the role of the caregiver very highly, it was important to them that the patient remain the primary focus of the patient-physician relationship (Figure 4). They consistently, even if briefly, communicated directly with the patient,

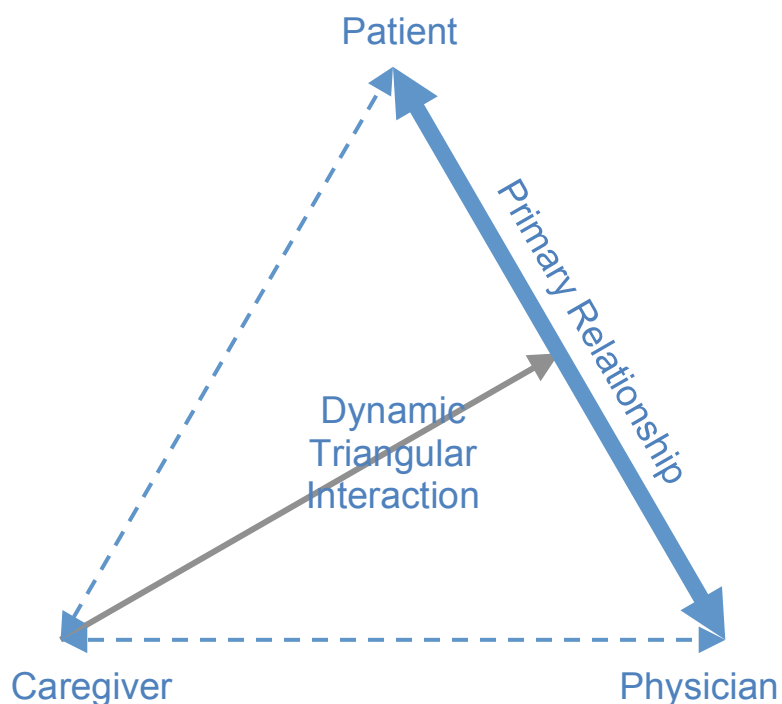
despite not knowing if there was any level of understanding or expecting any direct or immediately interpretable communication back. The family physicians valued this direct relationship which was independent of the caregiver.

*“I’m not the only person providing care, and so this notion that myself and others are in a relationship with the individual and how important it is that kind of we are able to work together, coordinate and so on. But also, I think, there is something about the individual relationship that ought not to get lost in all these other relationships.” (interview 13)*

*“so I have a non-verbal developmentally delayed patient, so obviously, they [caregivers] speak for her, but I still speak directly to her as if she is going to answer” (interview 10)*

Family physicians were cognizant of the important role of the caregiver but still defined themselves as being in a direct relationship with the patient. A direct relationship such as this requires the establishment of trust in order to develop further.

**Figure 4: Dynamic Triangular interaction – Physician Perspective**



The patient-caregiver-physician dynamic triangular interaction as perceived by the family physician appreciated the significant role of the caregiver, but also valued the primacy of the patient-physician relationship within this triadic interaction. This is depicted in Figure 4 by the bold side of the triangle between the patient and family physician, as opposed to the dotted sides linking the caregiver to the patient and family physician. The solid line through the middle of the triangle represents the significant facilitative role that the caregiver played in the primary patient-physician relationship as part of the dynamic triangular interaction of all three parties.

#### 5.2.1.2.2 The Role of the Family Physician in Establishing Trust

In defining their role in this relationship, family physicians realized their role in, and the importance of, establishing trust. This trust could not be taken for granted because patients had no or limited understanding of the concept of institutional trust—the generic trust in the medical profession. This meant that physicians had to make a concerted effort to establish a personal level of trust, starting at zero.

*“so you know initially it’s that being very tentative and trying to find the ways that you can help that person relate to you and trust you and that type of thing.” (interview 10)*

This trust took more effort to establish and had to be recognized in seemingly simple ways such as being allowed to examine a patient on a given day. Appreciating how important, yet delicate and often difficult it was to interpret this trust, was essential if the family physician was going to develop any significant type of relationship with their patient or at least be in a position to provide them with good care.

*“there is a trust. There is something that happens and it’s the amount of time that you spend with them. And it’s one of my favourite things about doing developmental disability, but I can’t explain it” (interview 12)*

As they took on the role of developing trust in their relationship with their patients, they had to be aware of actions that may have damaged that trust. When considering



interactions with others in the healthcare system, the family physician sometimes had to play the role of the advocate.

#### 5.2.1.2.3 The Role of the Family Physician as Advocate

To continue to define their role in this direct trusting relationship, family physicians realized the need to be a strong advocate for their patients. The advocate role is a well-recognized one that family physicians are required to play for all their patients. These patients' added vulnerability associated with interacting within healthcare and social contexts not designed for them however, heightening the need for the family physician advocate role.

*“you are their voice” (interview 12)*

*“I see a lot of individuals when people can't deal with them or don't want to deal with them they medicate them to sedate them. To make them, you know, malleable and less troublesome. And I think that's sad because you know, patients deserve better than that, but there's other ways to deal with those problems” (interview 2)*

As the family physician took on the role of advocate, and felt they won some battles on their patients' behalfs, such as minimizing the amount of medications they received or gaining access to required resources, they also began to appreciate their own sense of wellbeing as a result.

#### 5.2.1.2.4 The Role of Reciprocity of Emotions in the Relationship

Defining their role in these complex relationships also involved being open to and appreciating the positive reciprocal effect that these patients and the relationships had on the family physicians personally. This sense of wellbeing went beyond just knowing that a medical problem had been solved. It referred to the appreciation of the experience of being with that human being and the joy that brought the family physician.

*“just one of the most rewarding things, I think you know, when you see someone that’s doing well, for them.” (interview 2)*

*“just the mere fact of people with severe disabilities, nevertheless being joyful...to kind of just appreciate that.” (interview 13)*

This appreciation was also noted to be heightened in small communities where the family physician, clinic staff and other patients all knew each other and waiting rooms were described as “social places” where everyone relaxed and appreciated each other’s role in the community.

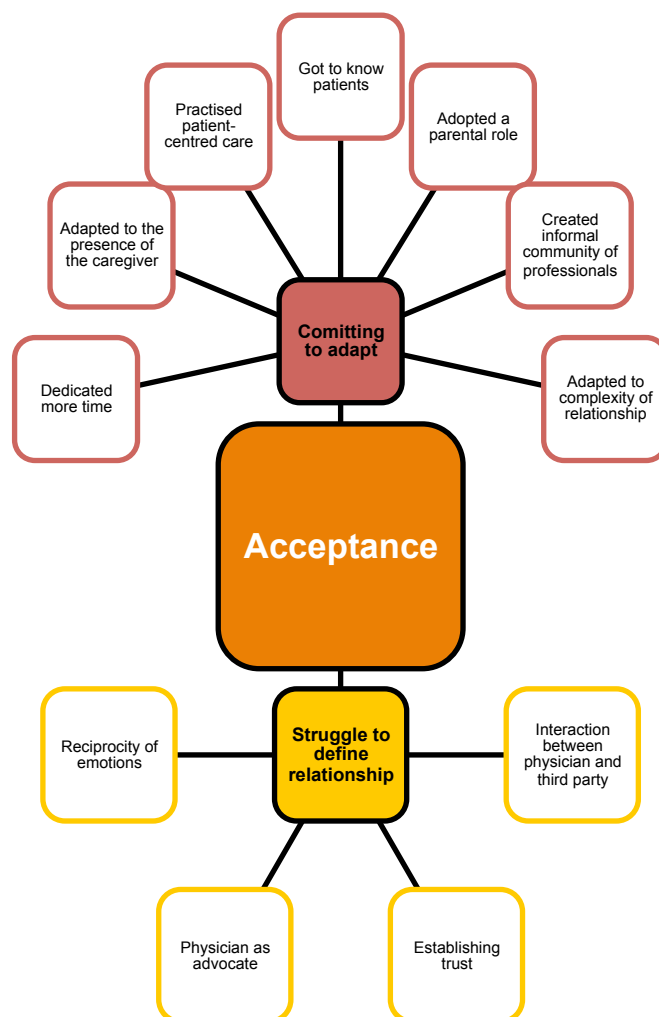
*“all these people [patients and caregivers] are my patients and so I feel more gratitude and I feel like we’ve grown and I feel like I’m really doing stuff to help” (interview 5)*

*“And so our waiting room is relaxed and chatty ... they are social places in small communities” (interview 7)*

This personal aspect of the relationship and the positive emotions felt by the family physicians provided comfort and satisfaction for the family physicians amongst the struggles of defining their role in these complex relationships and trying to provide good primary health care.

In summary, the central process involved in developing the patient-physician relationship between patients with severe and profound developmental disabilities and their family physicians was that of acceptance. This required a significant commitment on the part of family physicians to adapting the way they delivered primary health care to these patients. The family physician, in characterizing these relationships, were also required to go through the process of defining their role within this complex relationship.

**Figure 5: The Process of Acceptance**



### 5.3 Discussion

The main finding of Study Two was that family physicians engaged in a process of acceptance (Figure 5).

The patients in this study had severe and profound developmental disabilities. This meant that they had significant limitations in cognition and adaptive functioning, described as conceptual (including language), social (including interpersonal), and practical (including decision making) skills (1).

Family physicians accepted their patients with severe or profound developmental disabilities as individuals worthy of their respect, attention and empathy despite these

limitations. The family physicians spoke of being with their patients, of connecting with them beyond their disability. Jean Vanier described this as a learning process of “becoming human” (2) when speaking of his relationships with people with severe or profound developmental disabilities. Dr. Ian McWhinney describes connectional moments in family medicine as occurring when a family physician begins to relate to a patient as a fellow human being (3). Previous research confirms that patients with mild developmental disabilities desire acceptance as equals (4, 5).

Family physicians in return looked for acceptance by their patients with severe and profound developmental disabilities. Again, due to the nature of the limitations in communication, this was not always easy or possible and required adaptation on the part of the family physician to adjust their interpretation of acceptance. This acceptance could be something as simple as the patient agreeing to come into the family physician’s office, allowing the family physician into their home or to touch them. In the profoundly disabled patient, family physicians had to accept that they may not be able to interpret any overt sign of acceptance from the patient directly. In these situations, where present or possible, the patients’ interactions with caregivers and the caregivers’ comments to the physician were accepted as a proxy for this acceptance.

The process of acceptance required family physicians to commit to adapting the ways they used to interact with and provide primary health care to their patients without these limitations. This included adaptations within a health care system not designed for those with these limitations. Previous studies confirm the lack of support patients with developmental disabilities receive from the health care systems they are required to access (1, 6–9). The family physicians in this study committed to this level of adaptation, despite unsupportive health care systems.

### 5.3.1 Committing to Adapt

The family physicians committed to this process of adaptation in various ways:

#### 5.3.1.1 They Dedicated More Time to their Patients

These patients just took more time to care for. Practically this meant that family physicians had to adapt their schedules when booking these patients in advance, but also adapt on the fly as their patients needed them. These patients needed more time to give them the best chance of communicating and connecting with the family physician. They could not be rushed and this took more patience and effort. The fact that these patients took more time to care for is consistent with the literature on both patient and physician experience (3, 5, 10–14). This commitment to extra time also meant a commitment to not being remunerated appropriately, because the health care systems in which these family physicians worked did not acknowledge the increased time required. Family physicians have noted that dedicating extra time to care for adult patients with developmental disabilities without appropriate remuneration is a challenge in other healthcare systems (15).

Committing more time also related to the concept of continuity over time. Continuity of care in family medicine refers to the repeated provision of care by the same physician or clinical team to a particular patient over time. It has been well described as a fundamental aspect of the enduring patient-physician relationship in family medicine (3, 14). This study emphasized the extreme importance that family physicians placed on continuity of care. As a result of the limitations in adaptive functioning of patients with severe or profound developmental disabilities, the increase in time and effort required for the patient and physician to get to know each other and to have any chance of establishing a connection meant that continuity on the part of not only the physician, but also the caregivers (15), was very important.

Developing a meaningful connection with these patients required repeated encounters where attention was given to a very slow progression of interaction with the same physician. As such the passage of time and continuity of care within that time were

essential elements of building this personal trust relationship as each party learned to accept the other.

### 5.3.1.2 They Adapted to the Presence of the Caregiver in the Relationship

In this study, family physicians recognized and valued the caregiver as more than a source of information within the encounter. The caregivers knew the patient best and were therefore the best person to interpret the patient's symptoms. This is in keeping with a recent study on communication in patients with profound developmental disability where the caregiver was noted to be essential in distinguishing patient behavioural indicators (16). Prior studies support the involvement of caregivers in the primary health care of adults with developmental disabilities (1) and other types of triadic medical encounters such as the elderly and those with cancer (17–20).

Family physicians recognized the strong bond the caregivers had with the patients and how they served as role models in developing rapport with the patients. They also described how “you don't only get the patient, you get the family” with respect to committing to a long-term relationship with these patients and their caregivers. This consideration of the role of the caregivers in the long-term relationship went beyond considering the benefits and challenges of a caregiver's presence in the technical aspects of care during an encounter (17–19).

Patient autonomy and respecting a patient's wishes is an important aspect of family medicine. In this study, given the severe limitations of their patients with severe and profound developmental disabilities, family physicians accepted and appreciated the caregiver's role in the relationship. Despite this and the significant dependence of the patient on the caregiver for most daily and all advanced health care decisions, family physicians recognized any level of autonomy the patient could attain. The importance of the primacy of the patient, their involvement in the encounter and the resultant relationship with the physician was noted. The importance of not ignoring the patient in this triadic encounter was in keeping with other previous studies of patients with mild developmental disabilities (5). Recent recommendations on the approach to caring for

developmentally disabled adults in the community also note the importance of respecting the patient's wishes (21). Inclusion of the caregiver and their deep knowledge of the patient helped the family physician to practice patient-centred care.

### 5.3.1.3 Practising Excellent Patient-Centred Care

Recognizing that patient-centred care is a well described and beneficial approach in family medicine (3, 22, 23), family physicians in this study felt that the inability of their patients with severe and profound developmental disabilities to adjust challenged them to practice even better patient-centred medicine than they did with their patients without such disabilities. Patient-centred care and the ability of the physician to adapt were found to be essential in a similar study in patients with mild developmental disabilities. As part of patient-centred care, family physicians in this study adapted their communication strategies using for example, more simple language. This was similar to other findings of studies in patients with mild developmental disabilities (5, 10, 11, 24).

