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Alexandra Bonardi
University of Massachusetts Medical School

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The Balance between Choice and Control: Risk Management in New Zealand Intellectual Disability Services

Prepared by
Alixe Bonardi

July 2009

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Ian Axford (New Zealand) Fellowships in Public Policy were named in honour of Sir Ian Axford, an eminent New Zealand astrophysicist and space scientist who is patron of the fellowship programme.

Since his education in New Zealand and England, Sir Ian has held Professorships at Cornell University and the University of California, and was Vice-Chancellor of Victoria University of Wellington for three years. For many years, Sir Ian was director of the Max Planck Institute for Aeronomy in Germany, where he was involved in the planning of several space missions, including those of the Voyager planetary explorers, the Giotto space probe and the Ulysses galaxy explorer.

Sir Ian is recognised as one of the great thinkers and communicators in the world of space science, and is a highly respected and influential administrator. A recipient of numerous science awards, he was knighted and named New Zealander of the Year in 1995.

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Fellows are based at a host institution and carefully partnered with a leading specialist who will act as a mentor. In addition, fellows spend a substantial part of their time in contact with relevant organisations outside their host institutions, to gain practical experience in their fields.

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ACKNOWLEDGEMENTS

EXECUTIVE SUMMARY

Support for people with intellectual disability (ID) in New Zealand has been through great changes in the past 20 years, many of them positive and driven by a vision for real participation in the community for all New Zealanders.[1] Movement from a service model of institutional care to a model that supports community participation, flexibility, and choice has been steady and in many cases has shown positive change in people's lives.[2] There is growing concern, however that the pace of progress has slowed, and that people with intellectual disabilities continue to experience barriers to living an 'ordinary' life[3] in New Zealand.

Approximately 17% of New Zealanders report that they have a disability, of which 5% (33,700) have an intellectual disability.[4] The Ministry of Health is responsible for strategic planning and funding needs assessment and disability support for adults with disability, including approximately 6,500 people with intellectual disability who require 24 hour residential support. Studies completed in New Zealand, as well as international studies, suggest that people with intellectual disability experience greater vulnerability to poor health outcomes, higher behavioural support needs, and are at greater risk of abuse or neglect, compared to the general population.[5,6]

Examining Risk

This report examines the approach to risk management in New Zealand, particularly in the context of services for people with intellectual disability. It reviews the development of the philosophy of service provision to provide necessary background, followed by an analysis of how risk management is perceived and applied by a number of stakeholders, including people with intellectual disability and their families. Both individual and systems level risk is explored.

Risk is a concept that is closely associated with the balance between individual choice and the controls that may be imposed by the supports system. In the context of support planning and delivery, there are many areas in which risk is a consideration either explicitly or implicitly. These include:

- clinical interpretation of risk,

- accountability demands,

- occupational health and safety requirements,

- contractual obligations to 'manage risk',

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[1] New Zealand received the Franklin Delano Roosevelt International Disability Award on 6 May 2008. The award was presented by Ban Ki-Moon, secretary general of the UN who commended New Zealand's leadership in the international community and praised New Zealand's deep commitment to disability issues domestically. UN News Center: Remarks at the Presentation of the Franklin Delano Roosevelt International Disability Award 6 May 2008. www.un.org

[2] Milner, P., Donald Beasley Institute (2008), p. 177

[3] National Advisory Committee on Health and Disability (2003) *To Have an 'Ordinary' Life: Community membership for adults with intellectual disability.* A report to the Minister of Health and the Minister for Disability Issues, Wellington.

[4] New Zealand Disability Survey 2006: Statistics New Zealand

[5] Bray (2002), p. iv

[6] Galanctowicz (2005), p.3

- funding frameworks that mange risk through bulk funding, and

- multiple values systems, including a public that expects the government to 'protect' people with intellectual disability and keep them 'safe'.

All of these factors can influence the support and services that people with intellectual disabilities access and in many cases can result in controls that limit the ability of people to live and participate in their communities in the way that they choose.

A review of contracts and service specifications, in combination with 39 interviews and multiple meetings within the service sector, suggest that, while risk is a significant part of life for everyone including people with intellectual disabilities, it is not well-defined, documented, or consistently managed in the support sector both at an individual and systems level. Implicit or explicit assessments of risk to the individual or the system have been responsible for significant tensions in policy and regulation, as well as in service delivery and have led some to describe a 'risk averse' bias in the system. This can limit progress towards the vision supporting individual choice that is described in the New Zealand Disability Strategy.[7]

Well-designed systems of risk management must include an individual's /family/whanau assessment of risk and making choices, leadership that values and supports risk-taking (with appropriate safeguards), data systems that inform the system about population risks and factors that place people at risk of harm, and a workforce that is skilled at facilitating choice and negotiating 'risk dilemmas'. This is complex, since risk management systems that are bluntly applied can lead to over-regulation and limitations on flexibility, as has been reported in recent Occupational Safety and Health examples.[8]

New Zealand's health and disability sector is grappling with short and long range forecasts for increases in health and disability service demand, at the same time as spending has been constrained. The public sector is being advised that it must adopt a new way of working that takes long-range sustainability into consideration and focuses on "delivering better services with the same resources."[9] Improving quality of services includes identifying, analysing, and mitigating risks of negative outcomes so that public funds are used in the most effective manner possible.

Priorities

There are multiple recommendations noted throughout the report, and summarised in chapter 5. High priority recommendations that are as follows:

1. Consider where risk management will fit in flexible services. The Ministry of Health's Disability Support Services (DSS) Group is currently rethinking the 'front-door' to services with a review of Local Area Coordination (LAC) models that hold promise for greater individualisation and flexibility of services. As part of this assessment, it is essential to consider how people will be supported to take risks, and

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[7] Ministry of Health (2001), *The New Zealand Disability Strategy: Making a World of Difference* Whakanui Oranga. Select objectives are summarized in Appendix C.
[8] Examples are detailed in chapter 2.
[9] New Zealand Treasury (2009) Minister's Executive Summary. p. 8

where risk management should lie in current and future needs assessment and service planning (NASC) processes.

2. Data is essential. New Zealand has made progress in developing health data systems, and is working towards developing health and disability data systems, but there is little attention being paid to 'disability' at present as data strategies are being developed within the Ministry of Health. Risk management activities should be grounded in a sound understanding of what are real risks, based on data wherever possible. This will require a focus on disability population data that is not currently evident. Opportunities to use existing data systems are identified in Chapter 3. Areas within the Ministry of Health in which there is a most pressing need for information about people with intellectual disability follow:

a) Population health status, including health outcomes, morbidity and mortality data to allow for benchmarking and trends analysis.

b) Evaluation of Individualised and flexible funding models. In the case of LAC[10], any pilot must be accompanied by evaluation that investigates risk management processes and outcomes.

c) ID(CC&R)[11] evaluation. The restrictive supports provided through this complex legislative framework are exposed to questions regarding the effectiveness of the approaches used without a robust evaluation of the risk management process and support delivery framework in relation to outcomes. An evaluation that includes the experience of care recipients will add to the body of evidence, and provide valuable programmatic information.

3. Promote long term partnerships between government, researchers, advocates and self-advocates with intellectual disability, and the support sector. While some cross-sector partnerships exist, there is a significant opportunity to coordinate efforts among these groups. The current Ministerial Committee on Disability Issues is well-positioned to create high level linkages between and within Ministries. As this committee receives input from the public and non-governmental sector, it is important to also recognise and foster 'mid level' linkages between committed individuals in the governmental and non-governmental sectors as a way to tie organisations together and establish enduring relationships.[12] Partnerships that enhance the ability to collect, analyse, and disseminate meaningful information will be particularly important.

Conclusion

Building on the foundation of solid values, New Zealand is well-positioned to offer people greater choice and flexibility in the supports they receive, but it will require conscious attention to issues relating to risk. The balance between choice (flexibility) and control (safety) will be best achieved through well-considered attention to the role of risk and risk management in these supports.

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[10] Local Area Coordination
[11] Intellectual Disability (Compulsory Care & Rehabilitation)
[12] Institute of Policy Studies (2008), p.6

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INTRODUCTION

Support for people with intellectual disability in New Zealand has been through great changes in the past 20 years, many of them positive and driven by a vision for participation in the community for all New Zealanders.[13] Movement from a service model of institutional care to a model that supports community living and participation has been steady and in many cases, has shown positive change in people's lives.[14] The pace of positive change has slowed however, and there are concerns building that New Zealand is no longer making the necessary progress towards the goal of meaningful community integration.

The current situation in New Zealand has been described as a period of 'backsliding' in terms of the rights of people with intellectual disabilities in New Zealand.[15,16] The 1990s in New Zealand were characterised by greater movement toward disability advocacy, and structural changes in service delivery in an effort to align with the emerging values of providing support to meet individual need, which led to the development of the New Zealand Disability Strategy (2001) (NZDS). The NZDS vision is based on the belief that people with disabilities are valued members of society and that key government departments will be able to implement activities to support efforts toward this inclusive vision.

A preliminary review of progress of the NZDS[17] indicated that there was progress being made toward full participation in society by people with disabilities but that implementation was being hampered by structural challenges that impeded the development of flexible supports and the need for improvements in information systems. Progress across government departments in implementation continues to be slow, as noted in subsequent implementation reviews.[18]

In recent years, two national reports have highlighted concerns regarding services and support for people with disabilities living in New Zealand,[19] and for people with intellectual disability in particular.[20] There have been some targeted disability sector efforts to expand service options yet poorly integrated services, a lack of attention to emerging and chronic health issues, the need for behavioural support, a desire for a revised approach to needs assessment, and inflexibility in the service system continue to figure prominently in the discourse regarding publicly funded supports.

Getting 'stuck' in the implementation phase
There is an apparent disconnect between the clear and valued vision of full participation in society and the experience of people with disability. This is not new, and is not necessarily surprising to policymakers and analysts who know that even the

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[13] New Zealand received the Franklin Delano Roosevelt International Disability Award on 6 May 2008. The award was presented by Ban Ki-Moon, secretary general of the UN who commended New Zealand's leadership in the international community and praised New Zealand's deep commitment to disability issues domestically. UN News Center (6 May 2008)
[14] Milner, P., Donald Beasley Institute (2008)
[15] Self-advocate and family member key informant, April 2009.
[16] National Advisory Committee on Health and Disability (2003)
[17] Saucier, P. (2002)
[18] Ministry for Social Development (2008)
[19] Social Services Select Committee (2008)
[20] National Advisory Committee on Health and Disability (2003)

most enlightened and accepted policy will meet its greatest challenges in implementation.

Purpose

This paper addresses the challenges that emerge when the drive for services that are person-centred and support people with intellectual disability to live lives of their choosing, intersects with the systems that aim to improve quality and assure safety, often through regulation, standardisation, and demands for accountability. This can be simply described as the balance that must be achieved between choice and control in the delivery of supports.

Risk is a concept that is closely associated with the balance between choice and control. Effective assessment of possible risks and benefits associated with choices creates a basis for decision making that is expected and desirable in many settings.[21,22] In the context of support planning and delivery, there are many areas in which risk is a consideration either explicitly or implicitly. These include:

- clinical interpretation of risk,
- accountability demands,
- occupational health and safety requirements,
- contractual obligations to 'manage risk',
- funding frameworks that mange risk through bulk funding, and
- multiple values systems, including a public that expects the government to 'protect' people with intellectual disability and keep them 'safe'.

All of these factors can influence the supports and services that people with intellectual disabilities access and in many cases can result in controls that limit the ability of people to live and participate in their communities in the way that they choose.

This descriptive study of intellectual disability support and services in New Zealand has wide-ranging application. The struggle between 'dignity of risk' and the requirement for 'safety and accountability' is encountered in countries and states around that world. The author expects that this discussion will contribute to an understanding of the issue beyond New Zealand.

Methodology

The process of gathering information for this project included preliminary interviews in Wellington, within the Ministry of Health, a review of the literature, relevant legislation and policy documents, and the development of a preliminary list of contacts. The author developed a semi-structured framework for subsequent interviews and built up a list of key informant contacts in the provider and non-governmental organisation (NGO) sector, among self-advocates, and with researchers.