Alternate forms of communication have not always been recognized in patients with developmental disabilities resulting in the failure of physicians to note important symptoms (25). In this study, family physicians reported taking careful note of gestures and behaviours as alternate forms of communication and mirroring these to connect with their patients if appropriate.

Observing patients with developmental disabilities carefully to ascertain their level of ability has been noted (26). This includes recognizing altered levels of receptive and expressive communication skills, such as in patients with autism whose senses may be hyper-acute (27).

Empathy is the capacity to enter into another person's experience (3). In this study, family physicians reported having to observe their patients closely to understand the effect of stimuli which were not always obviously noxious or medical in nature. This included the way food was presented, the arrival of a new client in a group home, the smell of a hospital clinic or the colour of the clothes the physician was wearing. Only by observing their patients carefully and being observant of the details of their surrounding

environment, could the family physicians in this study truly empathize with their patients. In this way, they avoided attributing behavioural changes to the developmental disability itself (25). By observing their patients carefully as a function of patient-centred care, the family physicians got to know their patients really well.

#### **5.3.1.4 They Got to Know their Patients Personally**

Getting to know individual patients as an aspect of continuity of care is an essential quality that has been shown to improve patient and physician satisfaction (28). In this study, family physicians recognized that getting to know their patients with severe or profound developmental disabilities required an extra level of commitment. More than an added benefit to improve satisfaction on both sides, this deep personal knowledge was an essential aspect of care which allowed the physician to adjust the way they interacted with their patients taking into account their likes and dislikes.

True reciprocity in a patient physician relationship may only come when the doctor has shown that they too are human (3). Family physician satisfaction in this study improved as the physician strove to get to know their patient as their equal and form a personal connection with them as they would with any other human being.

Given that the problems for these patients with severe or profound developmental disability could not always be solved, recognizing and adapting to the fact that getting to know their patients was a therapeutic goal in itself, was a new finding not found elsewhere in the literature.

As the family physicians in this study got to know their patients really well, they were then in a good place to provide mentorship to their patients and their caregivers.

#### **5.3.1.5 They Adapted to the Power Imbalance of the Parental Role**

The balance of power in patient-physician relationships ranges from mainly physician power (paternalism) to mainly patient power (consumerism) with the middle approach demonstrating mutuality of power (13). In this study, family physicians described using a paternalistic approach when essentially dealing with a child in an adult's body. While this could represent an unconscious bias on the part of the family physicians (11, 12), these



family physicians referred to this as a process of being proactive in their thinking, using their knowledge of the patient, the patient's particular condition, or their knowledge and experience of these types of situations to plan for possible future challenges.

While the power in decision-making was definitely on the side of the family physician and caregiver, the family physicians also described how some patients with severe and profound developmental disabilities were quite capable of expressing the mutuality of power in certain aspects of their care. This was expressed in ways unique to that individual. If the patients were not able to express themselves verbally, this may have included behaviours such as aggression, screaming, or refusing to be examined. The reasons for these behaviours may have been a challenge to interpret initially, but once known were used when planning future health care interventions.

In this study, family physicians tried to balance the practical need for them to make decisions for their patients, with respecting their right to as much autonomy as possible. In their review of autonomy in relation to health among people with developmental disabilities, Wullink et al. agreed that finding the balance between independence and appropriate professional care can be challenging (5).

As they struggled with these various adaptations, family physicians felt the need for support themselves.

#### **5.3.1.6 They Reached out to Create their Own Informal Community of Health Care Professionals.**

The importance of working more closely in teams to ensure a sustainable future for family physicians and the continued provision of high quality family medicine in Canada had been noted (28, 29). Learning and caring in communities of practice has also been suggested as an improved method of care for patients with multimorbidity and their primary health care providers (30).

As a result of deinstitutionalization, people with developmental disabilities are seeking care from community based primary health care practices (11). While deinstitutionalization has been occurring for the past 30 years, the recognition of its

impact on primary healthcare access and service delivery is still relatively new. As such, development of formal communities of practice and associated resources in this clinical area is still relatively new (31). Formal training and exposure to these patients in medical school, while improving, is still inadequate (32). Family physicians have spoken of “operating without a map” when describing their approach to the care of their patients with developmental disabilities (33).

In this study, the majority of physicians had no formal training in the primary health care of adults with developmental disabilities and formal communities of practice did not exist. As a result, most family physicians, including those in Newfoundland, adapted in innovative ways to provide what they felt was the appropriate level of patient care and avoid burnout themselves. This adaptation included accepting the responsibility of creating informal supportive networks of health care providers to assist them in the sometimes challenging management of their patients and these complex relationships.

### **5.3.1.7 They Adapted to the Complexity of the Relationship**

Consensus guidelines on the primary care of adults with developmental disabilities in Canada were last published in 2011 and are going through a process of being updated for publication in 2017 (1, 31). These guidelines synthesize the numerous issues of these adults and present the recommendations with these individuals’ developmental disabilities in mind. Primary health care guidelines for the specific diseases these patients suffer from at increased rates, however, such as diabetes and cardiac disease (1, 34), were not developed with this population in mind. In this study, family physicians considered the level of ability of the patient and adapted recommendations described in established chronic disease guidelines as appropriate.

Patients with developmental disabilities have complex health issues with shorter life expectancy and higher levels of diagnosed and undiagnosed disease than the general population (16, 35, 36). This multimorbidity in itself added to the complexity to which family physicians adapted in this study.

By virtue of their severe and profound developmental disabilities, the relationships referred to in this study always included at least one extra person—the caregiver. A caregiver’s presence can influence the patient-physician relationship and increase the complexity of the encounter (17). The relationships in this study were therefore complex both medically and socially. Despite challenges including balancing patient autonomy with caregiver inclusion and establishing a joint understanding of the role of the caregiver, it is generally accepted that caregivers are a positive influence and should be integrated into the healthcare team where possible (11, 18).

To conclude the discussion on the process of committing to adapt, the family physician accepted the patient by adapting to their individual level of ability and the complexity of the triadic relationship. As they sought out alternate ways of interacting with the patient, they struggled to define the relationship itself and their role in it.

### **5.3.2 The Struggle to Define the Relationship and the Family Physician’s Role in it**

Intersubjectivity refers to the interaction between two subjects. Understanding the nature of this interaction and resultant relationships has been the subject of discussion amongst many philosophers and psychoanalysts (37). The importance of the patient’s role in the patient-physician relationship has been noted and described as a mutual commitment (3). Previous research on patient’s perspectives of the patient-physician relationship in general, revealed the importance of the human connection (14). Research on the patient-physician relationship in patients with developmental disabilities is extremely limited (11). This study added to this research by focussing on patients who, by virtue of their severe or profound developmental disabilities, could often not connect in any typically recognizable way with their family physician.

This lack of interpretable feedback or sign of mutual commitment was a challenge for some family physicians who doubted that a relationship existed whilst others were content to continue providing care, assuming it did not. Other family physicians accepted this mutuality as existing independent of the feedback they could not interpret and hence did not feel it impeded their ability to form relationships with their patients. While they

accepted that these relationships were different from those with patients without severe or profound developmental disabilities, they described them as extremely deep, rewarding and fulfilling.

In addition to assessing the depth of the relationship they had with their patients with severe or profound developmental disabilities, the family physicians in this study also described having to define their role in these relationships. This was not always straightforward given the complexity of all the people involved, that problems encountered were not all medical, yet affected their patient's well-being, and the lack of easily understood feedback from the patient.

The definition of the family physician's role involved the following considerations:

#### **5.3.2.1 The Role of the Interaction Between the Family Physician and the Third Party**

By virtue of the patients' developmental disabilities, these relationships always required at least one extra person's involvement. This triadic communication can be helpful but is also challenging (17, 18). A recent systematic review revealed that there have been a number of studies on the role of companions in triadic relationships (17). Caregivers of patients with mild developmental disabilities have been described by family physicians as a proxy for communication (11). This study enhanced these findings by focussing on patients with severe and profound developmental disabilities and introducing the concept of the family physician defining their own role in this triadic relationship.

Family physicians in this study valued the triadic encounter experience, but were cognizant of their role in establishing trust in a direct patient-physician relationship independent of the caregiver.

#### **5.3.2.2 The Role of the Family Physician in Establishing Trust**

Trust exists when one party has confidence in an exchange with another partner's reliability and integrity (38). In relationships with patients without developmental disabilities, trust can begin at a generic level of trust in the medical profession and then deepen to a level of personal trust (14).

In this study, family physicians had the challenge that most of their patients with severe or profound disabilities did not come to their encounters with an appreciation of this generic trust to begin with.

Trust in a specific physician is rooted in experience (39), and continuity of care is an important factor in establishing that trust (40). The family physicians in this study defined their role as the one responsible for building that personal level of trust through repeated experiences with their patients. They chose to tread extremely gently to begin with, conscious of the fragility of this trust during these interactions, yet appreciative of the small and incremental increase in trust as the relationship progressed.

### **5.3.2.3 The Role of the Family Physician as Advocate**

Patients with developmental disabilities are not well supported by their healthcare systems (8, 9). This therefore necessitates an added level of advocacy on the part of the family physician. Assuming the role of a patient's advocate is one of the recognized competencies of a family physician (41).

In this study, the vulnerability of the patients and the lack of supportive healthcare resulted in the family physicians feeling a need to be strong advocates for their patients.

Negative perceptions of patients with developmental disabilities unfortunately still exist even amongst attending physicians (33). Family physicians in this study referred to occasions where they felt their patients were not receiving appropriate medical care. They felt their patients deserved better and this required their input as advocates.

This role of advocate was challenged but was balanced by a sense of appreciation and accomplishment for the family physician.

### **5.3.2.4 The Role of Reciprocity of Emotions in the Relationship**

Emotional intelligence, involving a physician's ability to adapt and recognize the role of emotion has been noted to be important in developing trust relationships (42).

Reciprocity in the form of a friendship was described in other patient-physician relationships as both parties feeling the same bond (14). In this study reciprocity referred to the bond and positive emotions family physicians felt professionally and personally following their interactions with their patients with severe or profound developmental disabilities without knowing for sure if their patients felt that same bond or not.

Family physicians' positive feelings about their relationships with patients with mild developmental disabilities, relates to being viewed positively by others or having a certain perception of themselves that they valued (11). Family physicians in this study referred to feeling a sense of reward when they saw their patients doing well and a sense of gratitude for being able to be involved in their patients' care and "do good stuff".

### 5.3.3 Conclusion

This study provided a detailed description of the process of acceptance as the process required to form a relationship with patients with severe or profound developmental disabilities from the perspective of family physicians. This process of acceptance required a commitment on the part of the family physician to adapt the way they delivered care as compared to their other patients. The family physicians characterized these relationships differently according to their own philosophical beliefs as to the nature of relationships. The process of acceptance also required the physicians to define their role in this complex relationship, in which the patient was central, but the caregiver played a significant part. Ultimately this study highlighted the family physician's acceptance of their patients' humanity, regardless of the type of relationship that was created between them.

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## Chapter 6

### 6 General Discussion and Integration of Findings

The inspirations for this research were both systemic and personal, as mentioned in the preface to this thesis. The strong evidence of health inequities and unmet health needs of people with developmental disabilities is well documented (1–4). The author’s personal experience of these inequities and their noted effect on both patients’ and caregivers’ quality of life and the development of the patient-physician relationship were important motivating factors for this study.

Research on the patient-physician relationship in patients with developmental disabilities, is scarce (5–7). No studies specifically focusing on this relationship development in patients with severe or profound developmental disabilities could be found. This study therefore aimed to explore the development of this relationship.

Constructivist grounded theory qualitative methodology was used, to explore the processes involved in developing such a relationship. Two studies were conducted to highlight first the perspective of the caregiver and second the perspective of the family physician.

The findings of this research can be used as a foundation for future studies on this topic, as well as to inform the development of evidence-based guidelines on how to proceed in these interactions, to ensure a positive patient-caregiver-physician relationship experience for all.

#### 6.1 Main Processes

The findings in Study One, the perspectives of the caregiver, described the main process involved in relationship development as that of protection. The main process identified in Study Two, the perspective of the family physicians, was that of acceptance. The position of the caregiver and patient as compared to the physician in this relationship with respect to their perceptions of power and control over the relationship provides an interesting perspective in relation to these findings. The inherent power and control imbalance in the

patient-physician relationship has been well described (8–10), as have the health disparities experienced by this population within our current health care systems (1–4, 11).

In Study One, caregivers recognized their patients' vulnerability and lack of power within this relationship and the health care system in which it existed and reacted by trying to protect their patients from the associated health disparities. Their experience of how much the family physician empowered both the caregiver and the patient by accepting their shared involvement in and control over the relationship, determined the trajectory of the relationship. In Trajectories One (Up Front Knowledge Acquisition) and Two (Familiarization with Time), caregivers experienced the benefit of the balance of power and control. In Trajectory Three (Stable and Functional Resource), caregivers took the desire for protection and control to the extreme by unilaterally directing the care of their patient, involving the family physician as stable and functional resource only. In Trajectory Four (Assumption of Physician Authority), caregivers and patients experienced total lack of active involvement, power and control as the physician assumed total authority.

In Study Two, family physicians also recognized the patient's vulnerability and the lack of acceptance and adaptation of present health care systems to patients with developmental disabilities. They reacted by ensuring they at least accepted their patients as individuals worthy of respect, attention and empathy. They practiced the art of demonstrating mutuality of power by ensuring they used their medical expertise to guide the relationship, whilst also seeking input from the caregiver and recognizing and adapting to the patient's unique attempts to communicate their wishes where possible. By doing so, they practiced empowering patient-centred care.

Caregivers and family physicians need to be aware of the differing but complementary processes in order to gain a greater understanding of the relationship and the actions of all involved. Both processes have as their central focus the wellbeing of the patient.

## 6.2 Integrated findings

Integrated findings within these two processes included:

### 6.2.1 Respect of the Patient and Acceptance as any Other Human Being

In 1964, Jean Vanier founded the now international movement of L'Arche communities. Described as communities where people who have developmental disabilities and their friends who assist them create homes and share life together, their focus is on acceptance of all human beings as worthy of respect and love (12). In his book, *Becoming Human*, Vanier states that all humans, whatever their capacities or incapacities, strengths or weaknesses, are sacred. He follows this by suggesting that all of us have something to offer to humanity, but that each one of us needs help to realize our potential (13). The findings of both studies alluded to this concept of accepting adult patients with developmental disabilities with respect and dignity, worthy of the assistance they required to realize their potential.

In Study One, caregivers valued their patients as human beings, deserving of the same level of healthcare as anyone else, but felt the need to have to fight for this in a healthcare system that perhaps did not recognize this value to the same degree. The caregivers' recognition of the value of the adults with severe or profound developmental they cared for was illustrated by the strong bonds they formed with them.

In Study Two, family physicians spoke of the many ways they adapted their practices in order to meet the needs of their patients with developmental disabilities. Whether they felt they were ultimately able to form a relationship with their patients or not, as views differed across the participants, they all recognized their value as human beings, deserving of their efforts to step up and provide an appropriately higher level of patient-centred care.

Regardless of differing motivations and actions of caregivers and family physicians, all expressed a commitment to caring for patients with developmental disabilities. The implication for care is that caregivers and physicians can take comfort in knowing that

the patient is valued, respected and recognized as deserving of an equal and ethical standard of care by both parties. This should allow for a common starting point for the resultant triadic relationship.

## 6.2.2 The Recognition of a Triadic Relationship

A physician's active attempts to involve the caregiver are extremely important when caring for adults with developmental disabilities (14). Despite the challenge of balancing caregiver inclusion and patient autonomy, it is generally accepted that caregivers are a valuable resource and should be integrated into the health care team where possible (15–17). While both studies agreed on the importance of the triadic involvement, they described slight differences as to how that integration occurred.

In Study One, caregivers perceived themselves as encountering the family physician as one caregiver-patient unit. This unit then decided as one whether or not to let the physician into their bond and then how to proceed with the triadic relationship development.

In Study Two, the family physician reported valuing the primacy of the patient-physician unit but recognized the value of including the caregiver in a similar triadic type relationship.

These two perspectives are fundamentally different and affect the development of the future relationship. To the caregivers, this inextricable connection with their family member/client meant that they had to be included one hundred percent in all levels of interactions between the family physician and the patient. The caregiver felt they knew the patient very well and hence were confident they could assess their wants and needs accurately. Any sense of a lack of acknowledgement of the primacy of this patient-caregiver bond was interpreted as increasing the patient's vulnerability. The caregivers reacted to this by either assuming back total control of the medical care of the patient including the relationship with the family physician, as seen in Trajectory Three (Stable and Functional Resource) or a giving in to a sense of hopelessness as they followed Trajectory Four (Assumption of Physician Authority).

For the family physician, while they acknowledged the importance of the caregiver and their bond with the patient, the centrality of the patient was still a hallmark of the patient-centred care they offered all their patients regardless of their lack or level of developmental disability. This did not mean that they did not value the caregiver and their involvement. Caregivers were described as role models, assisting the physician in knowing the details of particular patient preferences with regards to interaction. At the same time, family physicians also described themselves as patient advocates having sometimes to ensure that the needs of caregivers did not overshadow those of the patients. This speaks to their interpretation of the primacy of the patient-physician relationship.

The implications of these two related but different perspectives, both with a common outcome of a triadic relationship, is that the understanding thereof by both parties is an essential part of maximizing the therapeutic benefits of this relationship. The common goal is that of meeting the patient's needs, the goal of patient-centred care. These patient needs are best met if both caregivers and family physicians respect each other's personal relationship with the patient yet understand their significant and related role in the larger triadic relationship.

For the caregiver, allowing the physician the space to form a relationship with the patient may assist with the development of mutual trust. This in turn could pave the way to making the medical encounter less stressful for the patient and more productive in terms of for example the patient agreeing to attend appointments or allowing the physician to examine them when required.

For the family physicians, awareness that caregivers may interpret the physician's desire for a patient-physician relationship as a threat to the patient-caregiver bond, and hence the safety of the patient, could assist in relationship development. The family physician should focus on building trust and providing a safe place for both the patient and the caregiver. As this trust is built, the patient-caregiver bond should open more easily allowing the physician more meaningful access to the patient as was seen in Trajectory One (Up Front Knowledge Acquisition) and Trajectory Two (Familiarity with Time). The

caregiver can then be drawn in as a facilitator to the relationship as opposed to protector of the caregiver-patient unit.

### 6.2.3 Continuity of Care

The central role of continuity of care in the patient-physician relationship has been noted (18, 19). Severe limitations in intellectual and adaptive functioning (conceptual, social and practical skills) in patients with severe or profound developmental disabilities mean that developing relationships takes more time and effort.

In Study One, the description of Trajectory Two (Familiarity with Time) emphasized the passage of time and resultant growing familiarity, knowledge and trust linked to the continuity of the provider. This allowed for the development of a deep, personal and familial relationship.

In Study Two, the patients' significant limitations in ability to understand the concept of generic trust in medical providers highlighted the findings from the family physicians of the importance of assisting the patient to develop a personal level of trust in the family physician. This required physicians to dedicate extra time for each encounter, as this process had to begin slowly. Family physicians also had to ensure regular encounters with their patients over a longer period of time as trust was built incrementally. The value of this dedicated time was not recognized by the majority of healthcare systems in which they worked.

The implications for practice are that both family physicians and health care systems need to make provisions to allow for continuity of care for this population.

### 6.2.4 The Concept of Family and the Family Physician

While a previous study of caregivers of youth with developmental disabilities noted the importance of placing the whole family at the centre of care (20). Study One highlighted a new finding of the family physician being incorporated into the patient's family and the patient being incorporated into the "health care team" family. This extended the role of the family physician from professional to family member and deepened the personal experience of the relationship as perceived by the caregiver.

While this finding was less obvious in Study Two, family physicians did report the importance of accepting not only the patient, but also the family into the patient-physician relationship. They also noted the importance of the patient as a member of the “community family” particularly in the smaller communities. These findings suggest that the family physician accepted that their responsibility was to the family as a whole, not only the patient.

The implication of this is that both caregivers and family physicians need to be aware of the possible benefits to the patient of incorporating each other into their respective “families” where possible.

### 6.2.5 Extremes of Need

The higher prevalence of physical and mental illness (1, 4, 11), coupled with significant limitations in adaptive and intellectual functioning, make this population especially vulnerable to health disparities (1–4). People with severe developmental disabilities are more severely affected and have even poorer health outcomes than those with mild disabilities (21).

In Study One, as part of the process of protection, caregivers described the extreme measures they had to employ to ensure the patients were able to receive what they felt was an appropriate and equitable level of health care as with any other patient with or without developmental disabilities.

In Study Two, this extreme need was focussed on the need of family physicians to provide an exceptionally high level of patient-centred care. In agreement with the literature, family physicians recognized the established benefits of patient-centred care (18, 22, 23) for all their patients. They added that they felt the inability of their patients with severe and profound developmental disabilities to adjust (resulting in vulnerability) challenged them to practice even better patient-centred medicine with their patients without such disabilities as a possible way to mitigate this vulnerability. This included making the effort to get to know their patients very well, adapting their means of



communication, recognizing the level of intellectual and adaptive functioning ability of their patients and recognizing the sometimes unexpected effect of “routine” daily stimuli.

The implication of this finding is that family physicians need to be aware of the struggles the patient and caregiver may have experienced in order to access their care, and they need to react by offering the best patient-centred care they can in recognition of this effort. It may also deepen family physicians’ appreciation of patients’ and caregivers’ possible previous negative experiences of the healthcare system and resultant initial reticence to trust the family physician.

### **6.2.6 Defining the Relationship and the Roles of Those Within It**

In Study One, caregivers did not specifically identify the need to define either their or the family physician’s role in the triadic relationship. They did however identify the centrality of the patient-caregiver bond and as such assumed their vital role in the relationship.

Study Two added to Study One by further developing the caregivers’ interpretation of the concept of the patient-caregiver bond as the physicians echoed its importance and hence questioned their own personal role in this triadic relationship. Some family physicians in Study Two were comforted by the presence of the patient-caregiver bond as it illustrated that a personal relationship could exist. They recognized that caregivers served as role models in forming such a relationship with their patients with severe and profound developmental disabilities.

The implication of this finding is that it highlights (as with any relationship) the importance of role definition of all involved parties. This is particularly the case with this complex relationship involving three adults, one of whom is very limited in their ability to partake in the discussion.

### **6.2.7 The Existence of a Personal Relationship with Another Human Being**

In Study One, caregivers did not doubt the very existence of a relationship with the family member/client. This could be explained by their deep knowledge of the person and

resultant ability to interpret feedback from them. This feedback may not be initially obvious to anyone else.

In Study Two, physicians did not have the luxury of this deep knowledge and hence struggled at times to interpret any feedback on the relationship at all. This is in comparison to patients without developmental disabilities where a noticeable mutual commitment is expected (18).

Regardless of the family physicians' interpretation of the role of the patient or themselves or the construct of the relationship itself, they all valued getting to know their patients. This desire to connect, to form a personal relationship, and in doing so respect the humanity of these patients as they would any other human being without developmental disabilities was expressed clearly and is worth noting.

These above notable points relate to what both caregivers and family physicians expressed as to the process of relationship development. These processes all occurred with the health care context and mostly in the province of Newfoundland and Labrador.

### 6.2.8 The Impact of Context

These research findings and their implications are interpreted within a particular social and health care context.

The majority of participants in both studies were from St. John's and surrounding communities in Newfoundland and Labrador, Canada. This relatively small, tight knit and consistent community set the stage for long-term relationships to occur, physicians to be incorporated into patients' families, and physicians to develop informal supportive communities of practice within the local medical community.

This island province released its updated Primary Health Care Framework in 2015, which promoted primary health care services. Despite this, the provision of well-supported, team-based primary health care services is still in its infancy for the general population, let alone for this vulnerable population with specific needs (24). Both studies were congruent with previous studies illustrating the lack of support patients with

developmental disabilities and their family physicians receive from the health care systems within which they are required to operate (1, 5, 15).

The implications of the integrated findings for patients, caregivers and family physicians have been discussed. There are, however, broader implications of the findings, particularly in relation to the health care context above, for other involved stakeholders, including policymakers and medical educators.

### **6.2.9 Implications for Policymakers**

People with severe developmental disabilities have higher health care needs yet due to various barriers, access health care services less (1, 4, 25). The importance of well-designed practice systems to meet the needs of chronically ill patients and those with developmental disabilities has been argued (23, 26).

The findings of Study One indicate that patients' and caregivers' needs are not being met and suggests a mismatch between the services being provided and the needs of the population being served. Policymakers should explore this mismatch further if service delivery is to be improved.

In Study Two, the majority of family physicians reported caring for their patients in relative isolation and a lack of formal health care system support or recognition for the extra time and effort dedicated to their patients with severe or profound developmental disabilities.

The reality described above compels policy makers to wrestle with some difficult questions of why these problems of health care access and health disparities continue to exist in our health care systems today. Has health care lagged behind the broader social context in respect to exposure to and acceptance of patients with severe and profound developmental disabilities?

### **6.2.10 Implications for Medical Educators**

Family physicians' perceptions of a lack of clinical knowledge and support in providing care to their patients with developmental disabilities has been documented (1, 2, 7, 27).

Formal training and exposure to these patients in medical school, while improving, is still inadequate (28).

In Study One, caregivers felt that family physicians' lack of exposure to patients with severe or profound developmental disabilities during training and practice resulted in a lower standard of care for the patients.

In Study Two, family physicians reported having to adapt standard primary health care guidelines to the uniquely complex context of their patients with severe or profound developmental disabilities. They also reported feeling isolated and lacking the clinical knowledge and support they required to care for their patients. As a result, they actively sought out informal communities of practice to provide these supports.

The findings of this study can inform curriculum development in undergraduate, postgraduate and continuing professional education environments by providing the fundamental knowledge of why and how to form appropriate patient-physician relationships with adult patients with severe or profound developmental disabilities.

### 6.3 Strengths of this Study

While there are a small number of other studies reporting findings on aspects of the patient-physician relationship in patients with developmental disabilities (5, 6, 15, 25, 29, 30), this study makes an important new contribution to the literature by focusing specifically on this relationship in patients with severe and profound developmental disabilities.

The focus on this specific population and the use of constructivist grounded theory methodology allowed this research to highlight two findings in addition to those reported in the existing literature: First, existing studies have focused primarily on the technical aspects of the relationship between adult patients with developmental disabilities within particular medical encounters. These include discussions related to individualized communication strategies (6, 15, 25), recommendations regarding the best way to include support workers and the best way to make patients feel respected and valued (15, 25).

The focus of this thesis on patients with severe and profound developmental disabilities

and its use of constructivist grounded theory methodology allowed for a unique exploration of the process of relationship development. It resulted in a deeper more philosophical illumination of dimensions of caring for this population, from both the caregiver's and family physician's perspectives, not previously discussed in the literature. Second, the use of constructivist grounded theory allowed this study to extend the findings of the previous studies mentioned above by describing the longitudinal process of relationship development over time rather than the cross-sectional experience of this relationship within one encounter. Ultimately, the greatest strength of this research is that, in comparison to existing research, it brings a greater understanding to the as yet unanswered questions of why and how adult patients with severe or profound developmental disabilities, their caregivers and their family physicians become involved in relationships.

#### **6.4 Limitations of this Study**

While the majority of participants involved in this research were from one geographical area in Canada, the breadth and variety of the samples in both studies allowed for an appropriate illumination of the processes involved in this relationship development in this area. It is still possible however that further trajectories of patient-physician relationships involving adult patients with severe and profound developmental disabilities and their family physicians may exist which were not possible to uncover in Study One. Study Two included family physicians from other areas in Canada. Saturation of data was achieved in both studies. The findings from the caregivers and physicians located in that one geographical area allowed for a rich and unique local perspective to be included in the data analysis and discussion.

An inherent limitation of studying this population who have severe limitations in communication skills is that the researcher must by necessity rely on the views and perspectives of another. To mitigate the effect of this limitation, those closest to the adult patient with severe or profound developmental were purposely recruited. In Study One, primary caregivers who knew the patients well and had taken them to numerous medical appointments with the same providers were identified and recruited by the family physician. In Study Two, family physicians with specific experience and extra training of

caring for patients with severe or profound developmental disabilities, as well as community family physicians with full scope family practices including long-term experience caring for patients with severe and profound developmental disabilities were recruited.