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[21] Standards Australia and Standards New Zealand (2004)
[22] Ministry of Health (2003a), p. 5

Interviews and site visits were conducted over a period of 10 weeks, with the author recording notes at each of 39 interviews. Appendix A lists people who granted interviews or otherwise provided direct support to the development of this project. Field notes were also taken during and following site visits to facilities and community residences.

In addition to key informant interviews and site visits, the author attended two Ministry of Health (MoH) consumer forum/hui meetings, a MoH consumer consortium meeting, a two-day training session on "Imagining a Better Life" and multiple ministry and support sector meetings as an observer, as a way to learn about interactions between the Ministry of Health and key stakeholder organisations.

Notes taken during and following the 39 interviews for this project, as well as field notes from site visits were manually grouped into themes in preparation for the development of this summary report. To complete this, the author created a template for the report, organised into 'Background', 'Risk/choice', 'Data', and 'Training', with sub-sections in each area. Manual grouping was done by sorting interview notes, comments, quotes, and field notes into these areas. Quotes from interviews are included throughout the report, without direct attribution of names.

The author developed a brief survey regarding risk management processes that was electronically distributed to 44 members of the National Residential Intellectual Disability (NRID) provider group in order to gain broader input from this stakeholder. A total of eight surveys were completed, from eight provider agencies (18% return). Results from the survey are included in Appendix B. The limited number of surveys completed provided feedback from individual agencies that was useful for follow up discussions but did not allow for significant aggregate analyses.

Limited quantitative research was performed directly; however the author collaborated with MoH advisors to develop an understanding of the capacity to use existing data systems to explore ways to use the information that is currently available to describe the population of people with intellectual disability New Zealand. This is discussed further in Chapter 3.

The intended audience is people within the disability support sector, policymakers, and others concerned with ensuring the vision of the New Zealand Disability Strategy becomes a reality. The overarching goal of living in a society that fully values the participation of people with disability is not at all unique to New Zealand; so much of the discussion should be useful for people in the United States and other countries.

Defining Risk Management
The 'Standards New Zealand and Standards Australia' joint risk management standard defines risk management as "the culture, processes and structures which are directed towards the effective management of potential opportunities and adverse effects."[23]

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[23] Standards Australia and Standards New Zealand (2004)

Figure 1: Risk Management Process[24]
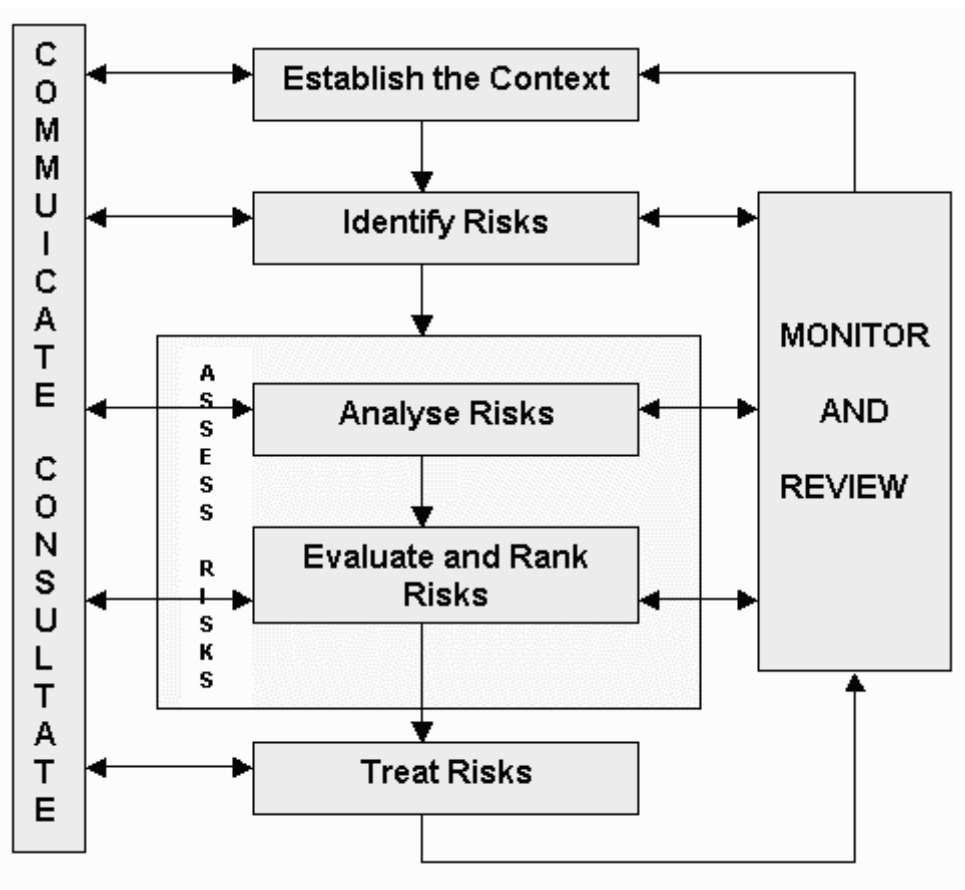
For people with intellectual disability and policymakers, the overriding goal is to create a sustainable system that appropriately supports people, meets their individual needs, and assures their health and welfare.

Applying a risk management framework to systems planning allows for a review of the planned progress toward the goal, and the barriers that may arise. Once the nature of those barriers is understood, steps can be taken to reduce the likelihood or impact of them, and increase the likelihood of positive outcomes.

The risk management approach is mostly intuitive and informed by common sense. It applies to any number of areas of planning and decision-making and is common language in project management across the government and the private sectors.

The important elements and their relationship to this project are as follows:

1. Establish the context. This is not always included in risk management plans, but is particularly important. Knowing the 'lay of the land' means being better able to anticipate bumps in the road. Chapter 1 is devoted to describing the historical, social, legislative, and policy context for support for people with intellectual disability. It highlights the current model of support

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[24] ibid

2. Identify the risks. Recalling that the goal is to create a sustainable system of support, the risks (things that may emerge that could delay or prevent the achievement of the goal) are identified at the end of Chapter 1:

    a) Changing population needs

    b) Competing Priorities

    c) Financial pressures

    d) Need for better accountability/risk issues push the system toward greater control.

3. Assess the risks. This includes both analysis and evaluation of risks. Chapter 2 takes up the last risk identified in the list above (noting that they are interrelated). It 'unpacks' the issues of risk, control, and choice-making with a review of findings from the current system and a range of literature sources. Chapter 3 is a discussion of approaches to evaluating risk, including how NZ could better use data to understand risks in this population and improve supports.

4. Treat risk. Addressing barriers requires action at multiple levels. Chapter 4 discusses training and staff development. Chapter 5 brings the discussion together with a review of recommendations, and stakeholder-specific suggestions for using these findings to reduce risk. The action that will be taken to 'treat' the identified risk will be determined by leaders, policymakers and others who are committed to deepening their understanding of the balance between choice and control as a way to enhance people's ability to live an 'Ordinary Life'.

1 EXAMINING SUPPORTS FOR PEOPLE WITH INTELLECTUAL DISABILITY IN NEW ZEALAND

Overview

This chapter contains a broad review of the social and service system as a means to establish the context and foundation for a discussion of risk and risk management in today's support system for people with intellectual disabilities in New Zealand. The past decades have been a period of significant strategic shifts in funding and philosophy in the health system which provides for a significant portion of support for people with intellectual disability. Key points include:

- The United States and New Zealand (as well as other Western nations) share a roughly common history of values that first supported institutional models of support for people with intellectual disability, followed by the growth of the de-institutionalisation movement of the 1970s and 1980s.

- New Zealand possesses a strong values base regarding the rights of people with disability to achieve full and valued participation in their communities. The current model of support focuses on community participation and is working toward greater flexibility to meet the unique service needs of each individual. Ongoing calls for enhanced choice and flexibility are challenging the disability support sector to re-think how to effectively fund and structure supports for a changing population.

- New Zealand's small size and streamlined governmental processes have allowed for comparatively rapid restructuring of the health and disability support sector several times over the past two decades - with mixed results. The position of disability support has shifted in this time, from an entitlement based system to a needs based system that relies heavily on a devolved needs assessment and service coordination process as 'gate keeper' to a system that is increasingly under financial constraint.

- Current and pressing issues that relate to people with intellectual disability in New Zealand are summarised in the final section of this chapter. These include:

  - The population of people with intellectual disability in New Zealand is changing. Preliminary analyses indicate there is a relatively large youth population that may be ageing into intellectual disability services. At the same time, people using intellectual disability services are living longer in the community and experiencing a greater burden of chronic and preventable illness and disease. Demographic shifts in the New Zealand population will provide greater pressure to develop adequate culturally appropriate services for Māori and Pacific Islanders as these populations grow.

  - Competing priorities will continue to challenge people with intellectual disabilities and their advocates' efforts to have their needs addressed. Operating within the Ministry of Health, the Disability Support Services group is only one small part of a much larger organisation that has multiple strategic priorities relating to acute care, other population health issues and, most recently, pandemic response.

- Fiscal pressures have been driving a move toward greater transparency in funding that is more directly linked to individual support needs. In order to achieve this, there must be a consistent and valid method of identifying support needs, as well as monitoring outcomes.

- There are significant differences between the risk management and quality systems that are currently operating in the Ministry of Health's 'health' sector and the Ministry of Health funded 'disability support'. For example, DHBs have national reporting systems for incident reporting and have developed internal review panels to identify systems issues that should be addressed to reduce risk and improve patient outcomes. In contrast, the disability sector has a highly variable approach to identifying, assessing, and managing risk both on an individual and systems level, indicating an issue that must be addressed if the Ministry of Health's overarching quality initiatives are to be successfully implemented ministry-wide. The discussion of risk in support for people with intellectual disability is expanded in Chapter 2.

The Social and Political Context in New Zealand

Established in 1840, New Zealand is relatively young country with a deep history. The first New Zealanders, the Māori, have been living in Aotearoa (New Zealand – literally 'Land of the Long White Cloud') for centuries, following migration from their ancestral home in near or remote portions of Oceania.[25] European migrants who first arrived were whalers and missionaries, followed by waves of migrants who were offered paid passage from their colonising countries (primarily England).

In 2009 New Zealand has a population of just over 4.3 million people of Māori, European, Asian, and Pacific descent.[26]

Government Structures

New Zealand's parliamentary system of government has only one chamber, the House of Representatives, and the Prime Minister and Cabinet Ministers lead the executive branch. Government is structured into ministries, overseen by ministers who are responsible for the work of the government. The New Zealand system can result in rapid policy change once agreement is reached in Cabinet. The head of state is the monarch, currently Queen Elizabeth II, who is represented in New Zealand by the Governor-General.

In the United States, disability policy and funding is a shared responsibility between the federal and state governments. In general, policy decisions at the state level are responsible for variations in disability services from one state to the next. Since funding is shared between the state and federal governments, the process of legislative and structural change can be significantly slower.

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[25] The exact origin of the Māori people is the subject of debate within New Zealand.
Te Ara (n.d) Pacific Migrations
[26] Māori make up approximately 15% of the nation's population, those of European descent (~ 67%), Asian (~ 10%), Pacific Islanders (~8%). Statistics New Zealand (2006)

Significant American federal legislation and initiatives includes:

- The Developmental Disabilities Assistance and Bill of Rights Act (2000)[27] which funds programmes including: State Councils on Developmental Disabilities, Protection and Advocacy Agencies, and 67 University Centres for Excellence in Developmental Disabilities,

- The Americans with Disabilities Act (1990) (which protects people against discrimination on the basis of disability),[28] and

- The federal "New Freedom Initiative" (which provides grants to states to implement demonstration projects and infrastructure changes geared towards increasing individual choice in where and how they receive supports)[29].

At a state level, the bulk of community services are funded through Home and Community Based Services (HCBS) Waivers, which allow Medicaid funding to support individuals in the community, as an alternative to institutional care.

New Zealand does not have specific legislation relating to the care and support of people with intellectual disability, with the exception of the Intellectual Disability Compulsory Care and Rehabilitation Act (2003), which applies to a very small portion of people who have been charged with, or have committed an offence. Disability policy and financing are the responsibility of the central government. The Human Rights Act governs protection against discrimination on the basis of disability and financing of Disability Support Services is provided through New Zealand's national health programme, Vote:Health. Additional community support for people with disability are structured and financed through separate federal ministries, as noted in Appendix D.

Partnership and the Treaty of Waitangi

The concept of partnership is important in the New Zealand social context. The Treaty of Waitangi (1840), New Zealand's founding document, laid out a framework for partnership between Māori and European settlers (Pākehā). The commitment to partnership is acknowledged in present day policies and guidelines regarding service assessment, planning, and delivery for Māori people who represent about 15% of the population. When at all possible, health and disability services make an effort to provide services 'by Māori for Māori' and to ensure that Māori values and tikanga are honoured.

A brief History of Support for People with Intellectual Disability in New Zealand

New Zealand's history of support for people with intellectual disability has followed the trends in values and social structure in New Zealand society since before and after the foundation of New Zealand in 1840. Early society in New Zealand was, by necessity, highly self-reliant. Among Māori, the whanau or iwi supported mokopuna (grandchildren) as part of the community, while their identity in the community was influenced as much by their whanaungatanga (family relationships) as by their

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[27] PL (106-402) Originally authorized in 1963.
[28] Changes to legislation effective 1 January 2009 include an expanded definition of disability. ADA Amendments Act (September 25, 2008)
[29] New Freedom Initiative (2001)

personal abilities.[30] Among Pākehā settlers, children with intellectual disabilities remained and grew up within their families in the absence of any other support.[31]

By the beginning of the 20th century, the 'problem' of the 'feeble-minded' was being used to identify a need for greater social controls over this population, as argued in the Eugenics movement. This pseudo-scientific movement argued that the risk to society of social ills such as criminality and drunkenness could be controlled by limiting the fertility of the 'unfit', both through forced sterilisation and by limiting contact with the community at large.[32]

Both in New Zealand and in the United States, the early half of the 20th century was a time of establishment and expansion of institutions for people with disabilities, as well as those who could not be cared for by their families. Medical advice guided families towards placing their children in care settings outside the home, often with pressure on parents to do this for the good of the rest of the family. While some families did choose to keep their family member at home or in the community, a growing number of people with intellectual disabilities were sent to special 'residential schools'.

Templeton Farm School opened just outside Christchurch in 1928, with the bucolic vision of creating a self-sufficient community that employed boys and girls with intellectual disability and taught them 'occupations' that would be of use in maintaining the institution. Over time, three additional specialist 'psychopaedic hospitals' for people with intellectual disability opened across New Zealand, the largest of which was Kimberly Hospital. By 1977, Kimberly had a population of over 700 people, (estimated to be about 15% of all people with intellectual disability in New Zealand) and was a well-established psychopaedic nurse training site. In addition to psychopaedic hospitals, a significant number of people were housed in psychiatric hospital 'back wards'.[33]

Both in New Zealand and in the United States, institutionalisation of people with disabilities emerged at a time when social values towards people with disabilities were paternalistic at best. At their worst, social values could be dismissive of people's value and worth, and based on a belief that people with disability should not expect the same rights and privileges as other members of society.

Institutional living, at its core, was a situation in which vulnerable people were cared for in large, congregate settings that provided the basics for survival (shelter, food, medical care), with little attention to individual needs or desires. These settings effectively removed the opportunity for people to exercise choice and control over large portions of their lives. In many cases, the institutions were staffed by people who had the best of intentions, yet the very nature of the 'closed' system created a situation where abuses and neglect could go on for a long time, unnoticed or unchallenged.

By the mid 1970s, both in New Zealand and the United States, national and international influences had resulted in a shift that recognised that institutional

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[30] Kinji, J. and Bray, A. (2001)
[31] Milner, P. (2008), p. 5
[32] Thompson, J. (1995), referenced by Milner (2008), p.6
[33] Personal communication Lester Mundell, 21 June 2009

settings often placed severe limits on individual's rights to choice, freedom, and dignity.[34,35]

Community supports in New Zealand began with family advocacy and the establishment of the Intellectually Handicapped Children's Parents Association (IHCAP), later renamed IHC. It began as an advocacy organisation, founded by parents searching for alternatives to institutional placement for their children, along with some clinicians. In 1953, the IHCAP articulated a clear call for 'choice' in service delivery with a goal to replace large institutions with "cottage" homes.[36] Governmental support for community living was slow in coming however, resulting in IHC becoming established as a voluntary organisation, initially providing day-programme and residential supports.[37]

The Disabled Persons Community Welfare Act (1975) provided the first legislative move toward supporting individuals in the community, with provision for assistance for home modifications and equipment, and for support to approved "voluntary and charitable organisations".[38] The act was administered by the Department of Social Welfare and symbolically marked a shift away from a medical approach to disability to a social model (in which society is seen as 'disabling' and support is aimed at addressing barriers, rather than 'fixing' or 'curing' the individual). As the government recognised a need for supporting people in the community, they were provided through funding of community organizations, such as IHC.

1980's Deinstitutionalisation and Normalisation

The drive for deinstitutionalisation and the de-medicalisation in New Zealand and in the United States was supported by the principle of normalisation, developed by the sociologist Wolf Wolfensburger. The principles of normalisation, and its refinement to Social Role Valorisation were a drive to help people with disability move into culturally valued roles in society through a process that included an exploration of cultural norms and values and the "enhancement of behaviour, appearance, and status of the devalued person".[39]

The focus on the individual and their social roles was part of a major sea change in the approach to service planning in the 1970s and 1980s. The person's own strengths and valued social roles took precedence over any medical diagnoses (e.g. cerebral palsy, intellectual disability, diabetes) in keeping with the shift toward a social model. This promised to be a very positive and empowering model for many people with disabilities but critics of the normalisation movement identified that the principles did not address issues such as lack of choice and autonomy. In this new service philosophy, people were treated as individuals and individualised plans were

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[34] *Intermediate Care Facilities For the Developmentally Disabled: Meeting the Long Term Care Needs and Maximizing the Potential of Individuals with Mental Retardation and/or Developmental Disabilities* (n.d.), American Health Care Association
[35] Milner, P. (2008)
[36] Mirfin-Veitch, B. (2005), cited in Milner, P. (2008), p.10
[37] IHC's service provision arm was renamed to IDEA (Intellectual Disability Empowerment in Action) in 2005.
[38] Disabled Persons Community Welfare Act (1975) http://legislation.knowledge-basket.co.nz/gpacts/public/text/1975/se/122se17.html
[39] Chappell (1992)

discussed, but in practice the service system continued to provide services that were for the most part packaged and pre-determined.[40] For example, choice in where and with whom one lived was often still held in the control of the service system.

The closure of the Kimberly Centre in October 2006 marked the end of large scale institutional care for people with intellectual disability. The occasion was much celebrated in the disability community, and New Zealand is recognised as the first western country to be completely free of large-scale institutions.[41]

1993 – 1999 Health system influences on Disability Supports

Introducing Competition and Choice in the Health and Disability sector

The Health and Disability Services Act (1993) and other reforms in the early 1990s were developed in response to growing concerns about increasing costs in the social welfare, entitlement based funding system and the health sector, and introduced major changes in both the health and disability supports sector. The key relevant events in this time period were:

- Funding for disability supports was shifted from the Department of Social Welfare to the Ministry of Health as a "capped and ring-fenced" component of Vote: Health. This was objected to by many in the disability advocacy movement,[42] as it was seen as having the potential to 're-medicalise' disability. In addition, the legislated shift in funding model changed people's statutory rights to services (as was codified in the DPCW Act 1975) to a model in which there was a limit on funds. As a result, rationing, and prioritisation became very real features of the service model, and valid methods of assessing need and support available became essential.[43]

- Health and disability supports were funded through four Regional Health Authorities (RHAs). Each RHA was expected to provide innovative solutions to respond to needs identified within their region.

- The role of the Ministry of Health was to provide policy and strategic planning and it established the Disability Support Services Framework, which described a new model for service provision. In response to concerns about conflicts of interest with provider agencies identifying the most appropriate support for individuals, the Support Services Framework included a model in which Needs Assessment and Service Coordination were separate from service provision.

- Needs Assessment Service Coordination Agencies (NASCs) were identified as a new feature of service provision. These agencies would provide people with disabilities and their families/whanau with a holistic assessment of strengths and needs, followed by development of a service plan that integrated funded and natural (community supports), and continued with ongoing service coordination. What emerged was a network of what is now 15 independent

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[40] Sullivan, M. and Munford, R. (2005), in O'Brien and Sullivan (2005), p.22

[41] 'Mini-institutional' care continues however in New Zealand, with many group residences housing five or more people.

[42] The Disabled Persons Assembly (DPA) is a well established and vocal advocacy organization in New Zealand.

[43] Sullivan, M. and Munford, R (2005), in O'Brien and Sullivan (2005), p. 24

NASCs that are contracted to the Ministry of Health. NASCS were to be used as gateways to services and there was explicit direction that NASCs should be given the opportunity to come up with innovative models to use funded supports (based on assessed need) in combination with a person's natural supports to achieve the person's life goals.[44]

- The Health and Disability Services Act (1993) established a market-based system in which public and private providers were to compete for service contracts from the Ministry of Health to provide specific health and disability support services. The new system aimed to bring open market competition into the health and social services system. This environment allowed the establishment of new service providers (mostly non-governmental organisations) to compete with the few that had traditionally provided the bulk of residential and other services for people with intellectual disability, such as IHC. These reforms promised greater consumer choice and were aligned with demands from disability advocacy groups for greater control over service options, while promising increased efficiency and effectiveness of taxpayer spending.

- Perhaps as a means of reducing the administrative burden, contracted funding for services was established. In this model, a provider contracted in advance with the Ministry (through the RHA) to provide a set amount of services over the course of a year. Service units are tallied as a cost function. The model did support a shift of funding from institutional services to the community providers of 'group settings', but there was little in this model that supported service delivery from an individual perspective. Rather, a set number of service units ('beds') were purchased and people with disabilities were often required to fit their service needs to what was available.

- By 1997 the government had developed a new funding model for health and disability support, dismantling the Regional Health Authorities and shifting to what was ultimately a centralised Health Funding Authority, with administration of services structured through the Ministry of Health.

- The 1999 change of government in New Zealand brought in a shift in philosophy and another wave of reforms in the health and disability system. In an explicit rejection of the centrist approach to administration of the health system, the Labour-Coalition government passed the New Zealand Public Health and Disability Act (2000) that created 21 District Health Boards (DHBs) and devolved hospital funding and other health services to the level of local communities. The DHBs include planning and funding arms and are administered by both appointed and locally elected members with the aim to ensure that DHB planning and services are responsive to the local communities. The Act stipulated in the legislation that each DHB has a Disability Support Advisory Committee.

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[44] Bray (2002)

Outcomes by the end of 1990s: Increased choice, with limits

Some Increased Choice
Services for people with intellectual disability did indeed see an increase in choice among residential providers, with the establishment in the early and mid-1990s of a number of community trusts and service providers of residential and other support services as alternatives to the largest provider of service, the IHC.

Questioning Market Efficiency
New Zealand's health (market) reforms reportedly did not achieve the significant efficiency gains that were anticipated across the health delivery system, including both primary and hospital-based care.[45] For people with disabilities, this approach had particular problems, as pointed out by Sullivan and Munford in 2005:

> …the New Deal was based on the flawed premise that DSS [Disability Support Services] could be created which would increase efficiency and effectiveness, giving better and more DSS for the taxpayer's dollar. Given our relatively small and dispersed population of disabled people, this was never going to work; it was little more than an ideologically induced dream. There was some resonance, however, with the demand by disabled people for more individual choice in services and the neo-liberal construction of the autonomous individual making rational choices in a market competing for his or her custom. Where this resonance ended, was that disabled people wanted control of their services, whereas the government was happy to hand control over to the market and, by default, the disability industry. [46]

It could be argued that the government model to promote marketplace pressures (competition) was only prepared to devolve risk to the level of providers because of the accountability and control that it could exert as the major funder. Without an 'industry' or 'programme' that includes monitoring accountable to the funder, it is difficult to assure accountability of government funds.