## 6.5 Future Research and Knowledge Translation

The literature review revealed only one article reporting findings specifically regarding the patient-physician relationship in patients with developmental disabilities (15). Other studies focused on related topics such as communication issues (6, 25). No studies were found focusing on this relationship in patients with significant limitations in intellectual and adaptive functioning skills due to their severe and profound developmental disabilities. The constructivist grounded theory findings in this study are significant as they identified the underlying processes involved in relationship development between these patients and their family physicians. This information can be used to inform future research and primary care resources in this area.

The following is a list of suggested areas for future research and recommendations following the findings of this thesis:

1. Epidemiological information on the population of patients with developmental disabilities in Newfoundland and Labrador needs to be gathered to address the lack thereof noted during the literature review.
2. Descriptive studies should be conducted to describe the provision of services to patients with developmental disabilities in specific provincial and regional health care systems. This information would then provide a starting point from which further studies on the impact of this service provision on the patient-physician relationship within Newfoundland and Labrador as well as other health care systems could be explored.
3. Further studies on the patient-physician relationship in patients with severe or profound developmental disabilities in areas beyond Newfoundland and Labrador may be valuable in adding other contextual insights to this research.

4. Given the importance of mixed methodology in understanding complex phenomena, further quantitative research should be undertaken to describe the impact of various patient-physician relationships on the health outcomes of patients with severe or profound developmental disabilities outcomes.
5. Dissemination of these findings may influence changes in health care delivery in Newfoundland and Labrador. If so, the impact of these findings should be evaluated and understood through further research.
6. This research may inform curriculum re-development, particularly as it relates to the care provided to people with severe and profound developmental disabilities. Medical educational research should be implemented to evaluate these curriculum changes with regards to outcomes such as the confidence levels of family physicians in providing care for this population.
7. Knowledge translation in the form of developing practical relationship development guidelines for caregivers and family physicians of patients with severe or profound developmental disabilities is the next step in this line of research.

## 6.6 Conclusion

This thesis utilized a constructivist grounded theory approach in two related studies to discover the underlying processes of protection and acceptance used to form patient-physician relationships in adult patients with severe and profound developmental disabilities. Both studies recognized the patient's extreme vulnerability as a starting point for these processes to occur. Study One highlighted the centrality of the patient-caregiver bond and the four distinct trajectories the patient-caregiver-physician relationships took depending on the caregivers' perception of the recognition of this bond within the relationship. Study Two highlighted the process of mutual acceptance requiring adaptation and role definition on the part of the family physicians in relation to this complex triadic relationship.

Respecting the patient's humanity as an essential part of the development of this relationship was an important and notable finding.



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# Appendices

## Appendix A: Thesis Proposal

### DEPARTMENT OF FAMILY MEDICINE

Master of Clinical Science Program  
Western University

A Thesis Research Proposal By:

Full Name: Katherine Stringer

Student Number: [REDACTED]

Email Address: [REDACTED]

Title of Thesis: Patient Centered Primary Care of Adults with Severe and Profound Developmental Disabilities: The patient – doctor relationship.

Supervisor(s): Dr. Amanda Terry, Dr. Bridget Ryan

Date of Review: September 25 2014

*I declare that the work I am submitting for assessment contains no section copied in whole or in part from any other source unless explicitly identified and with detailed, complete and accurate referencing.*

\_\_\_\_\_ (Signature)

## Summary

- People with Developmental Disabilities (DD) are living longer and are more likely to have multiple and complex medical problems<sup>1</sup>. Lack of appropriate transition of care from a well coordinated pediatric service to more fragmented adult services renders this group of people vulnerable to health care disparities.
- Family Physicians by virtue of their commitment to a whole person regardless of age or condition are ideally suited to provide continuous and coordinated care to people with severe and profound DD. Provision of this care is however challenging and requires family physicians who are competent and supported in doing so.
- Due to the relative lack of research on people with severe and profound DD, recent resources and publications in this area have relied mostly on expert opinion and consensus.
- This qualitative study will use in depth interviews to firstly understand and describe the process of development of the patient – doctor relationship between adult patients with severe/profound developmental disabilities and their family physician as perceived by the patient's primary caregiver. Participants will be asked, by reflecting on their own experiences, what they feel contributes this process and what advice they have for family physicians to positively impact this process.
- The second part of this study will describe the same process as perceived by family doctors who have relationships with adult patients with severe/profound developmental disabilities. Physicians will be asked by reflecting on their own experiences, what they feel contributes to this process and what advice they have for other family physicians to positively impact this process.
- This research involving patients with severe and profound DD, their caregivers and family physicians is essential to ensure that we identify their needs correctly and build enduring relationships with each other. Appropriate transfer of knowledge into practice is essential to assist family physicians and develop an approach to the coordinated delivery of primary care to patients with severe and profound DD in Newfoundland.

### 1.1 Key Literature review, rationale and objectives of this Study

The prevalence of DD in Canada is estimated at 1-3%.<sup>1</sup> People with DD are now living longer and are more likely to have multiple and complex medical problems. Unfortunately this renders them vulnerable to health disparities as more people with DD enter a medical system with fewer accessible resources.<sup>2</sup>

Hart's inverse care law states that "the availability of good medical care tends to vary inversely with the need for it in the population served."<sup>3</sup> Studies in Canada, the United Kingdom and Australia confirm that people with DD are poorly supported by their health systems.<sup>1,4</sup>

People with DD are especially vulnerable after transition of their health care from a highly coordinated and specialized pediatric system to a more fragmented and

less specialized adult system. A recent study of 13 Dutch patients transferring from pediatric to adult care showed that parents of young people with profound intellectual and multiple disabilities valued the care provided by the pediatrician and wished to see it continued.<sup>5</sup> This is obviously not a sustainable solution although people with developmental disabilities are often cared for beyond the age of usual transition to adult care.

Unfortunately, information from the National Physician Survey does not include data on caring for this specific patient population.<sup>6</sup> One might assume that family physicians, as the most common primary care providers in Newfoundland and Labrador (NL), would be the most consistently available health care providers for people with DD.

Continuity in the sense of the enduring doctor patient relationship is fundamental to the practice of family medicine.<sup>7</sup> Longitudinal care and commitment, and the consultation experience, including valuing patients and the experience and appreciating power differentials have been shown to be the main processes that prompt such a relationship.<sup>8,9</sup>

The development of this relationship and the provision of continuous, coordinated care to this unique group of people is not without its challenges. Little is known of the process or outcomes thereof in this context.

Patients with severe and profound Developmental Disabilities<sup>10,11</sup> require continuous support and hence present to their family physician with a caregiver. The level of developmental disability in these patients present unique challenges in communication and relationship development. In addition, research on the effect of a third person in the medical encounter in older patients with dementia reveals that the interactional dynamics change and may influence the development of a trusting and effective doctor patient relationship.<sup>12</sup> Effective and empathic management of a triadic requires specific communication skills.<sup>13</sup>

The Developmental Disabilities Primary Care Initiative in Ontario recently brought together clinicians with expertise in the care of adults with DD to improve primary care and quality of life for these people.<sup>11</sup> Some of their published guidelines recommend the use of resources and specialized services that, while generally available in Canada, may be lacking in some regional health service systems. This is the situation in most areas of Newfoundland and Labrador (NL). It is also noted that people with disabling conditions, including those with DD are low priority for researchers, as a result many of the recommendations are based on expert opinion or published consensus statements.

Due to the relative lack of research in the area of provision of care for people with DD, the family physician is left to adapt what knowledge he or she can access, such as the references and guidelines above, to the people they are caring for – individuals with multiple, complex and often unknown underlying conditions and



needs. Use of similar guidelines in Australia has resulted in better outcomes for these patients, but also numerous challenges for the family physicians using them.<sup>14</sup> these challenges in NL include family physicians suddenly having to care for patients they have not had the luxury of getting to know over time. The circumstances in each country or area within a country vary significantly<sup>15</sup> which decreases the generalizability of previous research. This dictates the need for further research examining the unique circumstances surrounding the interaction of family physicians and their patients and the resultant patient-doctor relationships.

Generation of further knowledge, is needed to ensure adequate and appropriate knowledge transfer. This involves studying the people and the problems where they exist<sup>16</sup>, in this case the community and the physician's clinics on the Avalon Peninsula, Newfoundland as well as expert knowledge from physicians involved in the care of adults with developmental disabilities across Canada.

The first study will describe the process of the development of the patient – doctor relationship between adult patients with severe/profound developmental disabilities and their family physician as perceived by the patients primary caregiver. Participants will be asked, by reflecting on their own experiences, what they feel contributes this process and what advice they have for family physicians to positively impact this process.

The second study will describe the same process as perceived by family doctors who have relationships with adult patients with severe/profound developmental disabilities. Physicians will be asked by reflecting on their own experiences, what they feel contributes to this process and what advice they have for other family physicians to positively impact this process.

The findings from both studies will then be combined to gain a deeper understanding of the process of the development of the patient – doctor relationship in this context. This knowledge will be used to encourage and assist family physicians not already doing so to form relationships with and care for these patients.

## **Study One**

### **1.2 Research Problem**

Most family physicians in NL do not play an active role in their pediatric patients' with Developmental Disabilities care. When the highly specialized and coordinated pediatric care ends, family doctors are asked to care for these patients whom they barely know. Despite recent significant improvements to resources for patients, caregivers and primary care physicians, this information is largely based on expert opinion and consensus, and is not always generalizable to all areas in Canada. Further research of the enduring patient – doctor relationships that have developed between adult patients with severe and profound developmental disabilities and their family physicians is needed to inform others on how to navigate this sometimes challenging process.

### 1.3 and 1.4 Objectives and Research Questions

#### Purpose

The purpose of this study is to describe the process of the development of the patient – doctor relationship between adult patients with severe/profound developmental disabilities and their family physician as perceived by the patients' primary caregiver/advocate.

#### Specific Objectives:

1. To explore how the patient – doctor relationship develops in the context of adult patients with severe or profound DD and their family physicians
2. To describe the trajectory of this relationship
3. To identify factors that impact or facilitate that process
4. To use this knowledge to assist family physicians in caring for these patients.

#### Specific Questions:

1. What was the initial experience of this relationship?
2. How has this experience changed with time?
3. What has helped shape this process of change?
4. What has hindered this process of change?
5. What is the trajectory of this relationship?
6. What advice would caregivers have for family physicians to optimize this relationship?

## 2. Proposed Methodology

### 2.1 Research Design:

This study will use the qualitative methodology of constructivist grounded theory using in-depth interviews with primary caregivers of adult patient with severe and profound DD as the primary source. Analysis of these experiences and insights of the participants and the researcher will then be used to propose themes and develop hypotheses on the process of the development of the patient – doctor relationship.

### 2.2 Sampling and Recruitment

Potential participants will be identified and recruited by family physicians at the Waterford Hospital, St John's, NL who have experience and relationships with these patients. Purposeful sampling will involve the initial seeking of primary care givers of adult patients with a diagnosis of severe or profound DD. Information about the study and consent forms will be provided on recruitment.



Written consent from the caregiver participants will be obtained before Data Collection commences. Sampling and data collection will continue until the point of saturation at which new participants provide no new additional concepts relevant to the central themes. Expected sample size of N=10-20 participants.

### **2.3 Data Source and Collection Techniques:**

Audio recorded in-depth interviews and field notes will be used. Due to the relative lack of research in this area and a desire to understand this process through the sharing of stories and experiences, this research will utilize an open exploratory approach. A semi-structured interview guide will be used which includes open-ended questions and subsequent probes.

### **2.4 Data Analysis and interpretation**

Data will be analyzed by 2 independent investigators using an iterative approach. A team approach will then be used to develop the themes from which the theory will be constructed. Credibility and trustworthiness of the data collection and analysis will be achieved through usage of a team approach and reflexivity (discussed further in Study 2).

## **Study Two**

### **1.2 Research Problem**

Information on how family physicians in NL care for the 1-3% of our population with DD is scarce. Most family physicians in NL do not play an active role in their pediatric patients' with Developmental Disabilities care. When the highly specialized and coordinated pediatric care ends, family doctors are asked to care for these patients whom they barely know. Despite recent significant improvements to resources for patients, caregivers and primary care physicians, this information is largely based on expert opinion and consensus, and is not always generalizable to all areas in Canada. Research of family doctors in NL as well as those with special interest and expertise in this clinical area Nationally who have formed enduring patient – doctor relationships with their adult patients with severe and profound developmental disabilities is needed to inform others on how to navigate this sometimes challenging process.

### **1.3 and 1.4 Objectives and Research Questions**

#### **Purpose**

The purpose of this study is to describe the process of the development of the patient – doctor relationship between adult patients with severe/profound developmental disabilities and their family physician as perceived by the family physician.

#### **Specific Objectives**

1. To explore how the patient – doctor relationship develops in the context of adult patients with severe or profound DD and their family physicians
2. To describe the trajectory of this relationship
3. To identify factors that impact or facilitate that process
4. To use this knowledge to assist family physicians in caring for these patients.

#### Specific questions

1. What was the initial experience of this relationship?
2. How has this experience changed with time?
3. What has helped shape this process of change?
4. What has hindered this process of change?
5. What is the trajectory of this relationship?
6. What advice would these family physicians have for other family physicians with regards too optimizing this relationship?

## 2. Proposed Methodology

### 2.1 Research Design

This study will use the qualitative methodology of constructivist grounded theory using in-depth interviews with family doctors of adult patient with severe and profound DD as the primary source. Analysis of these experiences and insights of the participants and the researcher will then be used to propose themes and develop hypotheses on the process of the development of the patient – doctor relationship.

### 2.2 Sampling and Recruitment:

Potential participants will be identified through purposeful sampling of family physicians with a variety of experience in developing enduring relationships with adults with severe or profound developmental disabilities. As this is a qualitative study, sampling and data collection will continue until the point of saturation at which new participants provide no new additional concepts relevant to the central themes. Expected total size of family physician participants will be approximately 10 – 15 and will be divided into the following groups:

1. Family physicians at the Waterford Hospital, St John's, NL, who see a larger number of these otherwise "orphaned" patients with severe or profound DD without community family physicians. (N=5)
2. Family physicians from the College of Family Physicians interest group on Primary Care of patients with Developmental Disability who have expertise and experience in forming relationships with adults with severe or profound DD. (N=5)
3. Community Family Physicians from the Avalon Peninsula who have/have

had a minimum of 2 patients with severe or profound DD in their practice and have some experience of forming relationships with such patients in this context. (N=5)

These 3 areas of participant recruitment for this study represent an attempt to ensure variation but still allow for depth of information received by targeting family physicians with both depth of clinical experience in the area as well as depth of knowledge of the specific community context.