Devolution of Disability Supports to District Health Boards

When the NZ Public Health and Disability Act was passed in 2000, devolution from centralised administration and funding was planned to occur in a staged and controlled fashion, beginning with hospital and health services, followed by disability and other supports. This was the impetus for the establishment of a Disability Support Advisory Committee as one of the core advisory groups for each DHB.

In 2003, funding for age-related disability services (65 and over) was devolved to the DHBs. At the time, it was felt that older people with disability support needs were more comfortable with accessing services through their general practitioners or hospitals and that DHBs were well situated to meet the needs of the local population of older adults, including the provision of services integrated across the continuum of care. At the same time, funding for people with mental health needs was devolved to the DHBs.

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[45] Ashton (2005)
[46] Sullivan, M. and Munford, R (2005), in O'Brien and Sullivan (2005), p. 25

Disability support services for younger adults (under age 65) remain funded and administered by the Ministry of Health Disability Support Services. For those over the age of 65, the Ministry continues to fund residential and home support services, unless the person is assessed as requiring aged-related care, in which funding and support shifts to DHB funding.

It is possible that the government may opt to shift supports and services for younger adults to DHBs. Discussions of the pros and cons over the past decade have focussed on the fact that younger people with disability are often connected with and receiving supports from a range of agencies, not only those from within the Ministry of Health. As a population, it is unclear how their needs would be better served through a devolved method of funding, although advocates for increased attention to health issues in this population suggest that DHBs may be better suited to address these issues, although there is little current evidence to support this.

The New Zealand Disability Strategy

As part of the restructuring of New Zealand's health system, the New Zealand Public Health and Disability Act (2000) included direction to the Minister of Health to establish a New Zealand Health Strategy and a New Zealand Disability Strategy (NZDS). The NZDS was rolled out in April 2001 and is a long-term, government-wide plan for changing New Zealand from a disabling to an inclusive society. It is developed with a social model of disability as its underpinning, in which individuals with impairments (sensory, neurological, intellectual, or other) experience disabling barriers in society.

The desire to break down barriers that cause disability is closely linked to human rights, including those that allow for personal freedom from unnecessary restrictions, and the ability to express oneself. The Strategy points out that "disabled people, especially those with psychiatric or intellectual impairments, are often shut out of social networks and full participation in community activities, because people are ignorant or fearful of behaviour they perceive as different".[47] The values of people in the community have an effect on risk perceptions, as is further discussed in chapter 2.

The New Zealand Disability Strategy includes 15 objectives which serve as guidance to the government departments as they develop NZDS implementation work plans. Select objectives are listed in Appendix C.

The Office for Disability Issues (ODI), based in the Ministry of Social Development is charged with monitoring of and annual reporting on progress on implementation of the Strategy across the government ministries. Initial implementation was reviewed in 2002 and the findings were that the NZDS had the effect of some positive change, but that New Zealand had work to do in order to achieve the vision of a society in which people with disabilities are able to fully participate. Overarching themes included the need to:

1. Improve capacity to collect and use data to evaluate current programmes and inform service improvements.

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[47] Ministry of Health (2001), *The New Zealand Disability Strategy* (NZDS)

2. Improve the ability of government to work together, to share relevant information, to improve efficiency, and to improve the ability to work together to better coordinate supports for people with disabilities.[48]

The ODI reports on individual ministry's progress on specific goals, as identified in the ministry's work plan. Most report progress on their individual (self-determined) indicators and work plans,[49] yet there is little sense that the NZDS is driving major progress in increasing opportunities and community participation for people with intellectual disabilities.

To have an 'Ordinary Life'

In 2003, the National Health Committee's[50] report: "To have an ordinary life" found that people with intellectual disability experienced ongoing challenges in their quest to live an 'ordinary life'. People's descriptions of the lack of ability to make choices about important issues such as housing, as well as a lack of support for their aspirations and goals was clearly inconsistent with the vision of the New Zealand Disability Strategy.

Priority Issues in this report were:

1. The need to *refocus Needs Assessment and Service Coordination (NASC)* to allow for 'strategic assessment' or planning for life with the disabled person, their family and whanau. The service design process should move from allocating people a limited range of available services to one in which a person's changing support needs can be met over time. Staff training or 'upskilling' was emphasised as a priority area.

2. *Moving away from the 'custodial ownership model'* of service delivery. Many people with intellectual disability live in homes that are owned by service providers. The service providers receive their benefits as partial payment for the supports they receive, and provide a very small 'allowance' to the person with intellectual disability. The report recommends that this model should not be allowed to continue as a 'default', rather that people should receive their benefits directly, and then be supported (if necessary) to manage their own funds, including paying rent or working toward purchasing their own home.

3. *Addressing basic health needs*. Health was not one of the main areas of focus at the inception of the National Health Committee's report but the issues that emerged during the discovery process of the project identified health as one of the most significant priorities. The report noted that many people with intellectual disability "endure prolonged suffering from health conditions that are treatable, relievable, and curable"[51] and suggests that high priority be given to addressing health issues in people with intellectual disability.

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[48] Saucier, P. (2002)
[49] Ministry of Social Development (December 2008)
[50] The National Health Committee (NHC) is also known as the National Advisory Committee on Health and Disability. It is an independent committee charged with providing advice to the Minister of Health on a broad range of health and disability issues.
[51] National Advisory Committee on Health and Disability (2003) p. 9

While it has not been formally adopted by the government, the report is commonly referred to in governmental and service delivery sectors and is often mentioned as a guiding document for the future direction of support for people with intellectual disability.

Background papers[52] were commissioned to inform the work of the committee and provide a useful base of literature and research findings up to 2003.

The Select Committee Report

The Report of the *Social Services Select Committee: Inquiry into the quality of care and services for people with disabilities*[53] was developed in response to concerns about support services for people with disabilities in New Zealand in 2005 and 2006. Media attention focused on abuse within services and misuse of public funds combined with findings, such as those in the 'Ordinary Life' report, which prompted a governmental inquiry into the quality of care and service for people with disabilities.

The report, published in 2008, highlighted significant areas of concern regarding services for people with disability, including a lack of leadership, fragmented services, geographic variability of services, and ineffective implementation of the New Zealand Disability Strategy.

Priority Issues:
Select recommendations from the report include:

1. The appointment of an appropriate lead agency responsible for disability issues, accountability for the disability sector, and a role monitoring the sector. In addition, the Committee suggested investigating the appointment of an independent Disability Commissioner.

2. Establishment of a new entry point to services that is more community and individual focused, and follows the Local Area Coordination model that has been successfully employed in Western Australia. The role of Needs Assessment Service Coordination (NASC) agencies should be changed so that the function is not duplicating Local Area Coordination.

3. Ensure that evaluations and audits of disability services focus on quality of life and opportunities for disabled people.

4. Establish a strategy for improved training that includes "…values-based training for all staff, and consistent and appropriate conditions of work, including health and safety, safeguards…".[54]

System Responses:
The government's response to the report agreed that there are issues that need to be addressed, but the recommendations of the Select Committee were not uniformly adopted. For example, the government does not favour the establishment of a Disability Commission or major structural change at this time, as it had the potential

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[52] Available from the Donald Beasley Institute, www.donaldbeasley.org.nz
[53] Social Services Select Committee (2008)
[54] Social Services Select Committee (2008), p.40

to be "costly and distract officials from carrying out the substantial work programme" that is underway. [55] Select responses to date include:

1. High level consultation and Cross-Ministry Committee. In February 2009 the Minister for Disability Issues announced the convening of a Ministerial Committee on Disability Issues, including Ministers from related ministries (and others on invitation) to:

- Determine the priority and respond to issues identified in the Social Services Select Committee report.

- Identify areas of poor performance in government agencies related to disability services and issues, and how to rectify them.

- Develop accountability arrangements on disability matters for government agencies and Ministers.

- Identify more effective use of government resources to support disabled people. [56]

The committee is currently receiving testimony and advice from stakeholders across the sector on work plan priorities.

2. Re-thinking the 'front door' In response to the report's recommendations to review Local Area Coordination as a means to achieve greater flexibility, the Ministry of Health and the service sector are investigating how such processes could work in New Zealand.

NASC
Currently, access to disability support services begins with an assessment of 'needs' through either a NASC or a RIDCA.[57] The original concept of the NASC was to provide a holistic picture of a person, their family/whanau, and the develop a plan for using community and specialist supports that could meet the person's assessed needs in a cost effective manner.[58] The 15 NASCs have evolved as organisations independent of each other and independent of the Ministry of Health.[59] As a contracted organisation, NASC employees are not government employees, so the Ministry of Health does not have direct 'front line' employees. Anecdotally, some NASC employees and managers see their role as including some advocacy for their clients, a role that is not included in the contracted agreement with the Ministry of Health and suggests a conflict if the NASCs are being charged with managing resources as well.

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[55] Government Response to Report of the Social Services Select Committee on its Inquiry into the Quality of Care and Services Provision for People with Disabilities (February 2009)
[56] Ministerial Committee on Disability Issues (2009) Terms of Reference
[57] The Regional Intellectual Disability Care Agency provides evaluation and assessment for people with high and complex behavioural or forensic support needs. These are further described in the context of the ID(CC&R) Act.
[58] Ministry of Health (1994), p. 42
[59] The Ministry of Health has developed a NASC Development work plan, which includes workforce development, information sharing, and consideration of the use of standardised tools.

Local Area Coordination
In response to the Select Committee's Report, the government is actively pursuing the concept of an alternative 'front door' to services: Local Area Coordination (LAC), as developed in Western Australia. The foundation values of LAC are:

- Getting to know people over time, with a view to identifying what represents a good life for them;

- Assisting vulnerable people to build connections in their local communities;

- Having positive values and assumptions about individuals/families, and communities; and

- Emphasising community capacity rather than relying solely on service provision. [60]

Key service features of LAC include:

- Location in the community (e.g. next to the grocery shop) that allows people to 'drop in', as opposed to in a 'government office'.

- There is no immediate requirement for eligibility when people first make contact. The determination of eligibility comes once people want to move to more formal processes of developing plans and identifying support needs.

- There is a significant amount of time allowed for the Local Area Coordinator to get to know the person and their family/whanau. A discussion of support needs comes 'when they are ready'. Planning is thus based on a solid foundation, rather than rushing to put support in place that is not actually the most important for a particular person. [61]

Ministry of Health staff are currently actively engaged in a review of LAC and its applicability within New Zealand, and development of a pilot of this programme, yet there remain many questions about adapting this approach. Some within the sector feel that this approach is already happening; others report that this was the *intended* model, but that reality does not match intentions. It is likely that if LAC is adopted in some form, the role of government funded support, such as NASCs and community based Disability Information and Advisory Services (DIAS) will shift.

Human Rights

The UN Convention on the Rights of People with Disabilities
New Zealand was active in the drafting and development of the United Nations Convention on Human Rights of Persons with Disabilities (UNCRPD) which came into force in May 2008 and was ratified by the New Zealand government in September 2008. The Convention highlights the rights of people to have choice in how and where they live, as well as to exercise choice and control over their lives. It does not necessarily establish new rights for people with disability in New Zealand, but it is heralded as a legal and political tool to help reinvigorate the work that was outlined as part of the NZDS. [62]

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[60] Deschamp. P. et al, (2003), p. 64
[61] One in Five (March 15, 2009)
[62] UN Convention on the Rights of People with Disabilities (2008)

A bill was introduced in the United States House of Representatives on 7 May 2009 to ratify and implement core features of the UN CRPD. It is possible that ratification may extend greater specific rights to people with psychiatric conditions and place limitations on involuntary psychiatric treatment.[63]

The Human Rights Act
The Human Rights Act 1993 (HRA), and its Amendment in 2001, protects people in New Zealand from discrimination based on disability, among other things. It is analogous to the Americans with Disability Act in the US. Legal challenges to the NZ HRA seem to show signs of weakness. For example, the requirement of reasonable accommodation does not translate to the requirement for meaningful support provided by employers or public businesses.

The Health and Disability Commissioner Act
The Health and Disability Commissioner Act (1994) created the Office of the Health and Disability Commissioner whose role is to promote and protect the rights of health and disability consumers, and facilitate the fair, simple, speedy, and efficient resolution of complaints.

The Code of Health and Disability Services Consumers' Rights was made by regulation in 1996, and applies to all providers of health and disability services. The Code sets out 10 rights, including the right to be treated with respect, to be free from discrimination or exploitation, to dignity and independence, to services of an appropriate standard, to give informed consent, and to complain.[64]

In April 2009, the government announced the establishment of a Deputy Health and Disability Commissioner – Disability. This was a shift of one of the deputy commissioner roles to allow greater emphasis and focus on disability issues within the office.

Describing the Population of Individuals with Intellectual Disability
'People with intellectual disability' describes a collection of individuals with a broad range of abilities and support needs. While some people may live independently, or with minimal support from their family/whanau or community, others may need greater amounts of support some of which may be funded by government agencies. It is important to note that, just as people's lives are often changing, people's support needs may be dynamic. This must be part of the planning for a person's support.

Within New Zealand, there is not one definition of intellectual disability; rather different agencies employ different means to establish eligibility for services.[65] The primary focus of this discussion will be on needs assessment, service coordination, and support provision that is funded through the Ministry of Health. The MoH definition is summarised as follows:

1. Intelligence quotient (IQ) of 70 or less, as assessed by standard tests generally used by clinicians.

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[63] American Association of Persons With Disability (2009)
[64] Health and Disability Commissioner Act. http://www.hdc.org.nz/aboutus
[65] Within education, for example, there is a hesitancy to label children with an intellectual disability.

2. Significant deficits in at least two areas of life-functioning (for example, communication, self-care, social skills, health and safety).

3. The condition became apparent during the developmental period (generally before a person turns 18).[66]

This is very similar to criteria established by the American Psychiatric Association's Diagnostic and Statistical Manual (DSM IV) reflected in numerous US state statutes. The requirement for a measure of IQ is the subject of debate, and some organisations such as the National Health Committee have adopted a variation on this which excludes the IQ measure.

In practical terms, people with intellectual disabilities may need extra time or support to learn new things, or may need help to understand information in order to make choices. This is particularly relevant to the theme of this project, since autonomy and the ability to make choices independently cannot always be assumed.

Defining Intellectual Disability

The most common international term used to describe this population is 'people with intellectual disability' but several additional terms are offered here to ensure clarity.

- The term 'people who use services' is sometimes used by PeopleFirst, the self-advocacy movement for people with intellectual disability, as it affirms their position as no different from the rest of the population. This is not consistently used, however, and documents by advocacy organisations may also include reference to intellectual or learning disabilities.

- 'Developmental Disabilities' is a broader term that is often used in the United States and generally describes a broader range of impairments that emerged before the age of 18, often including intellectual disability, but also others such as autism spectrum disorder and cerebral palsy, that are not necessarily associated with an intellectual disability.

- 'Learning Disability' is the term used in the UK. This is sometimes a confusing term, since learning disability is used to describe a different set of academic challenges in the United States.

- 'Mental Retardation' has become a pejorative term and has not been used for years in many parts of the world. There has been a slow transition in the United States towards replacing it in official and commonly used language and progress is being made both at state and federal levels, largely due to the self-advocacy movement's campaign to get rid of the 'R word'.[67]

Demographics and Services

The prevalence rate for intellectual disability in New Zealand is estimated to be 7-13 people per 1,000.[68] This gives an estimated population of 22,120 - 41,080 adults (over

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[66] For the complete definition, refer to the ID(CC&R), Ministry of Health (2004): A guide to Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003

[67] *Label falls short for those with mental retardation* (January 22, 2007).

[68] Bray A. (2003)

age 15) for 2006.[69] The Donald Beasley Institute estimates that about 3-4 people per 1,000 have a more severe disability and need ongoing support which equates to 9,480-12,640 adults (over 15), which is generally consistent with international data and small sample size studies in New Zealand.[70]

Since 1996, New Zealand has been performing a national Disability Survey every five years. The 2006 survey indicated that 17% (n=570, 300) of New Zealanders report that they have a disability and approximately 33,700 (5%) reported an intellectual disability.[71] The results of the survey may be taken as a general indication of number but questions as to the definitions used, as well as to how questions are posed suggest that there may be a significant margin for error when using this to determine the number of people with intellectual disability. [72]

IHC, the nation's largest provider of support services suggests that there are over 50,000 people (children and adults) with intellectual disability living in New Zealand.[73]

The Ministry of Health funds residential support services at approximately $339M per year (2008 data) but does not currently report on specific numbers of individuals served. For the purposes of policy planning, the Ministry uses a general 1% prevalence estimate for intellectual disability.

The Ministry estimates that approximately 11,000 people receive community support, including approximately 6,500 people with intellectual disability who receive 24-hour residential supports, funded through the Ministry of Health's Department of Disability Services (DDS). An additional 1050 are funded through supported independent living contracts[74] and approximately 240 through individualised funding contracts.[75]

Flexible Community Support Models

The Ministry of Health funds a number of service models for support options that can allow for more individualised support as an alternative to the traditional 'community residential support' ('group homes'). These include:

Individualised Funding (IF), in which a person is allocated a set amount of funds which they can use to hire their own support. This model was introduced prior to 2000, but was subject to a moratorium on any new IF packages, because of concerns about how funds were being managed and used. The service model is again being rolled out nationally, with contracted administrative and evaluation support from an individualised funding agency. [76] As of January 2009, there were 238 people across New Zealand who were accessing IF which allows for funding of personal care or

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[69] Author's calculation based on a NZ national population over the age of 15 in 2006 of 3,160,371 [Statistics New Zealand Census 2006].
[70] National Advisory Committee on Health and Disability (2003), p. 15
[71] Statistics New Zealand (2006) Disabilities
[72] Statistics New Zealand (2007) "Hot off the Press" 2006 Disability Survey Report, p.6
[73] IHC (2008)
[74] Source: Ministry of Health CCPS database as of April 30 2009. People with a primary diagnosis of intellectual disability in the CCPS database represent 68% of the total number of SIL contracts.
[75] Manawanui InCharge (February 19, 2009)
[76] Manawanui InCharge is currently the only individualised funding agency operating in New Zealand.

home support. Current statistics do not indicate how many people with intellectual disability may be using IF.

'Job coaches' from the individualised funding agency can help guide a budget holder through the hiring process and management of their 'staff', including the use of the payroll service. In many cases, another person may be assigned help manage a person's budget. In New Zealand's individualised funding model, this person is not paid, as is the case in some 'support broker' functions that are described in other individualised funding models internationally.[77,78]

In the United States, a study of people with developmental disabilities suggested the strong connection between individuals who had an individual budget (similar to Individualised Funding) and their feelings of control over a range of critical areas of their lives. People's ability to make choices was even more prominent among those individuals who had individual budgets and the services of a fiscal intermediary. [79]

Supported Independent Living provides funding for an agency to support an individual in their own home, and for the individual to direct how necessary support is used, usually up to a maximum of $40,000 worth of services per year. Individuals do not have to manage the human resource issues required by individualised funding. There are a limited number of provider agencies in New Zealand who provide supports to people with intellectual disability through this model. Other provider agencies have expressed a desire to move to greater use of this model, in favour of the homes they currently operate, but have had difficulties changing the contracted model they currently have operating with the Ministry of Health.

Home and Community Support Services
This new service specification (rolled out in 2008) allows for a set number of hours of 'core services' (i.e. essential for maintaining health and safety), and additional 'flexible' hours that a person can choose to use to support activities that are important to them, such as leisure or cultural pursuits. This service specification is relatively new, so there is little information about the uptake and outcomes of people using this service model.

Accessing Supports across Government Agencies

> We don't really have a service system, just a collection of programmes. (Government advisor, March 2009)

In New Zealand, people with intellectual disabilities who need support generally access them through the same process as people with any other disability.[80] For most people this means they are supported by multiple government agencies, and often undergo more than one needs or eligibility assessment. Disability services are currently funded through 11 separate Votes (agency funding streams), resulting in a

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[77] Holman, A.(1999)

[78] Standards and Monitoring Service (2008), Appendix 4 in Ministry of Health (2008), Individualized Funding Scheme Interim/Phase One Review Project Report

[79] National Core Indicators Data Brief: Self Determination and Consumer Outcomes, (March 10, 2004)

[80] There are two notable exceptions. The first is people whose disabilities result from an accident, in which case they access services through the Accident Compensation Commission (ACC). Issues related to ACC are discussed briefly in this paper. The second exception is people whose support needs fall under the Intellectual Disability Compulsory Care and Rehabilitation Act (2003).

multi-silo system of supports with limited cross-agency interaction.[81] Appendix D includes a summary of the 11 Government agencies that fund supports for people with disabilities, including those with intellectual disability. This is presented as background for the reader, and as evidence of the complexity of the current system that individuals face when trying to access necessary support.

ACC
The Accident Compensation Corporation (ACC) is another significant agency that funds community disability supports in New Zealand. ACC provides no-fault rehabilitation and disability compensation insurance to all New Zealanders and visitors who are injured by an accident (vehicle, medical mistake, recreation or work accident, among others), regardless of location (work/home/community). ACC provides individuals with rehabilitation to restore functioning to pre-accident levels and/or compensates people for loss of function.

Since its beginning in 1974, two parallel systems for people with disabilities have been in place in New Zealand. Because intellectual disability is not generally the result of a defined 'accident', the majority of people with intellectual disabilities are supported by the Ministry of Health Disability Support. The ACC system is generally thought to be more generous than the DSS system and allocation of supports.

Due to its targeted mission, ACC is a major sponsor of safety and injury prevention programmes and advertising across New Zealand.

Health Issues affecting the population of People with Intellectual Disability

Many people with intellectual disabilities have higher or different patterns of health needs than the general population[82] and preliminary data in the New Zealand population bears this out. From a person-centred perspective, it is essential that a person's health be considered as a core element in planning activities and that risks be identified and addressed if possible. Risks may include access issues, unhealthy lifestyle, a poorly managed medication regime, or a poor ability to identify signs and symptoms of illness.

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[81] Social Services Select Committee (2008), p. 12
[82] National Health Committee (2004), p. 63

Figure 2: Unmet need reported by adults with disabilities or parents or carers of children with disabilities, 2001 and 2006[83]
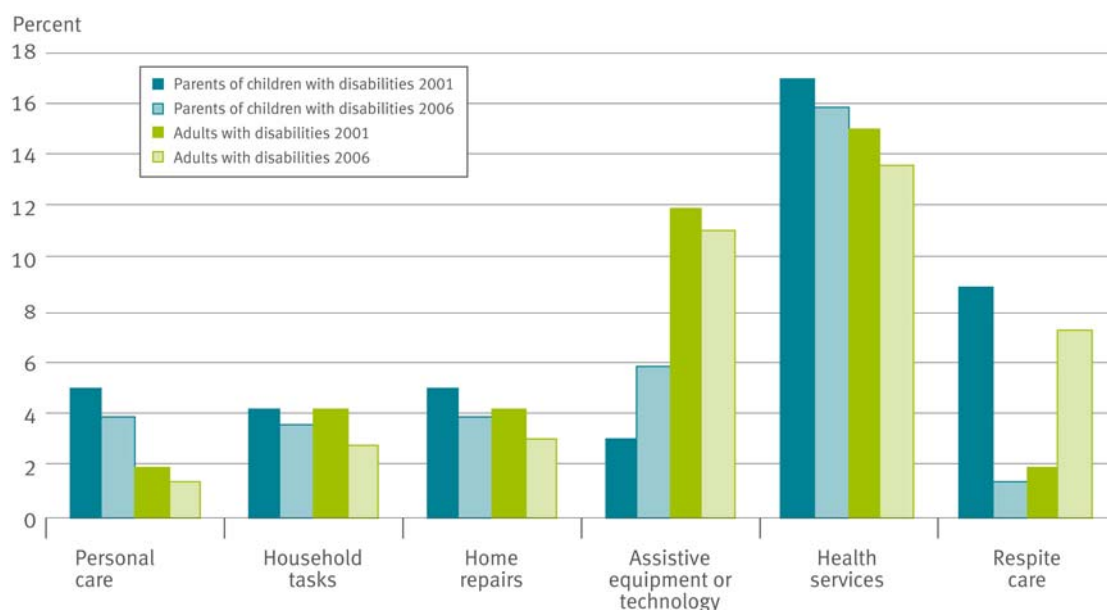
Barriers to health care that have been described in New Zealand and internationally include communication difficulties, a reliance on others to access health care, and low income, which increases the burden of health care costs.[84] Unlike in many Home and Community Based Service (HCBS) waiver-funded services in the United States, there is no contracted requirement for residential providers to ensure that people have regular health reviews with their general practitioner (GP).