### **2.3 Data Source and Collection Technique:**

Audio recorded in-depth interviews and field notes will be used. Transcription will be verbatim.

Due to the relative lack of research in this area and a desire to understand this process through the sharing of stories and experiences, this research will utilize an open exploratory approach. A semi-structured interview guide will be used including open-ended questions and subsequent probes.

### **2.4 Data Analysis and Interpretation:**

Data will be analyzed by 2 independent investigators using an iterative approach. A team approach will then be used to develop the themes from which the theory will be constructed. Credibility and trustworthiness of the data collection and analysis will be achieved through usage of a team approach and reflexivity.

To appreciate the value of reflexivity I must examine the biases I bring to this research study. As a family physician caring for adults with DD, I have received extra training in this area and am involved in trying to start a primary care clinic to assist in the coordination of their care in St John's, Newfoundland. Having been asked to accept a number of these patients who on discharge from pediatric care, have been left without a family physician, I have experienced my own challenges in forming new relationships with these patients. I recognize however that I have never stopped to ask my patients or their caregivers for their ideas and perspectives on this process. I feel strongly about the power of the patient – doctor relationship in family medicine our responsibility to be able to provide this aspect of care to all our patients. I do appreciate that as a salaried academic family physician the barriers and challenges I face may be different from those of my colleagues in different clinical situations. I hope to remain open to the experiences, reflections and opinions of the study participants yet balance that with the important realization that my interpretations are in themselves part of the construct.

### **Implication of results:**

While recent dissemination of resources for family physicians caring for adult patients with DD is welcomed, the specific experience of the relationship between adult patients with severe or profound DD and their family physicians in has not been previously explored. Results from this study will inform those



involved in the delivery of health services to this population in NL and may apply to other areas.

## **2.5 Ethical Considerations:**

Ethical approval will be applied for through the Health Research Ethics Board in Newfoundland and Labrador, which adheres to Tri-Council Policy Standards for ethical research.

Participation in both studies will be voluntary and written consent will be obtained from each participant. Participants will be advised that data and quotes from the interview or focus group may be used for publication, but individual participants, patients or other health care providers will not be identified. The names will be retained confidentially, and only non-identifying transcriptive data will be analyzed and reported.

## **Definition of key terms used in Study One and Two**

Adult – a person over the age of 18 years

Developmental Disabilities (DD) - a range of conditions which all result in lifelong limitations in intellectual functioning. This, together with limitations in conceptual, social and practical skills is noticeable before the age of 18 years

Severe Developmental Disability - Patients with an IQ of 25 – 35 or age equivalent cognitive functioning of 3-6years.

Profound Developmental Disability – Patients with an IQ of <20-25 or age equivalent cognitive functioning of 0-3 years.

Family Physician – A physician who is registered with the Newfoundland and Labrador Medical Association and are in active practice in communities of Newfoundland and Labrador.

Constructivist Grounded theory – a form of grounded theory arising from interaction between the researcher and participants. The researchers perspective is part of the mutual process of data collection, analysis and theoretical framework construction.<sup>17</sup>

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## Appendix B: Interview Guide 1 (October 2014)



### Semi-structured Interview Guide

Study title: Patient Centered Primary Care of Adults with Severe and Profound Developmental Disabilities: The Patient – Physician Relationship

Name of Principle Investigator: Katherine Stringer

#### Study 1 – Caregiver Interview Guide

##### Introduction

1. Before we get started, I would have some questions I would like to ask you for the study if that is okay? Please note that you may decline to answer any question you do not feel comfortable answering.
  - a. What is your age?
  - b. What is your sex?
  - c. What type of education have you received/Any specialized training in caregiving?
  - d. What is your relationship to the person you care for eg. family/friend/employee
  - e. Where do you provide the majority of your care to this person? Eg. private home/family home/group home
2. Is there anything else you would like to tell me about yourself and your relationship with the person you care for?

##### Questions re patient – family physician relationship

1. Tell me a bit from your perspective as caregiver about the relationship between the person you care for and their family doctor  
*(ask the following if not volunteered by participant)*
  - Duration of attending family physician appointments with the person they care for
2. Can you remember back to your initial experience of the relationship? Tell me a bit about it, what was it like?
  - a. Has this experience changed over time? How?

Patient Centered Primary Care of Adults with Severe and Profound Developmental Disabilities: the Patient-Doctor Relationship

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October 15, 2014

- b. What do you think has helped shape this process of change?
- c. Could you describe any number of things that have changed it for the better?

Prompts if needed:

- i. Anything from the doctor or medical systems side?
- ii. Anything from your and the person you care for's side?
- iii. Anything from the community's side?
- d. Could you describe any things that have hindered or slowed or not allowed the relationship to develop and change?

Prompts if needed:

- i. Anything from the doctor or medical systems side?
- ii. Anything from your and the person you care for's side?
- iii. Anything from the community side?
- 3. Do you think this relationship is still changing? Where do you think it is going?
- 4. Do you have any advice for caregivers, patients or family physicians on what makes for a successful relationship?

## Study 2 – Family Physicians Interview Guide

### Introduction

Before we get started, I would have some questions I would like to ask you for the study if that is okay? Please note that you may decline to answer any question you do not feel comfortable answering.

1. How many years have you been a family physician (since graduation)
2. How many years experience have you had dealing with adult patients with severe/profound DD?
3. Do you have any formal extra training in this area?
4. Approximately how many patients have you cared for that have severe/profound DD?

### Questions re patient – family physician relationship

1. Tell me a bit about your relationships with your patients with severe/profound DD
2. Can you remember back to your initial experience of these relationships? Tell me a bit about it, what was it like?
  - a. Has this experience changed over time? How?
  - b. What do you think has helped shape this process of change?
  - c. Could you describe any number of things that have changed it for the better?

*(Prompt: if needed)*

- i. Anything from the patient or caregiver's side?
- ii. Anything from your or the medical system's side?
- iii. Anything from the community's side?
- d. Could you describe any things that have hindered or slowed or not allowed the relationship to develop and change?

*(Prompt: if needed)*

- i. Anything from the patient or caregiver's side?
- ii. Anything from your or the medical system's side?
- iii. Anything from the community's side?
3. Do you think this relationship is still changing/developing? Where do you think it is going, does it have a trajectory?
4. Do you have any advice for caregivers, patients or family physicians on what makes for a successful relationship?



## Appendix C: Invitational Letter

HR08 Version June 2014



### Consent to Take Part in Research

**TITLE:**

Patient Centered Primary Care of Adults with Severe and Profound Developmental Disabilities: The Patient – Doctor Relationship

**INVESTIGATOR(S):**

Katherine Stringer, Bridget Ryan, Amanda Terry

You have been invited to take part in a research study. Taking part in this study is voluntary. It is up to you to decide whether to be in the study or not. You can decide not to take part in the study. If you decide to take part, you are free to leave at any time. This will not affect your usual health care or status as health care professional. Your specific viewpoints expressed in the interview will not be shared with those in the health care system. Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explains the study.

Please read this carefully. Take as much time as you like. Mark anything you do not understand, or want explained better. After you have read it, please ask questions about anything that is not clear.

The researchers will:

- discuss the study with you
- answer your questions
- keep confidential any information which could identify you personally
- be available during the study to deal with problems and answer questions

**1. Introduction/Background:**

People with developmental disabilities are especially vulnerable when they have to change from a very organized and specialized pediatric health care system to a more fragmented adult one. Some of these patients' parents have said that they would rather their children stayed with their pediatrician. Unfortunately this is not possible forever, although in reality these patients are often cared for by the paediatric system beyond the age of usual transition to adult care.

While we don't have any formal data on who actually coordinates and provides care for adults with developmental disabilities, we assume that family physicians would be the most available health care providers for this.

Being able to provide good continuous and coordinated care and the resultant relationship that develops from this is very important to family physicians. Providing this care and developing these particular

Version date: October 15, 2014

Patient Centered Primary Care of Adults with Severe and Profound Developmental Disabilities: the Patient-Doctor Relationship

-1-

Subject's Initials: \_\_\_\_\_



**Invitational Letter for Research Study from Family Physician to Caregiver**

Date:

Dear

*As the primary caregiver of one of my patients with severe or profound developmental disabilities, I am writing to invite you to participate in a Research Study.*

**Title: Patient Centered Primary Care of Adults with Severe and Profound Developmental Disabilities: The Patient – Physician Relationship**

**Principle Investigator: Dr. Katherine Stringer, Assistant Professor, Discipline of Family Medicine, Memorial University of Newfoundland.**

*Her research involves studying the patient-doctor relationship between patients with severe and profound developmental disabilities and their family physicians. People with developmental disabilities are vulnerable when they have to change from the pediatric care system to the adult health care system. This research aims to help Family Physicians in providing ongoing care to these adult patients by learning more about how to develop successful patient – physician relationships with adults with severe and profound developmental disabilities.*

*Dr. Stringer would like to interview both caregivers and family physicians of these patients. It will mean giving up one hour of your time to be interviewed by her.*

*I have enclosed some detailed information regarding this study as well as a consent form should you wish to participate.*

*If you wish to participate or have any questions, please contact Dr. Katherine Stringer at the Ross Family Medicine Clinic, ph [REDACTED] or email [REDACTED]*

Sincerely,

Dr. \_\_\_\_\_

**Patient Centered Primary Care of Adults with Severe and Profound Developmental Disabilities: the Patient-Physician Relationship**

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October 15, 2014

## Appendix D: Introductory Letter



### Introductory Letter

Date

Dear

Research Study: Patient Centered Primary Care of Adults with Severe and Profound Developmental Disabilities: The Patient - Doctor Relationship

INVESTIGATOR(S): Katherine Stringer, Bridget Ryan, Amanda Terry

Thank you for considering to participate in the above study.

People with developmental disabilities are especially vulnerable when they have to change from the pediatric health care system to the adult one. Some of these patient's parents have said that they would rather their children stayed with their pediatrician that they know. Unfortunately this is not possible forever, although sometimes these patients are cared for in the pediatric system much later than the usual age of changing to adult care. (In Newfoundland this is age 18 years)

While we don't have any real information on who actually organizes and provides care for adults with developmental disabilities, we assume that family physicians would be the most available health care providers for this.

Being able to provide good continuous care and forming longstanding relationships with patients is very important to family physicians. Providing this care and developing these relationships with patients with severe developmental disabilities may not always be easy. Little is known of how this relationship develops or whether it affects the patient, the doctor or how care is provided.

We would like therefore to conduct further research to examine the various aspects of the relationship that people with severe developmental disabilities have with their family physicians. We hope to share this knowledge with family physicians and local health authorities to help those involved develop meaningful relationships with, and care for, more of these patients

Version date: October 15 2014

## Appendix E: Consent–Caregiver

HRIR Version June 2014



### Consent to Take Part in Research

**TITLE:**

Patient Centered Primary Care of Adults with Severe and Profound Developmental Disabilities: The Patient – Doctor Relationship

**INVESTIGATOR(S):**

Katherine Stringer, Bridget Ryan, Amanda Terry

You have been invited to take part in a research study. Taking part in this study is voluntary. It is up to you to decide whether to be in the study or not. You can decide not to take part in the study. If you decide to take part, you are free to leave at any time. This will not affect your usual health care or status as health care professional. Your specific viewpoints expressed in the interview will not be shared with those in the health care system. Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explains the study.

Please read this carefully. Take as much time as you like. Mark anything you do not understand, or want explained better. After you have read it, please ask questions about anything that is not clear.

The researchers will:

- discuss the study with you
- answer your questions
- keep confidential any information which could identify you personally
- be available during the study to deal with problems and answer questions

**1. Introduction/Background:**

People with developmental disabilities are especially vulnerable when they have to change from a very organized and specialized pediatric health care system to a more fragmented adult one. Some of these patient's parents have said that they would rather their children stayed with their pediatrician. Unfortunately this is not possible forever, although in reality these patients are often cared for by the paediatric system beyond the age of usual transition to adult care.

While we don't have any formal data on who actually coordinates and provides care for adults with developmental disabilities, we assume that family physicians would be the most available health care providers for this.

Being able to provide good continuous and coordinated care and the resultant relationship that develops from this is very important to family physicians. Providing this care and developing these particular

Version date: October 15, 2014

Patient Centered Primary Care of Adults with Severe and Profound Developmental Disabilities: the Patient-Doctor Relationship

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Subject's Initials: \_\_\_\_\_

relationships may not always be easy. Little is known of how this relationship develops or whether it affects the patient, the physician or how care is provided.

We would like therefore to conduct further research to examine the unique circumstances surrounding the relationship of people with severe and profound developmental disabilities and their family physicians. We hope to share this knowledge with family physicians and local health authorities to assist in developing relationships with, and providing continuous coordinated care to these patients.

**2. Purpose of study:**

The purpose of this study is to examine the development of patient –physician relationship between patients with severe and profound developmental disabilities and their family physicians. This will be done through interviews with family physicians and caregivers of adult patients with severe and profound developmental disabilities.

**3. Description of the study procedures:**

You will be invited to participate in a 1 hour one-one interview with the principle investigator, Dr Katherine Stringer. This can take place at either your place of work or home or the clinic of Dr Katherine Stringer, whichever is more convenient for you. If this is not possible, you will be offered a telephone interview. All interviews will be audio recorded. The results of all interviews will be analyzed by the research team.

**4. Length of time:**

You will be expected to participate in a 1 hour interview.

**5. Possible risks and discomforts:**

**Risks:** Should you feel in any way emotionally distressed by the interview, the principle investigator conducting the interview will explore ways to provide further support to you in this regard.

**Discomfort:** There are no known discomforts for participation in this study

**Inconveniences:** Committed time to participate in the interview.

**6. Benefits:**

It is not known whether this study will benefit you.

**7. Liability statement:**

Signing this form gives us your consent to be in this study. It tells us that you understand the information about the research study. When you sign this form, you do not give up your legal rights. Researchers or agencies involved in this research study still have their legal and professional responsibilities.

**8. What about my privacy and confidentiality?**

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Patient Centred Primary Care of Adults with Severe and Profound Developmental Disabilities: the Patient-Doctor Relationship

Protecting your privacy is an important part of this study. Every effort to protect your privacy will be made. However it cannot be guaranteed. For example we may be required by law to allow access to research records

When you sign this consent form you give us permission to

- Collect information from you
- Share information with the people conducting the study
- Share information with the people responsible for protecting your safety

Access to records

Only the primary investigator will see study records that identify you by name. Other people may need to look at the study records that identify you by name. This might include the research ethics board. You may ask to see the list of these people. They can look at your records only when supervised by a member of the research team.