In response to the identified health needs of this population, the IHC has provided specific support though:

- Employing health advisors (nurses) who operate in the community to provide advisory support. They may work in an area that covers 400-500 people.

- Implementing an annual health assessment (based on the Cardiff Health Check). At present, the Ministry of Health does not fund this so individuals may need to pay for their own health screening at an 'extended consultation' rate (that can range up to $200). When put to a service user as an option, many choose not to have the annual health check it because it is too expensive.

In order to address this pressing need, the Minister of Health requested that the Ministry deliver a report on options to improve access to and quality of health support for people with intellectual disabilities. The preliminary report was delivered to the Minister in mid-June 2009. It includes several preliminary options for next steps. The options, while very general, suggest the development of enhanced health information for people with intellectual disability, better collaboration with DHBs and primary care organisations, training for professionals, and an examination of the possibility of funding an annual health check.

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[83] Ministry of Health and Minister of Health (2008) Health and Independence Report, p. 29
[84] National Health Committee (2004), p.65

Support for people with High and Complex Behaviour Support Needs

Within the population of people with intellectual disabilities, there are a small number of people whose behaviour puts themselves or others at risk of harm, and may extend to criminal behaviour that involves the police, judicial, prison and parole system. While this number is relatively small in any population, the ongoing complexity of support needs often means that the service systems are required to devote a significant portion of attention and resources to supporting this group of people, often in collaboration with mental health and other community supports, clinicians, and crisis intervention teams.[85]

In the situation where a person's behaviour is so severe as to be deemed criminal, even greater complexity emerges. New Zealand has developed a robust and legislatively complicated solution to the particular challenges in this population through the Intellectual Disability (Compulsory Care and Rehabilitation) Act (2003) and the High and Complex Support Services System. Both are funded and administered through the Ministry of Health's Disability Support Services. These programs are briefly described below in order to lay the framework for a discussion of risk in chapter 2.

ID(CC&R)

The Intellectual Disability (Compulsory Care and Rehabilitation) Act (2003) (IDCC&R) was developed to allow for the provision of compulsory care and rehabilitation to individuals with an intellectual disability who have been charged with, or convicted of, an imprisonable offence. [86] The service model does not have relevant international service models to follow as it is unique in the legislative framework that established and provides for its operation.

The act was broadly modelled on New Zealand's Mental Health (Compulsory Assessment and Treatment) Act, to provide a legal framework for the provision of prison or hospital level care for people who are 'criminally insane', unfit to stand trial, or who are mentally impaired.

The criminal justice system is often not well suited to provide an appropriate level of support, supervision, and rehabilitation that would be required by many people with intellectual disability.[87] The effect of this and related legislative change was to provide courts with the option to order individuals to accept 'compulsory care and rehabilitation' in a setting other than the typical prison setting that is established through the IDCC&R Act.

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[85] Hughes and Daysh (2008)

[86] The act was necessary to address a gap in legislation that emerged when the 1969 Mental Health Act was replaced by the 1992 Mental Health (Compulsory Assessment and Treatment) (MH (CAT)). The relevant change that the MH(CAT) Act (1992) brought into effect was the introduction of a new definition of the term 'mental disorder'. This definition excluded people with intellectual disability from orders that they would previously have been subject to under the 1969 Mental Health Act. In effect, courts no longer had the option to remand people for specialised assessment and treatment if they had an intellectual disability (and no mental illness), with acquittal or mainstream imprisonment as their only option if someone had been found guilty of a crime.

[87] Ministry of Health (2006)

In February 2009 there were approximately 330 people receiving services under the IDCC&R. The following table summarizes key features of the population. [88]

As of September 2008:

- 135 people were care recipients under ID(CC&R) Orders
  - 50 in 'Secure' settings
  - 85 in 'Supervised' setting
- Additional 209 supported as High and Complex 'Civil' (voluntary) clients
- 19 people with primarily mental health support needs supported in ID(CC&R) services
- $75.5M allocated for IDCC&R and High and Complex Services for 2008/2009
- Male:Female ratio roughly 7:1
- Approx. 31% of care recipients were charged with a sexual offence (the most common offence types)

The IDCC&R Act laid out specific organisational structures and roles that must be in place in order to provide treatment. These include significant, structured safeguards to protect an individual's rights.

Organisational Structures:

1. Regional Intellectual Disability Care Agencies. (RIDCA). Four agencies are contracted to the Ministry of Health to provide and coordinate needs assessment and treatment planning under the IDCC&R. These agencies are sometimes referred to as 'super-NASCs' because their assessment and service coordination is similar, but is expected to be much more clinically oriented and robust due to the nature of the population.

2. National and Regional Intellectual Disability Secure Services (NIDSS and RIDSS), as well as Regional Intellectual Disability Supported Accommodation Services (RIDSAS). Community NGOs contracted with the Ministry of Health to provide secure residential support as specified in the Ministry of Health's contracted service specifications.

Positions

1. *Compulsory Care Coordinators* are employed by RIDCAs,[89] and are charged with administering the system created by the act. This includes oversight of needs assessment and care planning and liaison with courts and other interested parties and designation of specialist assessors and facilities in accordance with the Act.

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[88] Daysh, R. (2008)
[89] These individuals are designated by the Director General of Health .

2. *Care Managers* are employed by the RIDSAS and RIDSS and are legally entrusted with the care and rehabilitation of individuals assigned to them under the Act. This includes the development and implementation of individual care and rehabilitation plans, and regular care reviews. Many, but not all care managers are trained nurses.

3. *Specialist Assessors* are experienced health and disability professionals (often clinical psychologists), appointed and funded directly by the designated director-general of health, who are responsible for identifying whether a proposed care recipient has an intellectual disability, assessing the support needs of that person, and recommending the level of care that is "required to manage the risk that the care recipients behaviour poses."[90]

4. *Medical Consultants* are appointed to provide a second opinion regarding the use of medication to control behaviour.[91]

5. *District Inspectors* are lawyers appointed to perform an independent monitoring function and to ensure that people subject to the act have their rights upheld.[92]

In keeping with the values of providing services (or 'treatment') in the most 'home-like' and least-restrictive setting, care orders can specify the treatment setting across a security and supervision continuum, based on an individual's assessed risk and support needs:

- 'Hospital Secure' is the most restrictive setting. There are two such settings in New Zealand, with approximately 40 beds, plus contracted beds in three additional DHB forensic units. Environmental features include purpose-built seclusion rooms, escape-proof entry/exit, and vehicle air lock. Staffing includes immediate access to nursing and medical care, training in calming, restraint, and the use of seclusion, and ready access to a multidisciplinary team.

- 'Community Secure' describes the community home setting, but there is an expectation level of security features such as a single locked access, alarmed windows and high perimeter fencing. Staffing levels are generally higher (e.g. 2:1 in some settings) and staff must be trained in calming and restraint.

- 'Community Supervised' is the least restrictive setting. It includes a requirement for lockable doors and community-based supervision by staff trained in calming and breakaway techniques.

The intention is for people to start in the setting most appropriate to their level of need and progress through less restrictive settings to 'mainstream supports' – those that exist in the community and are available through NASC assessment.

People must have an intellectual disability to come under the care of the IDCC&R Act and can enter services through a transfer from prison, or directly following being accused or convicted of a crime. In recognition of a need for behavioural supports for people who are not necessarily under court order, individuals may be referred to

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[90] IDCC&R (2003) Section 37 (1)(b)
[91] IDCC&R (2003) Section 146
[92] IDCC&R (2003) Section 98

RIDCA from the community (NASC), because of high behavioural support needs, or at the end of their court or parole order, for ongoing treatment. If an individual is accepted through this process (i.e. without court involvement or 'compulsion'), the individual is included as a 'civil' client, with support and services coordinated by the RIDCA.

There are several features of the current implementation of the ID(CC&R) Act that are worth noting:

- The legislation is complex and has many points of intersection with other legislation, the judicial, police and prison systems. There appear to be few people within the Ministry of Health or the provider system with a full understanding of the legislation and the processes that are involved in entry into the system. The Ministry of Health has produced a comprehensive operations guidebook, but the complexity of the interactions often require significant work by several individuals to navigate the system for those not familiar with the Act.

- There is a need to develop specialists who are experienced in risk assessment in this area, as there are reportedly ongoing challenges with developing risk assessments of consistent high quality. This is particularly necessary because the Act has the ability to hold people in 'compulsory care' beyond the course of their sentence if risk is assessed as very high.

- Issues of proportionality. Advocates have questioned the fairness of some sentences in which people have served terms of compulsory care for crimes that are longer than prison for a relatively low level crime, such as theft or property damage. Legal appeals are currently underway that explore these issues.

- The service is being challenged by a higher than expected number of people in the programme. The ability to devolve services back to community supports is challenged by limitations on the availability of specialty assessment or behaviour support.

- To date, there has not been a formal or robust evaluation of the program. One research study will begin in June 2009 to consider the role of Care Coordinators. Beyond basic statistics, the Ministry of Health does not have a structured method to report on processes, measures or outcomes of the system.

Recommendation: The Ministry of Health should commission an external evaluation of the IDCCR. An evaluation of this new programme that includes the experience of care recipients will add to the body of evidence, and provide valuable programmatic information.

Quality Assurance in Intellectual Disability Services

The Ministry of Health monitors quality through a number of mechanisms including:

1. Audits
The Health and Disability Services (Safety) Act (2001) established provisions for the development of service Standards, against which providers of residential support, including rest homes or residences of five or more people would be certified. The

Ministry of Health contracts with independent auditing agencies to complete audits against the Health and Disability services Standards (8134:2008) on a periodic basis for each provider, or on an as needed basis if questions of service quality arise. Basic areas covered in the standards include:

- Consumer rights,

- Organisational management,

- Service delivery,

- Safe and appropriate environments,

- Infection control, and

- Restraint Minimisation.

Formal audits against the service standards are not required for homes for four or less people, although provider and audit agencies generally retain the standards as a structure for monitoring quality across the system. Ministry of Health Contract Relationship Managers (CRMs) monitor quality through reports and direct visits.

This approach to quality monitoring has been questioned in recent years as it is a 'minimum' standard approach, and focuses primarily on the organisational systems rather than the individual or relevant service outcomes.

> NZ services are sensitised to accreditation and certification and risk management. They do a good job monitoring systemic requirements but that can stifle the flexibility and creativity of services.
> (Researcher, May 2009)

2. Outcomes based Developmental Evaluations
In 2007 the Ministry of Health shifted from an audits-based to a 'developmental evaluation process' for community based residential services for people with intellectual disability.

In recognition of the importance of monitoring meaningful outcomes, and in line with the Select Committee Report's recommendations, the Ministry of Health implemented the 'Outcome Focus Developmental Evaluation Tool for Intellectual Disability Community Residential Services'. The tool is focused on quality of life (QoL) outcomes for the person who is receiving supports and probes areas such as individual choice in goal-setting, relationships, health, satisfaction, and personal health and security.[93] It is completed through interviews and observation with the individual and their family/whanau, and staff.

Any problem areas are reflected in a report that returns to the provider agency to use as a guide for service improvement. Serious concerns may prompt an issues-based audit to be ordered. The Ministry of Health has also funded a consultant to work with individual provider agencies to establish organisational plans to address areas in which they could enhance personal outcomes.

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[93] The tool is based on the Council on Quality and Leadership, Personal Outcomes Measure, 2000 Edition.

Findings from the first year indicated that providers are generally more positive about using this approach to quality improvement. Reports highlighted some individual providers who are supporting positive improvements in supporting choice, yet there are ongoing needs for organisational improvements in:

- Supporting communication,

- Developing personal plans,

- Implementing policies and procedures including medication and risk management, and

- Supporting people to be more involved within their home and community.

3. Incident level reporting.
Service providers are required through their service specifications to provide a report of service delivery every six months, including a record of significant or critical incidents that have occurred over the reporting period. The reports received by the Ministry of Health have significant variability as to their detail. The Ministry of Health has not provided significant guidance as to the content or detail expected in this report.

The Ministry of Health's Quality Improvement Committee initiative has focused attention on incident reporting through the development of a process for the analysis and annual pubic reporting of Serious and Sentinel Events across all 21 of New Zealand's DHBs. A draft Policy for the Management of Healthcare Incidents[94] was distributed within the Ministry of Health as a policy document for the entire health and disability sector, yet the frameworks, reportable events, and processes for severity assessment do not indicate that they are designed for anything other than hospital-based care. It is anticipated that the disability support system may be brought in 'at the tail end' of the work with DHBs. Currently, there are no specific plans in place to develop a system for reporting or analysing incidents, although high level discussions have begun to recognize the need to better integrate and report on mortality and incident data that is reported to the Ministry. As is noted in chapter 3, the disability support sector as a whole will require a significant level of support to get to the level of data recording, analysis, and interpretation that is suggested in this system.

The Quality of the Individualised Funding (IF) scheme is expected to be monitored through the individualised funding agency, Manawanui in Charge (MIC), as it is not subject to the same Ministry of Health audit and monitoring approach. As a person-centred programme, there is no sensible avenue to monitor workers who are hired by budget holders from a top-down approach, yet monitoring is still necessary. IF job coaches are charged with this responsibility. A report in 2008 suggested that MIC may need to be more involved in monitoring quality.[95]

4. Complaints
The Ministry of Health operates a complaints line for issues related to services that it provides. In 2007/2008, it received 96 complaints related to service delivery. The complaint process is structured in a way that keeps the complainant informed

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[94] New Zealand Health and Disability Sector (25 September 2008) Working Draft Version 1.0
[95] Standards and Monitoring Service (2008)

throughout the process. In 2007/2008, parents and family were the most likely to make complaints. Community members noted that the complaints process may not be an appropriate way to support quality services among Māori and Pacific Islands communities, since 'speaking up' or lodging a complaint in this manner is not necessarily an accepted cultural practice. This complaints line is additional to the one operated by the Health and Disability Commissioner.

Key issues relating to the system of supports for people with intellectual disability

When considering issues related to strategic planning for supports for people with intellectual disabilities, four key themes emerge:

1. The population is changing, as are the support needs.

2. Competing priorities can derail planning and implementation for this relatively small stakeholder group.

3. Fiscal issues arise related to transparency and efficient use of resources.

4. There are variable approaches to quality assurance and risk management across the health and disability supports sector.

These four (interrelated) factors are highlighted because they may challenge progress toward a system that supports people with intellectual disability in individualised services. As such, they may be considered 'risks'.

1. Changing population needs

- The rate of diagnosis of autism spectrum disorder is growing in New Zealand, as it is in other developed countries. One in 150 children are being diagnosed with autism[96], and about 75% of people with autism also have an intellectual disability[97], creating a need for services that better meet the needs of people with autism spectrum disorders. In 2008, the Autism Spectrum Disorder Guideline was launched, which provides a firm evidence-base for the development of effective services and support for people with ASD in New Zealand.[98]

- Recent preliminary analyses by the Ministry of Health suggest that there is a significant youth population with diagnosed intellectual disability, as suggested in the following figure.[99] Further investigation is merited to clarify this finding as there are questions as to the application of the 'ID' diagnosis. As it is, this points to the need to consider emerging population demands for service. Anecdotal evidence suggests that a larger percentage of this group may present with behaviour support needs and that demands for flexible funding and housing arrangements are particularly high among young adults.

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[96] Autism Collaborative (n.d.)
[97] Learning about Intellectual Disabilities (n.d.) www.intellectualdisability.info/diagnosis/autism.htm
[98] Ministries of Health and Education. (2008) New Zealand Autism Spectrum Disorder Guideline.
[99] Personal communication with Trish Davis, 3 March 2009

Figure 3: Preliminary MoH Dataset Analysis: Age Distribution Pyramid
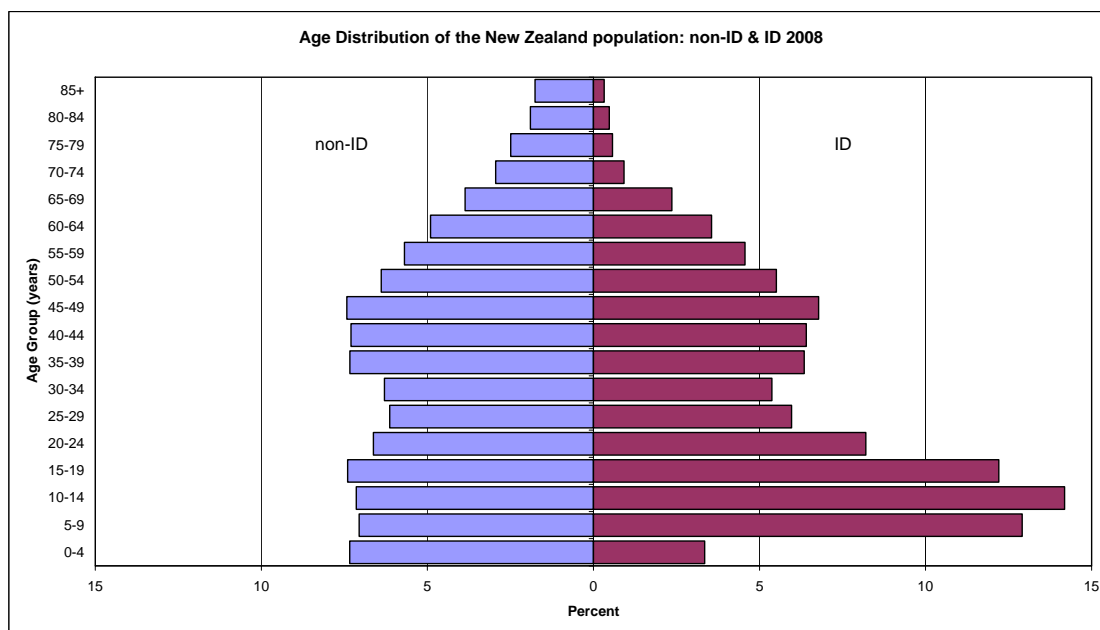
Source: MoH Dataset of people receiving ID services (n = 20,953) [100]

- People with intellectual disability are living longer and are therefore subject to an increasing number of chronic health conditions, as in the general population. The disabling effect of a chronic disease can have significant impact on this population. It is important to consider emerging and changing health needs in this population that is already experiencing less than average levels of health.

- The ethnic composition of New Zealand is geographically varied and changing. Growing numbers of Māori and Pacific Island populations will increase demand for services that are culturally appropriate and address particular population needs.

- There is reportedly a significant regional difference in the distribution of adults with an intellectual disability, partly as a result the development of significant community residential capacity near institutions during the time of deinstitutionalisation. Children with an intellectual disability are noted to be more evenly spread across the country and this will have implications for service delivery in the future. [101]

2. Competing Priorities

In a dynamic and complex public policy environment multiple priorities and work plans operate concurrently, often times competing for attention and resources from Ministers and government officials.

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[100] Includes DSS-known clients with an intellectual disability or those who attended services specifically for patients with intellectual disability (2005 to 2008) and/or NMDS patients with a diagnosis code of F70-F73 (Mental retardation) from 1988-2008. In order to be captured in the 'ID' group, a person must either have a diagnosis associated with a hospital medical encounter or the person must be receiving 'intellectual disability' services from the Ministry of Health.
[101] National Advisory Committee on Health and Disability (2003), p. 26

Funding and administration of the bulk of services for people with intellectual disabilities is located within the Ministry of Health's disability support system. This population represents only a portion of people with disability in New Zealand, but due to the nature of intellectual disability and ongoing support needs, there is a significant portion of resources spent on this population.[102] As is the experience in the United States and elsewhere, tensions can arise between disability groups in a public funding arena in which resources are limited and must be shared. During the course of interviews for this project, several people tempered suggestions for service improvements aimed at people with intellectual disability (such as funding annual health screening) with the notion that the improvements might not be supported because of the risk that other disability groups would demand equal treatment.

The competition and market forces that have been introduced into the disability support system may have contributed to choice among service providers, but it has also created a competitive environment that constrains trust and open sharing among and between providers, and with the government funder.

Several key informants shared the perception that concerns for people with disability were regularly being pushed aside by other important yet competing (and politically driven) priorities within the Ministry of Health such as reducing acute-care waiting times and,[103] most recently, pandemic preparedness and response.

The Office for Disability Issues provides an overarching role in overseeing and coordinating government disability supports, yet there is no single government organisation that focuses specifically on the issues related to people with intellectual disabilities.

New Zealand does, however, possess a well-developed advocacy community for people with intellectual disability. The IHC provides advocacy for the population, as well as self-advocacy groups such as PeopleFirst. The Donald Beasley Institute in Dunedin is a well established research organisation that focuses on intellectual disability research. Several informants for this study suggested that the advocacy and service delivery community has greater 'institutional memory' regarding the history, service models, and values that have led to today's system.

3. Financial pressures / managing financial resources.

- Disability supports have been experiencing rising demand for several years, and many interviewed for this project expressed the belief that eligibility criteria continue to be tightened as a way of guarding limited resources and managing financial risk. New Zealand does not currently have a significant waiting list for residential services in most areas, in contrast to many states in the United States and other countries where time on a waiting list of several years may be a feature of entry into residential services.

- The Ministry of Health has been making moves towards greater transparency in the process used to assign and fund supports. Aged care disability supports

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[103] Social Services Select Committee (2008)

(administered and operated by DHBs) have now begun to use the interRAI assessment tool[104] to establish a consistent approach to assessing need and allocating resources. There is no such common or standardised tool used by NASC, although some interviewed for this project did not discount this as a possibility. The Socrates database[105] that was developed for data collection by NASCs is intended to gather better information regarding functional needs and to support greater transparency in funding. Concerns raised about this approach centred around the validity of the functional categories that may be used.

- Following the devolution of disability supports for people over the age of 65 to DHBs, there was an expectation that this shift would also occur for supports for people with disabilities under age 65. Questions as to the advantages (such as better alignment with local population service models) and disadvantages (cost and disruption of structural reorganisation, disparate policy development) have not been fully resolved. There are no imminent plans to shift this service from the Ministry of Health to DHBs at present.

4. Accountability and Risk Monitoring

The Ministry of Health is responsible for monitoring and addressing quality in both the health and disability supports that it funds, yet there is a highly variable approach to quality and risk management, and the level of analysis that is possible. Varied perceptions of risk and how to manage it are introduced below and explored further in Chapter 2.

'Health'

Risk management is accepted as an integral part of the Ministry of Health's Quality Improvement system, as well as the incorporation of measures to allow for evaluation of quality outcomes across the system. Systems that identify risk of harm and reduce the likelihood of negative outcomes are viewed as an essential part of ensuring that health supports are being delivered in an effective manner. Programmes are set up to monitor risks, identify trends, and develop systems that reduce risk. These systems may provide effective risk management, or 'safety', but are regularly criticised for lacking a person-centred approach.