Use of your study information

The research team will collect and use only the information they need for this research study.

This information will include your

- Age
- Sex
- Level of education/specialized training
- Relationship with person with severe or profound developmental disabilities eg. friend, family, physician
- Duration of experience in caring for clients/patient with severe and profound developmental disabilities
- Primary place of caring for your client/patient eg home/clinic
- Information from study interviews

Your name and contact information will be kept secure by the research team in Newfoundland and Labrador. It will not be shared with others without your permission. Your name will not appear in any report or article published as a result of this study.

Information collected for this study will be kept for five years.

If you decide to withdraw from the study, the information collected up to that time will continue to be used by the research team. It may not be removed. This information will only be used for the purposes of this study.

Information collected and used by the research team will be stored in a locked cabinet in the office of Dr Katherine Stringer, [REDACTED]

[REDACTED] Katherine Stringer is the person responsible for keeping it secure

Version date: October 15, 2014

Patient-Centered Primary Care of Adults with Severe and Profound Developmental Disabilities: the Patient-Doctor Relationship

**Your access to records**

You may ask Dr Katherine Stringer to see the information that has been collected about you.

**9. Questions or problems:**

If you have any questions about taking part in this study, you can meet with the investigator who is in charge of the study at this institution. That person is: Dr Katherine Stringer

**Principal Investigator's Name and Phone Number:**

Katherine Stringer [REDACTED]

Or you can talk to someone who is not involved with the study at all, but can advise you on your rights as a participant in a research study. This person can be reached through:

Ethics Office  
Health Research Ethics Authority  
709-777-6974 or by email at [info@hrea.ca](mailto:info@hrea.ca)

**After signing this consent you will be given a copy.**

Version date: October 15, 2014

Patient Centred Primary Care of Adults with Severe and Profound Developmental Disabilities: the Patient-Doctor Relationship

→

Subject's Initials: \_\_\_\_\_

## Signature Page

Study title: \_\_\_\_\_

Name of principal investigator: \_\_\_\_\_

To be filled out and signed by the participant:

	Please check as appropriate:	
I have read the consent and information sheet.	Yes ( )	No ( )
I have had the opportunity to ask questions/to discuss this study.	Yes ( )	No ( )
I have received satisfactory answers to all of my questions.	Yes ( )	No ( )
I have received enough information about the study.	Yes ( )	No ( )
I have spoken to Dr. Katherine Stricker and he/she has answered my questions.	Yes ( )	No ( )
I understand that I am free to withdraw from the study	Yes ( )	No ( )
<ul style="list-style-type: none"> <li>• at any time</li> <li>• without having to give a reason</li> <li>• without affecting my future care or professional status</li> </ul>		
I understand that it is my choice to be in the study and that I may not benefit.	Yes ( )	No ( )
I understand how my privacy is protected and my records kept confidential	Yes ( )	No ( )
I agree to be audio taped	Yes ( )	No ( )
I agree to take part in this study.	Yes ( )	No ( )

\_\_\_\_\_  
Signature of participant                      Name printed                      Year Month Day

\_\_\_\_\_  
Signature of person authorized as                      Name printed                      Year Month Day  
Substitute decision maker, if applicable

**To be signed by the investigator or person obtaining consent**

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

\_\_\_\_\_  
Signature of investigator                      Name printed                      Year Month Day

Telephone number: \_\_\_\_\_

Version date: October 15, 2014

Patient-Centered Primary Care of Adults with Severe and Profound Developmental Disabilities: the Patient-Doctor Relationship



## Appendix F: Consent–Substitute Decision-Maker

HR088 Version June 2014



### Consent to Take Part in Research – Substitute Decision Maker

**TITLE:**

Patient Centered Primary Care of Adults with Severe and Profound Developmental Disabilities: The Patient – Doctor Relationship

**INVESTIGATOR(S):**

Katherine Stringer, Bridget Ryan, Amanda Terry

You have been identified as the substitute decision maker of a patient with developmental disabilities. The primary care giver of this patient has been invited to take part in a research study. Taking part in this study is voluntary. Although the patient will not be interviewed, their caregiver who attends the family physician visits with them, will be asked for information related to their patient doctor relationship. It is up to you to decide whether we may interview the caregiver or not. You can decide not to take part in the study. If you decide to take part, you are free to change your mind at any time. This will not affect the usual health care of the patient. The specific viewpoints of the caregiver expressed in the interview will not be shared with those in the health care system. Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explains the study.

Please read this carefully. Take as much time as you like. Mark anything you do not understand, or want explained better. After you have read it, please ask questions about anything that is not clear.

The researchers will:

- discuss the study with you
- answer your questions
- keep confidential any information which could identify you personally
- be available during the study to deal with problems and answer questions

**1. Introduction/Background:**

People with developmental disabilities are especially vulnerable when they have to change from a very organized and specialized pediatric health care system to a more fragmented adult one. Some of these patient's parents have said that they would rather their children stayed with their pediatrician. Unfortunately this is not possible forever, although in reality these patients are often cared for by the paediatric system beyond the age of usual transition to adult care.

While we don't have any formal data on who actually coordinates and provides care for adults with developmental disabilities, we assume that family physicians would be the most available health care providers for this.

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Patient Centered Primary Care of Adults with Severe and Profound Developmental Disabilities: the Patient-Doctor Relationship

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Subject's Initials: \_\_\_\_\_

Being able to provide good continuous and coordinated care and the resultant relationship that develops from this is very important to family physicians. Providing this care and developing these particular relationships may not always be easy. Little is known of how this relationship develops or whether it affects the patient, the physician or how care is provided.

We would like therefore to conduct further research to examine the unique circumstances surrounding the relationship of people with severe and profound developmental disabilities and their family physicians. We hope to share this knowledge with family physicians and local health authorities to assist in developing relationships with, and providing continuous coordinated care to these patients.

**2. Purpose of study:**

The purpose of this study is to examine the development of patient –doctor relationship between patients with severe and profound developmental disabilities and their family physicians. This will be done through interviews with family physicians and caregivers of adult patients with severe and profound developmental disabilities.

**3. Description of the study procedures:**

The caregivers and family physicians will be invited to participate in a 1 hour one-one interview with the principle investigator, Dr Katherine Stringer. Those on the Avalon Peninsula will be offered an in person interview which can take place at either their place of work or home or the clinic of Dr Katherine Stringer, whichever is more convenient. If this is not possible, they will be offered a telephone interview. Those further away will be offered a telephonic interview. All interviews will be audio recorded. The results of all interviews will be analyzed by the research team.

**4. Length of time:**

They will be expected to participate in a 1 hour interview.

**5. Possible risks and discomforts:**

**Risks:** There are no identified risks for the patient or substitute decision maker in this study. Should a caregiver feel in any way emotionally distressed by the interview, the principle investigator conducting the interview will explore ways to provide further support in this regard.

**Discomforts:** There are no known discomforts for participation in this study

**Inconveniences:** Committed time to participate in the interview

**6. Benefits:**

It is not known whether this study will benefit you.

**7. Liability statement:**

Signing this form gives us your consent to be in this study. It tells us that you understand the information about the research study. When you sign this form, you do not give up your legal rights.

Version date: October 15, 2014

Patient Centred Primary Care of Adults with Severe and Profound Developmental Disabilities: the Patient-Doctor Relationship

Researchers or agencies involved in this research study still have their legal and professional responsibilities.

### 8. What about my privacy and confidentiality?

Protecting your privacy is an important part of this study. Every effort to protect your privacy will be made. However it cannot be guaranteed. For example we may be required by law to allow access to research records (not health records/charts).

When you sign this consent form you give us permission to

- Collect information from the primary caregiver
- Share information with the people conducting the study
- Share information with the people responsible for protecting your safety

#### Access to records

Only the primary investigator will see study records that identify you by name.

Other people may need to look at the study records that identify you by name. This might include the research ethics board. You may ask to see the list of these people. They can look at your records only when supervised by a member of the research team.

#### Use of the primary caregiver's study information

The research team will collect and use only the information they need for this research study.

This information will include information about the relationship between the physician and the patient with severe developmental disabilities from the eyes of the both the physician and the primary care giver, such as:

- Relationship with person with severe or profound developmental disabilities eg. friend, family, physician
- Duration of experience in caring for clients/patient with severe and profound developmental disabilities
- Primary place of caring for your client/patient eg home/clinic
- Information from study interviews

Your name and contact information will be kept secure by the research team in Newfoundland and Labrador. It will not be shared with others without your permission. Your name will not appear in any report or article published as a result of this study.

Information collected for this study will be kept for five years.

If you decide to withdraw from the study, the information collected up to that time will continue to be used by the research team. It may not be removed. This information will only be used for the purposes of this study.

Version date: October 15, 2014

Patient Centred Primary Care of Adults with Severe and Profound Developmental Disabilities: the Patient-Doctor Relationship

Information collected and used by the research team will be stored in a locked cabinet in the office of Dr Katherine Stringer. [REDACTED]  
 [REDACTED] Katherine Stringer is the person responsible for keeping it secure

Your access to records

You may ask Dr Katherine Stringer to see the information that has been collected about you.

**9. Questions or problems:**

If you have any questions about taking part in this study, you can meet with the investigator who is in charge of the study at this institution. That person is: Dr Katherine Stringer

Principal Investigator's Name and Phone Number:

Katherine Stringer: [REDACTED]

Or you can talk to someone who is not involved with the study at all, but can advise you on your rights as a participant in a research study. This person can be reached through:

Ethics Office  
 Health Research Ethics Authority  
 709-777-6974 or by email at [info@hrea.ca](mailto:info@hrea.ca)

After signing this consent you will be given a copy.

Version date: October 15, 2014

Patient Centred Primary Care of Adults with Severe and Profound Developmental Disabilities: the Patient-Doctor Relationship

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Subject's Initials: \_\_\_\_\_

**Signature Page**

Study title: \_\_\_\_\_

Name of principal investigator: \_\_\_\_\_

To be filled out and signed by the participant:

	Please check as appropriate:	
I have read the consent and information sheet.	Yes ( )	No ( )
I have had the opportunity to ask questions/to discuss this study.	Yes ( )	No ( )
I have received satisfactory answers to all of my questions.	Yes ( )	No ( )
I have received enough information about the study.	Yes ( )	No ( )
I have spoken to Dr. Katherine Stricker and he/she has answered my questions.	Yes ( )	No ( )
I understand that I am free to withdraw from the study	Yes ( )	No ( )
• at any time		
• without having to give a reason		
• without affecting my future care or professional status		
I understand that it is my choice to be in the study and that I may not benefit.	Yes ( )	No ( )
I understand how my privacy is protected and my records kept confidential	Yes ( )	No ( )
I agree to be audio taped	Yes ( )	No ( )
I agree to take part in this study.	Yes ( )	No ( )

\_\_\_\_\_  
Signature of participant                      Name printed                      Year Month Day

\_\_\_\_\_  
Signature of person authorized as                      Name printed                      Year Month Day  
Substitute decision maker, if applicable

**To be signed by the investigator or person obtaining consent**

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

\_\_\_\_\_  
Signature of investigator                      Name printed                      Year Month Day

Telephone number: \_\_\_\_\_

Version date: October 15, 2014

Patient-Centered Primary Care of Adults with Severe and Profound Developmental Disabilities: the Patient-Doctor Relationship

## Appendix G: Ethics Approval and Renewal



Ethics Office  
Suite 209, Eastern Trust Building  
66 Bonaventure Avenue  
St. John's, NL  
A2B 2X3

November 21, 2014

Dr Katherine Stringer  
Discipline of Family Medicine  
Memorial University



Dear Dr Stringer:

Reference #14.218

RE: Patient-Centered Primary Care of Adults with Severe and Profound Developmental Disabilities: The Patient-Doctor Relationship

This will acknowledge receipt of your correspondence.

This correspondence has been reviewed by the Chair under the direction of the Board. *Full Board approval of this research study is granted for one year effective October 30, 2014.*

This is to confirm that the Health Research Ethics Board reviewed and approved or acknowledged the following documents (as indicated):

- Application, approved
- Introductory letter, approved
- Invitational letter, approved
- Revised consent form, dated October 15, 2014, approved
- Semi-structured Interview Guide, approved

### MARK THE DATE

**This approval will lapse on October 30, 2015. It is your responsibility to ensure that the Ethics Renewal form is forwarded to the HREB office prior to the renewal date; you may not receive a reminder, therefore the ultimate responsibility is with you as the Principle Investigator. The information provided to this form must be current to the time of submission and submitted to HREB not less than 20 nor more than 45 days of the anniversary of your approval date. The Ethics Renewal form can be downloaded from the HREB website: <http://www.hrea.ca>.**

**The Health Research Ethics Board advises THAT IF YOU DO NOT return the completed Ethics Renewal form prior to date of renewal:**

- Your ethics approval will lapse

email: [info@hrea.ca](mailto:info@hrea.ca)

Phone: 777-6974

FAX: 777-8776

- You will be required to stop research activity immediately
- You may not be permitted to restart the study until you reapply for and receive approval to undertake the study again

*Lapse to ethics approval may result in interruption or termination of funding*

It is your responsibility to seek the necessary approval from the Regional Health Authority or other organization as appropriate. You are also solely responsible for providing a copy of this letter, along with your application form, to the Office of Research Services should your research depend on funding administered through that office.

Modifications of the protocol/consent are not permitted without prior approval from the Health Research Ethics Board. Implementing changes in the protocol/consent without HREB approval may result in the approval of your research study being revoked, necessitating cessation of all related research activity. Request for modification to the protocol/consent must be outlined on an amendment form (available on the HREB website) and submitted to the HREB for review.

This research ethics board (the HREB) has reviewed and approved the research protocol and documentation as noted above for the study which is to be conducted by you as the qualified investigator named above at the specified site. This approval and the views of this Research Ethics Board have been documented in writing. In addition, please be advised that the Health Research Ethics Board currently operates according to *Trial Council Policy Statement: Ethical Considerations for Research Involving Humans; ICH Guidance for Good Clinical Practice* and applicable laws and regulations. The membership of this research ethics board is constituted in compliance with the membership requirements for research ethics boards as defined by *Health Canada Food and Drug Regulations Division 1; Part C*.

Notwithstanding the approval of the HREB, the primary responsibility for the ethical conduct of the investigation remains with you.

We wish you every success with your study.

Sincerely,



Dr. Fern Bringer, PhD (Chair Non-Clinical Trials)  
Ms. Patricia Craigen, (Vice-Chair Non-Clinical Trials)  
Health Research Ethics Board

For office use only: Nov 21, 2014

RECEIVED NOV 13 2015

May 2015

**Request For Ethics Renewal / Study Closure**

- The Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2) (2008) (article 6.14) requires ongoing review by the approving REB at least on an annual basis. The information provided in this form must be current to the date of submission and submitted to the REB not less than 30 days nor more than 45 days before the anniversary of your approval date.
- Ethics approval is required if there is ongoing subject contact or data collection/transfer to ethics.
- Ethics approval is not required and the file may be closed if the project is in analysis or the writing stage.
- Please forward a summary of findings or published abstract to the REB Office once the study is complete.
- Incomplete forms will not be accepted and may result in delay in the review and approval process.

IRB file number: 14-218	Expires Date of Current Approval: <b>October 30, 2015</b>
Principal Investigator: <b>Stéphane Lévesque</b>	
Title of study (with Protocol Number if applicable): <b>Patient-Centered Primary Care of Adults with Severe and Profound Development Disabilities: The Patient-Director Relationship</b>	
Site of IRB: [REDACTED]	Site of Key Center: [REDACTED]

First choice item:		
<input checked="" type="checkbox"/>	Form requesting renewal of ethics approval for this file.	X
<input type="checkbox"/>	Form requesting to close this file.	[REDACTED]

**Catherine Stanger** \_\_\_\_\_ **November 9, 2015**  
 Name (last or printed) \_\_\_\_\_ Date (MM/DD/YYYY)  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

**See REB Office Use Only**

This project was reviewed on **Nov 13, 2015** by **Paul Beard (Director)** | By **Stephan Lévesque**

ethics approval for this project has been granted for a period of 24 months effective from **Oct 30, 2015** to **Oct 30, 2016**

This requestable form is for the REB to record and approval for study which is to be conducted by you at the institution(s) identified on the form (IRB# 14-218). This approval and the status of this Requestable Form have been documented in writing. The Health Research Ethics Board system also reporting to the Council Policy Statement: Ethical Conduct for Research Involving Humans, 2008 (document 84) Good Clinical Practice (International guidelines and applicable laws and regulations). The membership of this research ethics board is also consistent with the requirements of the research ethics boards as defined by Health Canada Food and Drug Regulations (Section 9, Part C).

This file has been closed as requested

**APPROVED NOV 13 2015**



Sponsor Code: _____ ID#: _____			
<b>Recruitment/Data Collection</b>			
Has the study started?		Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>
If yes, please provide the following information as it applied to your project:			
	Total planned for this site	Total to date (if applicable)	N/A
A. Number of Participants enrolled	20	20	
B. Number of Health Records reviewed			0
C. Number of tissue samples collected			0
D. Number of surveys returned			0
If number lower than expected, why?			
<b>Consent Form</b>			
Does this project have a consent form?		Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>
If yes, Please give the date of the most recently approved consent form			

**Not Applicable | N/A |**

**For Clinical Trials Only** which are subject to RNI in Alberta Canada and required to report SAEs and SUSARs to the RNI  
**Serious Adverse Events (SAE's) Or Suspected Unconnected Serious Adverse Reactions (SUSARs)**

1. Since last Approval a. Have (Study) CRF reports been submitted to HRSD?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
2. Since Last Approval a. Has there been amendments to this protocol as a result of safety reports? If yes, please provide a list amendment dates	Yes <input type="checkbox"/>	No <input type="checkbox"/>
3. Since Last Approval a. Have you reported local SAE's? b. If yes, please provide number of local events: _____ c. If yes, please provide number of local SAE's related to study drug: _____	Yes <input type="checkbox"/>	No <input type="checkbox"/>
4. Since Last Approval a. Have you reported Deviations to the sponsor? b. If yes, please provide number of Deviations: _____	Yes <input type="checkbox"/>	No <input type="checkbox"/>
5. Since last Approval a. Have you requested rebids?	TRUE - 1 VIM Yes <input type="checkbox"/>	No <input type="checkbox"/>

After X000

6. If yes, please provide number of visitors: _____		
---	--	--

Not Applicable [ ]

<b>All Other Studies: Since Last Approval</b>		
Have there been unexpected events or problems related to participant risk since original approval or last ethics renewal?	Yes <input type="checkbox"/>	No <input checked="" type="checkbox"/>
1. Have there been amendments submitted for this project?	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>
Has the University's Model to be named a Research Facility on this project?		
If yes, please describe the events/problems/amendments - (Attach addendum to this form if necessary)		

All Studies - Status At Local Site (check all that apply)	YES	NO	N/A
1. Intervention/data collection active			<input checked="" type="checkbox"/>
2. Closed to recruitment/recruited			<input checked="" type="checkbox"/>
3. Participants in follow up			<input checked="" type="checkbox"/>
4. Site closed (if not local-site)			<input checked="" type="checkbox"/>
5. For secondary use of data only is Data Transfer Complete?			<input checked="" type="checkbox"/>

Knowledge Transfer	YES	NO	N/A
1. Have participants been informed of study findings?			<input checked="" type="checkbox"/>
2. Have findings been presented/published?			<input checked="" type="checkbox"/>
Please indicate where (date or addendum to this form if necessary)			

Not Applicable (N/A) [ ]

<b>For Study Closure:</b>	
1. Sponsor close out visit	Date: _____
2. Participants completed the study at this site	# _____
3. Data ready to be locked	Date: _____
4. Reason for closure	

Note: GCP requires a copy of the final report to be submitted to the Research Ethics Board  
 Additional Information:

## Appendix H: Consent–Family Physician

HREB Version: June 2014



### CHECKLIST

*This checklist is to be completed and submitted with this consent form.  
It is to be removed from the final version of the consent document.*

- x Most recent version of consent template (June 2014) has been used
- x Footer includes consent version, study name, line for patient initials
- x Font size no less than 12 (except for footer)
- x Left justification of text
- x Grade 9 or lower reading level. Assessed reading level is: \_\_\_\_\_ Grade 9 \_\_\_\_\_
- x Accepted definitions for specialized terms used where applicable
- x Plain language principles used for study specific wording – no jargon, no acronyms, short words, short sentences, active voice and, where appropriate, bulleted lists

Standard, required wording (in bold type) has been used in the following sections:

	Yes	No
Introduction	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Benefits (Q6)	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Liability Statement (Q7)	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Privacy and confidentiality (Q8)	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Questions or problem (Q9)	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Signature page	<input checked="" type="checkbox"/>	<input type="checkbox"/>

**If you have answered No to any of the above, please give the rationale for these changes below:**

TCPS2 guidelines provide a list of the information required for informed consent. Please refer to TCPS2, Chapter 3, available at: <http://www.ppe.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-qr/3/chapter3-chapitre3/>

The HREB Policy Manual provides detailed information on specific consent issues including: consent to research in emergency health situations; the use of substitute decision makers; assent for children; research involving special populations (children, cognitively impaired); managing consent in situations of difficult power relationships; and community consent to research involving Aboriginal communities. Please refer to [the HREB Policy Manual on the HREA website: www.hrea.ca](#)

Version date: October 15, 2014

Patient-Centered Primary Care of Adults with Severe and Profound Developmental Disabilities: the Patient-Doctor Relationship

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Subject's Initials: \_\_\_\_\_



## Consent to Take Part in Research – Family Physician

### TITLE:

Patient Centered Primary Care of Adults with Severe and Profound Developmental Disabilities: The Patient – Doctor Relationship

### INVESTIGATOR(S):

Katherine Stringer, Bridget Ryan, Amanda Terry

You have been invited to take part in a research study. Taking part in this study is voluntary. It is up to you to decide whether to be in the study or not. You can decide not to take part in the study. If you decide to take part, you are free to leave at any time. This will not affect your usual health care or status as health care professional. Your specific viewpoints expressed in the interview will not be shared with others in the health care system. Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explains the study.

Please read this carefully. Take as much time as you like. Mark anything you do not understand, or want explained better. After you have read it, please ask questions about anything that is not clear.

The researchers will:

- discuss the study with you
- answer your questions
- keep confidential any information which could identify you personally
- be available during the study to deal with problems and answer questions

### 1. Introduction/Background:

People with developmental disabilities (DD) are especially vulnerable after change of their health care from a highly coordinated and specialized paediatric system to a more fragmented and less specialized adult system. A recent study of patients changing from paediatric to adult care showed that parents of young people with profound intellectual and multiple disabilities valued the care provided by the paediatrician and wished to see it continued. This is not a sustainable solution although these patients are often cared for beyond the age of usual transition to adult care.

Information from the National Physician Survey does not include information on caring for this specific patient population. One might assume that family physicians, as the most common primary care providers in Newfoundland and Labrador, would be the most consistently available health care providers for people with developmental disabilities.

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Patient Centered Primary Care of Adults with Severe and Profound Developmental Disabilities: the Patient-Doctor Relationship

Continuity of care in the sense of the enduring patient doctor relationship is very important to the practice of family medicine. The development of this relationship and the provision of continuous, coordinated care to this unique group of people is not without its challenges. Little is known of the development of this relationship or whether it affects the patient, the doctor or the provision of care in this context.

The Developmental Disabilities Primary Care initiative in Ontario recently published guidelines for the primary care of adults with developmental disabilities to improve care and quality of life for these people. While very helpful, these guidelines are not always applicable to other areas in Canada and due to a lack of research are largely based on expert opinion.

The fact that not all areas in Canada have equal access to the same health care resources and the overall lack of research in this area, is why we need further research to examine the unique circumstances surrounding this patient – doctor relationship. We hope to provide family physicians and our local authorities guidance from this research on providing ongoing care in the form of a positive patient doctor relationship in this context.

## 2. Purpose of study:

The purpose of this study is to examine the development of patient –doctor relationship between patients with severe and profound developmental disabilities and their family physicians. This will be done through interviews with family physicians and caregivers of adult patients with severe and profound developmental disabilities.

## 3. Description of the study procedures:

You will be invited to participate in a 1 hour one-one interview with the principle investigator, Dr Katherine Stringer. For those of you on the Avalon Peninsula you will be offered either an in person which can take place at either at your place of work or home or the clinic of Dr Katherine Stringer, whichever is more convenient for you. If this is not possible, you will be offered a telephone interview. For those of you further away, you will be offered a telephonic interview. All interviews will be audio recorded. The results of all interviews will be analyzed by the research team.

## 4. Length of time:

You will be expected to participate in a 1 hour interview.

## 5. Possible risks and discomforts:

Risks: There are no identified risks for participation in this study.

Discomforts: There are no known discomforts for participation in this study

Inconveniences: Committed time to participate in the interview.

## 6. Benefits:

It is not known whether this study will benefit you.

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Patient Centred Primary Care of Adults with Severe and Profound Developmental Disabilities: the Patient-Doctor Relationship

#### 7. Liability statement:

Signing this form gives us your consent to be in this study. It tells us that you understand the information about the research study. When you sign this form, you do not give up your legal rights. Researchers or agencies involved in this research study still have their legal and professional responsibilities.

#### 8. What about my privacy and confidentiality?

Protecting your privacy is an important part of this study. Every effort to protect your privacy will be made. However it cannot be guaranteed. For example we may be required by law to allow access to research records

When you sign this consent form you give us permission to

- Collect information from you
- Share information with the people conducting the study
- Share information with the people responsible for protecting your safety

#### Access to records

Only the primary investigator will see study records that identify you by name.

Other people may need to look at the study records that identify you by name. This might include the research ethics board. You may ask to see the list of these people. They can look at your records only when supervised by a member of the research team.

#### Use of your study information

The research team will collect and use only the information they need for this research study.

This information will include your

- Sex
- Years of practice as a family physician
- Level of education/specialized training
- Relationship with person with severe or profound developmental disabilities eg. friend, family, physician
- Duration of experience in caring for patients with severe and profound developmental disabilities
- Primary place of caring for your client/patient eg home/clinic
- Information from study interviews

Your name and contact information will be kept secure by the research team in Newfoundland and Labrador. It will not be shared with others without your permission. Your name will not appear in any report or article published as a result of this study.

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Patient Centred Primary Care of Adults with Severe and Profound Developmental Disabilities: the Patient-Doctor Relationship

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Subject's Initials: \_\_\_\_\_

Information collected for this study will be kept for five years.

If you decide to withdraw from the study, the information collected up to that time will continue to be used by the research team. It may not be removed. This information will only be used for the purposes of this study.

Information collected and used by the research team will be stored in a locked cabinet in the office of Dr Katherine Stringer, [REDACTED]. Katherine Stringer is the person responsible for keeping it secure.

Your access to records

You may ask Dr Katherine Stringer to see the information that has been collected about you.

**9. Questions or problems:**

If you have any questions about taking part in this study, you can meet with the investigator who is in charge of the study at this institution. That person is: Dr Katherine Stringer

Principal Investigator's Name and Phone Number:

Katherine Stringer [REDACTED]

Or you can talk to someone who is not involved with the study at all, but can advise you on your rights as a participant in a research study. This person can be reached through:

Ethics Office  
Health Research Ethics Authority  
709-777-6974 or by email at [info@hrea.ca](mailto:info@hrea.ca)

After signing this consent you will be given a copy.

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Patient Centred Primary Care of Adults with Severe and Profound Developmental Disabilities: the Patient-Doctor Relationship

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Subject's Initials: \_\_\_\_\_

## Signature Page

Study title: \_\_\_\_\_

Name of principal investigator: \_\_\_\_\_

To be filled out and signed by the participant:

	Please check as appropriate:	
I have read the consent and information sheet.	Yes ( )	No ( )
I have had the opportunity to ask questions/to discuss this study.	Yes ( )	No ( )
I have received satisfactory answers to all of my questions.	Yes ( )	No ( )
I have received enough information about the study.	Yes ( )	No ( )
I have spoken to Dr. Katherine Stricker and he/she has answered my questions.	Yes ( )	No ( )
I understand that I am free to withdraw from the study	Yes ( )	No ( )
• at any time		
• without having to give a reason		
• without affecting my future care or professional status		
I understand that it is my choice to be in the study and that I may not benefit.	Yes ( )	No ( )
I understand how my privacy is protected and my records kept confidential	Yes ( )	No ( )
I agree to be audio taped	Yes ( )	No ( )
I agree to take part in this study.	Yes ( )	No ( )

\_\_\_\_\_  
Signature of participant                      Name printed                      Year Month Day

\_\_\_\_\_  
Signature of person authorized as                      Name printed                      Year Month Day  
Substitute decision maker, if applicable

**To be signed by the investigator or person obtaining consent**

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

\_\_\_\_\_  
Signature of investigator                      Name printed                      Year Month Day

Telephone number: \_\_\_\_\_

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Patient-Centered Primary Care of Adults with Severe and Profound Developmental Disabilities: the Patient-Doctor Relationship



## Appendix I: Interview Guide 2



### Semi-structured Interview Guide 2

Study title: Patient Centered Primary Care of Adults with Severe and Profound Developmental Disabilities: The Patient – Physician Relationship

Name of Principle Investigator: Katherine Stringer

#### Study 1 – Caregiver Interview Guide

##### Introduction

1. Before we get started, I would have some questions I would like to ask you for the study if that is okay? Please note that you may decline to answer any question you do not feel comfortable answering.
  - a. What is your age?
  - b. What is your sex?
  - c. What type of education have you received/Any specialized training in caregiving?
  - d. What is your relationship to the person you care for eg. family/friend/employee
  - e. Where to you provide the majority of your care to this person? Eg. private home/family home/group home
2. Is there anything else you would like to tell me a about yourself and your relationship with the person you care for?

##### Questions re patient – family physician relationship

1. Tell me a bit from your perspective as caregiver about the relationship between the person you care for and their family doctor
 

*(ask the following if not volunteered by participant)*

  - Duration of attending family physician appointments with the person they care for
  - **Are you as the caregiver included?**
2. Can you remember back to your initial experience of the relationship? Tell me a bit about it, what was it like?
  - a. Has this experience changed over time? How?

Patient Centered Primary Care of Adults with Severe and Profound Developmental Disabilities: the Patient-Doctor Relationship

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- b. What do you think has helped shape this process of change?
- c. Could you describe any number of things that have changed it for the better? **What do/did you like about any of the relationships you have experienced?**

Prompts if needed:

- i. Anything from the doctor or medical systems side?
- ii. Anything from your and the person you care for's side?
- iii. Anything from the community's side?
- d. Could you describe any things that have hindered or slowed or not allowed the relationship to develop and change? **What don't/didn't you like about any of the relationships you have experienced?**

Prompts if needed:

- i. Anything from the doctor or medical systems side?
  - ii. Anything from your and the person you care for's side?
  - iii. Anything from the community side?
- 3. Do you think this relationship is still changing? Where do you think it is going?
  - 4. Do you have any advice for caregivers, patients or family physicians on what makes for a successful relationship?

## Study 2 – Family Physicians Interview Guide

### Introduction

Before we get started, I would have some questions I would like to ask you for the study if that is okay? Please note that you may decline to answer any question you do not feel comfortable answering.

1. How many years have you been a family physician (since graduation)
2. How many years experience have you had dealing with adult patients with severe/profound DD?
3. Do you have any formal extra training in this area?
4. Approximately how many patients have you cared for that have severe/profound DD?

### Questions re patient – family physician relationship

1. Tell me a bit about your relationships with your patients with severe/profound DD
2. Can you remember back to your initial experience of these relationships? Tell me a bit about it, what was it like?
  - a. Has this experience changed over time? How?
  - b. What do you think has helped shape this process of change?
  - c. Could you describe any number of things that have changed it for the better?

*(Prompt: if needed)*

- i. Anything from the patient or caregiver's side?
- ii. Anything from your or the medical system's side?
- iii. Anything from the community's side?
- d. Could you describe any things that have hindered or slowed or not allowed the relationship to develop and change?

*(Prompt: if needed)*

- i. Anything from the patient or caregiver's side?
- ii. Anything from your or the medical system's side?
- iii. Anything from the community's side?
3. Do you think this relationship is still changing/developing? Where do you think it is going, does it have a trajectory?
4. Do you have any advice for caregivers, patients or family physicians on what makes for a successful relationship?

## Appendix J: Interview Guide 3



### Semi-structured Interview Guide 3

**Study title:** Patient Centered Primary Care of Adults with Severe and Profound Developmental Disabilities: The Patient – Physician Relationship

**Name of Principle Investigator:** Katherine Stringer

#### Study 1 – Caregiver Interview Guide

##### Introduction

1. Before we get started, I would have some questions I would like to ask you for the study if that is okay? Please note that you may decline to answer any question you do not feel comfortable answering.
  - a. What is your age?
  - b. What is your sex?
  - c. What type of education have you received/Any specialized training in caregiving?
  - d. What is your relationship to the person you care for eg. family/friend/employee
  - e. Where to you provide the majority of your care to this person? Eg. private home/family home/group home
2. Is there anything else you would like to tell me a about yourself and your relationship with the person you care for?

##### Questions re patient – family physician relationship

1. Tell me a bit from your perspective as caregiver about the relationship between the person you care for and their family doctor
 

*(ask the following if not volunteered by participant)*

  - Duration of attending family physician appointments with the person they care for
2. Can you remember back to your initial experience of the relationship? Tell me a bit about it, what was it like?
  - a. Has this experience changed over time? How?
  - b. What do your think has helped shape this process of change?

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- c. Could you describe any number of things that have changed it for the better?

Prompts if needed:

- i. Anything from the doctor or medical systems side?
  - ii. Anything from your and the person you care for's side?
  - iii. Anything from the community's side?
- d. Could you describe any things that have hindered or slowed or not allowed the relationship to develop and change?

Prompts if needed:

- i. Anything from the doctor or medical systems side?
  - ii. Anything from your and the person you care for's side?
  - iii. Anything from the community side?
3. Do you think this relationship is still changing? Where do you think it is going?
4. Do you have any advice for caregivers, patients or family physicians on what makes for a successful relationship?

## Study 2 – Family Physicians Interview Guide

### Introduction

Before we get started, I would have some questions I would like to ask you for the study if that is okay? Please note that you may decline to answer any question you do not feel comfortable answering.

1. How many years have you been a family physician (since graduation)
2. How many years experience have you had dealing with adult patients with severe/profound DD?
3. Do you have any formal extra training in this area?
4. Approximately how many patients have you cared for that have severe/profound DD?

### Questions re patient – family physician relationship

1. Tell me a bit about your relationships with your patients with severe/profound DD

*(Prompt if needed)*

- a. How does it differ from patients without DD?
2. Can you remember back to your initial experience of these relationships? Tell me a bit about it, what was it like?
  - a. Has this experience changed over time? How?
  - b. What do you think has helped shape this process of change?
  - c. Could you describe any number of things that have changed it for the better?

*(Prompts if needed)*

- i. Anything from the patient or caregiver's side?
- ii. Anything from your or the medical system's side?
- iii. Anything from the community's side?
- d. Could you describe any things that have hindered or slowed or not allowed the relationship to develop and change?

*(Prompts if needed)*

- i. Anything from the patient or caregiver's side?
- ii. Anything from your or the medical system's side?
- iii. Anything from the community's side?
3. What role does trust play?
4. Is there anything you have to look out for/prepare for?

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5. *Any aspects you struggle with? What makes it easier/more difficult than your patients without DD?*

*(Prompt when needed)*

- a. *Is there a relationship?*
  - b. *Ever feel overwhelmed or ill prepared?*
  - c. *Most challenging relationship?*
  - d. *Do you feel fulfilled? How are your needs met?*
6. *Do you think this relationship is still changing/developing? Where do you think it is going, does it have a trajectory?*
  7. *Do you have any advice for caregivers, patients or family physicians on what makes for a successful relationship?*

## Curriculum Vitae

Katherine Stringer, MBChB, CCFP, FCFP

DISCIPLINE OF FAMILY MEDICINE

MEMORIAL UNIVERSITY OF NEWFOUNDLAND

### **PERSONAL INFORMATION**

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Citizenship: Canadian and South African

### **CURRENT PROFESSIONAL STATUS**

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#### ACADEMIC:

2015–present Associate Professor, Discipline of Family Medicine, MUN

#### CLINICAL:

2009–present Family Practice, Ross Family Medicine Centre, Miller Centre, St. John's NL

### **PROFESSIONAL APPOINTMENTS/MEMBERSHIPS**

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#### Current:

- Medical Staff, Eastern Health, Newfoundland, Canada
- College of Family Physicians of Canada (National) – Section of Teachers and Chair of Family Medicine Group, committee member.
- College of Family Physicians of Canada – NL Chapter, committee member
- Canadian Undergraduate Family Medicine Education Directors
- Canadian Medical Association
- Newfoundland and Labrador Medical Association

### **ACADEMIC APPOINTMENTS**

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2009–2015 Assistant Professor, Discipline of Family Medicine, MUN, St. John's NL

2015–present Associate Professor, Discipline of Family Medicine, MUN, St. John's NL

### **ADMINISTRATIVE APPOINTMENTS**

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2016–present Chair, Discipline of Family Medicine, Faculty of Medicine, MUN

2014–2016 Phase 4 (Clerkship) Lead, UGME curriculum, Faculty of Medicine, MUN



2013–2016	Chair Clerkship Committee, Faculty of Medicine, MUN
2013–2015	Chair Community Engagement 2 and 3 Courses, Faculty of Medicine, MUN
2011–2014	Chair Family Medicine Black Bag, Faculty of Medicine, MUN
2012–2013	Interim Family Medicine Clerkship Coordinator, Faculty of Medicine, MUN
2009–2011	Faculty Liaison, Family Medicine Interest Group (FMIG), Faculty of Medicine, MUN

## **EDUCATION**

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MCIS FM	Masters in Clinical Sciences (Family Medicine), Schulich School of Medicine and Dentistry, Western University, Ontario, Canada) IN PROGRESS
FCFP	Fellow, College of Family Physicians of Canada, 2016
CCFP	Certificate, College of Family Physicians of Canada, 2004
LMCC I &II	Licentiate of the Medical Council of Canada 2003
DMH	Diploma in Mental Health, College of Medicine of South Africa 2001
DIP OBST	Diploma in Obstetrics, College of Medicine of South Africa 1998
DCH	Diploma in Child Health, College of Medicine of South Africa 1998
MBChB	University of Cape Town, South Africa 1994

## **HONORS & AWARDS**

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### **POSTGRADUATE:**

2016	Wallace Ingram Research Award, Faculty of Medicine, MUN
2014	Nomination Dr. Yong Kee Jeon Award in Family Medicine
2010	Nomination Family Medicine Residents Teachers Award
2011	Family Medicine Research Faculty Scholarship
2011	MUN Medical Research Fund Development Award

**MEDICAL SCHOOL:**

1989            University of Cape Town, South Africa, entrance Scholarship

**TEACHING EXPERIENCE**

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**UNDERGRADUATE MEDICAL EDUCATION:**

2009–present    Involvement in numerous aspects of pre-clerkship and clerkship medical education including curriculum development, new course innovation, regular lecturing, tutoring, mentoring, examining from 1<sup>st</sup> to 4<sup>th</sup> year medical school, Faculty of Medicine, MUN.

**POSTGRADUATE FAMILY MEDICINE:**

2009–present    Involvement in numerous aspects of post graduate medical education including curriculum development, teaching, tutoring, clinical preceptorship, group facilitation and examination.

**CONTINUING PROFESSIONAL DEVELOPMENT:**

2010 – present    Involvement in numerous aspects of CPD in NL and across Canada including plenary presentations on medical education, workshop facilitation and resource development,

**SCHOLARSHIP OF DISCOVERY**

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**Grants Awarded**

2016            MUN Wallace Ingram Research Award \$6,000

Title: An Evaluation Study of an Entrustable Professional Activities (EPAs) Assessment System in Undergraduate Medical Education.

2011            MUN Medical Research Fund Development Award \$10,000

Title: Home visits–Optimizing Medical Care in the Elderly (HOME Study). A pilot study on the effects of an interprofessional primary care program on emergency room visits and hospital admissions in the frail elderly.

**Publications**

2014            Dillon CM, Genge T, Mahoney j, Conway A, **Stringer K**. Prevalence of Medication Management by Community Pharmacists in Patients of a Newfoundland Family Medicine Clinic. Can Pharm J (Ott). 2014 May;147(3):154-8. Doi: 10.177/1715163514528869. PMID: 24847367

- 2013        **Stringer K**, Curran V, Asghari S, Pharmacists and family physicians: improving interprofessional collaboration through joint understanding of our competencies. *Front Pharmacol*, 05 December 2013.  
doi:10.3389/fphar.2013.00151
- 2012        **Katherine Stringer**, Narrative “Lake Louise Eyes”, Stories in Family Medicine, College of Family Physicians of Canada,  
<http://www.cfpc.ca/ProjectAssets/Templates/Resource.aspx?id=5081>

### Papers Presented

- 2016    Patient – Physician Relationship in Adult Patients with Severe or Profound Developmental Disabilities – Study One, Family Medicine Forum (FMF), Vancouver, BC
- 2016    Patient – Physician Relationship in Adult Patients with Severe or Profound Developmental Disabilities – Study One PriFor: Primary Health Care Research Forum, St. John’s, NL
- 2016    Memorial’s experience of using the AAMC’s Core EPAs for Entering Residency in Clerkship/Phase 4. New Brunswick Medical Education Forum
- 2012    Health Care of the Elderly Networking Breakfast, “House Calls: Anachronism of the Future, reference no. 3127131, FMF, Toronto
- Ten Practice Pearls for Improved Pharmacological Care of the Elderly in Long Term Care, reference no. 3093227, FMF, Toronto
- 

### Poster Presentations

- 2010-present    Presentations at International, National and local conferences including clinical and medical education topics.

### Research in Progress

- 2012–present    **Katherine Stringer**, Vernon Curran, Shabnam Asghari, Danielle O’Keefe, Carla Dillon. Exploring Pharmacists’ Expectations of the Competent Family Physician.
- 2013–present    Chafe, Gibson, McBride, **Stringer**, et al. Improving the transition from pediatric to adult care for childhood cancer survivors.
- 2013–present    **Katherine Stringer**, Bridget Ryan, Amanda Terry. Patient Centered Primary Care of Adults with Severe and Profound Developmental Disabilities: The patient–doctor relationship
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- 2014-present Rourke, Harris, Walsh, Hippe, **Stringer**, et al. From Pipelines to Pathways: The Memorial Experience in Educating Doctors for Rural Generalist Practice.
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