'Disability'

While a move away from institutional living has enhanced the lives of many, living in the community typically involves greater choice and may expose people to greater risk of adverse events. Rather than preventing this, the role of government is to ensure that individuals are not exposed to undue risk and that government funds are used to support activities that promote wellbeing and safety. Risk management is thus a key element of community service planning for people with disabilities, yet there is a variable and inconsistent approach across the service sector. This places the support system in a position of being less able to defend moves that encourage flexibility in the context of a system that values safety first and foremost.

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[104] Assessment tool information available at www.interrai.org
[105] This database was developed with funding from the Ministry of Health and rolled out in the sector starting in 2007. It is discussed in greater detail in chapter 3.

Summary

Adults with intellectual disabilities receive supports and are living lives in the community that are generally better than they were a generation ago, but there are enduring challenges to the quest for an 'ordinary life'. New Zealand's Disability Strategy provides a solid values base for the work that lies ahead to create a society that provides for 'full participation' of people with intellectual disability, as well as other disability.

Government, through the Ministry of Health, has been working to increase choice and flexibility through a number of service and funding initiatives, including individualised funding. Progress has been slow, however, with the bulk of people with intellectual disabilities who need residential supports living in settings where they have only limited choice on where they live, or with whom.

The ID(CC&R) Act is the most recent (and only) piece of legislation that is targeted at people with intellectual disability – and it only applies to the compulsory care of people who have been charged with or convicted of an imprisonable offence. The services offered under this act are challenged by an increasing demand for clinicians who have highly specialised skills in assessment and treatment. An external evaluation would help to identify progress to date and clarify issues that must be addressed for the ongoing sustainability of the programme.

Pressures on the system include a changing population with changing needs, financial pressures including a demand for greater transparency in funding decisions, competing priorities, and increasing demands for accountability and assurances of 'safe and effective' services.

2   RISK AND RISK MANAGEMENT IN INTELLECTUAL DISABILITY SERVICES

> Risk is an opportunity, both positive and negative. It is necessary and a part of life – we need to learn how to deal with it. (ID Provider agency executive, March 2009)

Risk is a part of ordinary life in communities where people live and work. People manage risk in all aspects of life – for example in their homes, in personal investing, when they drive or take public transportation. Support systems manage multiple types of risk through a variety of strategies – for example staff training in health and safety, strategic risk analyses, and in preparedness exercises for civil emergencies.

The opportunity to choose to be involved in a life that involves risk, and the need to address or 'manage' risk are both important parts of service planning in disability support systems. There is great variability in the understanding and application of risk management in the context of support for people with intellectual disability.

In the United States, the federal Centers for Medicare and Medicaid Services (CMS) have implemented requirements for states to demonstrate that they have policies and practices in place that ensure the health and safety of participants in the Home and Community Based Services (HCBS) Waiver, both on an individual and an aggregate basis. Risk management is an important component of these systems. In the monograph *Risk Management and Quality in HCBS: Individual Risk Planning and Prevention*, Galantowicz et al. suggest there are three important steps for successful risk management for people served in HCBS waivers:

1. Identification, documentation, and management of risk to an individual through effective supports planning,

2. Ongoing monitoring of risk, implementation of prevention strategies and training of staff, and

3. Individual and system-wide analysis of data and other information regarding risk.[106]

In New Zealand, this approach is equally applicable in order to ensure that people are effectively supported.

Defining Risk, Risk-Management, and Risk-taking

The Ministry of Health's Disability Services Strategic Plan (2008-2010) describes a vision that builds on the New Zealand Disability Strategy and includes supporting both families and adults with disabilities to have choices and 'take risks'.[107] The values of choice-making and risk-taking are not unfettered, however, as is noted in the accompanying implementation plan, Strategic Priorities (2008-2010): "Making the vision a reality".

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[106] Galanctowicz (2005), p. 3
[107] Ministry of Health Disability Services (2008) Strategic Plan 2008-2010: towards a more flexible disability support system

The DSS Strategic Priority 1.2 is as follows:

> The 'system' supports the disabled person to make some choices and trade-offs. To do this, it is important to:

- Identify, with the disabled person, what lifestyle choices are important to them.

- Identify which of those services they get they may be able to swap for other services that they want (within funding and policy limits and excludes services that are essential to the safety and well-being of the service user).

- Change the system to enable the person with a disability to make informed decisions about the supports they receive. [108]

In just this one portion of the implementation plan, the 'vision' of choice is tempered with three significant statements:

1. '…within funding and policy limits…' suggests an effort to manage **financial** risk through approved budgets, and capped and ring-fenced funding. **Organisational** risks are managed with policy that defines the scope of supports or services a person may receive.

2. '…excludes services that are essential to the safety and well-being of the service user…' suggests the management of **individual** risks to personal health, safety.

3. '…enable the person with a disability to make **informed decisions**…' implies that there may be information or supports that a person and their family/whanau need in order to make the best decision. Choice-making often involves weighing options, and often includes an implied assessment of the advantages and disadvantages of any risk.

Throughout the course of this project, the author interviewed people in a wide range of settings in relation to risk and the role of risk management in support for people with intellectual disability. What became clear early on is that, while risk is a word that is familiar to almost all, the value and meaning ascribed to risk varies significantly. Relevant interpretations of risk are summarised below and described in greater detail in the section that follows:

- While service users and their families/whanau described how they 'stay out of trouble', they did not generally identify with the term 'risk management'. Safeguarding is a term that was more familiar to some. People with intellectual disability and their families express a desire for support in managing risk in other terms, such as "thinking through the 'what if's, and making sure someone is 'safe'. [109]

- Service provider agencies have variable approaches to assessing for and managing individual risk. Those providers who supported people with more challenging behaviour were more likely to have developed risk management systems, although the systems ranged from 'well supported staff' to checklists

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[108]Ministry of Health Disability Services (2008) Strategic Priorities 2009-2010.
[109] Milner P. (2008), p. 12

that must be completed prior to community outings. Risks to 'Health and Safety' were often interpreted as meaning 'Occupational Health and Safety', rather than the health and safety of the people who receive supports.

- In a survey completed by eight residential provider agencies 'risks' that need to be managed ranged from 'risks to health and safety' and 'behavioural health risks' to the 'risk of negative media attention.'

- Ministry of Health contracts and service specifications are similarly variable in their reference to risk, with a mix of references to organisational risk (as in the community residential provider's 'Risk Plan'), and personal risks (as in the Home and Community Based Support service specification). Contracts and service specifications identify 'risks' as something to be 'controlled' or 'managed', with the notable exception of the NASC 'entry' to services, in which there is no explicit discussion of risk.

- Representatives from Needs Assessment Service Coordination Agencies (NASC) who were interviewed did not address risk specifically in their Client Driven needs assessment process. Perceptions of risk included concern that too much focus on risk might result in a 'deficits based' assessment, identification of barriers to a service plan, or create a picture of support needs that cannot be met within current budgetary constraints.

- Planning for flexible supports, such as through Individualised Funding should include an assessment of individual risks, as well as system risks (such as in contract employee arrangements). This will allow for the identification and resolution of potential problems early on, before problems emerge that result in the imposition of restrictions rather than the desired expansion of the programme.

- In settings in which risk management processes are most critical, such as in ID(CC&R) secure residential facilities, assessment and planning processes are highly developed. Both clinical and non-clinical staff are keenly aware of risks, and supports are regularly structured in a way to control or minimise risk.

Exploring Risk in New Zealand Disability Supports

New Zealand's Health and Disability Standards[110] were developed as a framework for quality audits across a wide range of community and hospital settings. They include specific criteria and guidance regarding restraint minimisation and safe practice, as well as approved quality and risk management systems, in line with national and international best practice. The definitions offered in these standards are useful to this discussion:

Risk: The chance of something that will have an adverse impact on objectives. [Objectives can include individual health and safety]

Risk Management: The culture, processes, and structures that are directed towards realising potential opportunities while managing adverse effects.[111]

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[110] Standards New Zealand (2008) Definitions p. 29
[111] Standards New Zealand (2008) Health and Disability service Standards

Ministry of Health requirements to 'manage risk'

The Ministry of Health standard provider contract includes a requirement for contractors to have policies and procedures to manage organisational and financial risks through processes that include identification, evaluation and prioritisation, addressing risks of hazards and accidents, monitoring and reporting incidents, and "staff debriefing as necessary".[112]

In the absence of any specific guidance, providers have developed their own risk management plans, in response to their organisational realities. As a general observation, providers who support people who have significant behavioural needs are more likely to establish and refer to behavioural risk plans, while others who support people with more significant physical support needs referred to environmental hazards and medical risks more often.[113]

Risk in Residential Supports Service Specifications
Service specifications describe specific funded services for which the Ministry of Health currently contract. A review of key service specifications reveals significant variability in how risk is considered.

- 'Mainstream' Community Residential Support Services for people with intellectual disability requires the provider's Risk Management Plan to include consideration of safety, security, dealing with challenging behaviours, documentation of crises and incidents, and "maintaining positive relationships with the community". [114]

- Home and Community Support Service defines 'core hours' as being necessary to keep the person free from health or safety risks, as determined during the NASC (or ACC) service planning process. There currently is no structured process or tool used by NASCs to consistently assess health and safety risks.

- Supported Independent Living describes the requirement of the provider to address 'safety' issues through policies and protocols regarding behaviour management, medication administration, minimisation of risk of physical or sexual abuse from others, clinical aspects of personal care, and healthy lifestyles issues.[115]

- Behavioural Support Survey Specifications (community based or residential) primarily refer to 'risk management' in relation to management of behavioural incidents, in order to ensure that staff and individuals are kept safe.[116,117]

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[112] Ministry of Health, Residential Heads of Agreement Contract, Section B7.2
[113] Survey to NRID providers (Appendix B) and interviews.
[114] Ministry of Health Service Specification: DSS 1031: Community Residential Support Services – Intellectual Disability 5.1(ii)
[115] Ministry of Health Service Specification: DSSL2621: Supported Independent Living – Intellectual Disability
[116] Ministry of Health Service Specification DSSIDSS Regional Intellectual Disability Secure Service 5.1(iii)
[117] Ministry of Health Service Specification DSSRIDSA Regional Intellectual Disability Supported Accommodation Service 5.1(iii)

- The one service area in which risk assessment and management is most formally defined and regularly employed is in the supports that are provided under the IDCC&R Act. Specialist assessors under the Act provide expert clinical assessments of risk for use by the courts and service planning team in the determination of risk. A formal plan is developed that includes risks, their likelihood and their impact. The value of 'taking risks' was described several times in this context, perhaps because the providers felt that they had adequate systems to support such risks.

Perspectives of risk among service users

'Risk management' is a term that is not part of an 'ordinary life'. While the term is immediately familiar to clinicians and managers, it became clear during key informant interviews that it is service delivery or systems' jargon that must be learned. People who receive support, including family and whanau did not generally identify with the term 'risk management', yet several people used other words to describe situations in which they expected processes that could be interpreted as risk management.

> The NASC asked me about what we wanted to help our daughter. It was a new and stressful process. Thinking back on it, I would have liked more help with thinking through some of the 'what ifs', maybe not the first time, but it would have helped me be better prepared for some situations that came up later.. (Family member of a service user reflecting on their first NASC assessment – April 2009)

The term 'safeguarding' has greater resonance with person-centred planning approaches and is often used in the provider community. In general, the term refers to the identification and provision of support needs necessary to guard a person's health and safety. What the 'dangers' are seems to depend on the context and perceived risks.[118,119,120] This has significant overlap with 'risk management' but is more acceptable in the service context because it does not impose the idea of a bureaucratic 'management' process into a person's life. The individual is the focus, rather than the system.[121]

NASC Perspectives of Risk

A significant feature of the NASC assessment is the Client Driven Needs Assessment, in which people present their own perceptions of priorities and needs. In discussion with NASC providers, it became clear that the needs assessment process does not explicitly address risk. If, during the process of a needs assessment, the individual or

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[118] The medical safeguarding initiative in Massachusetts (http://medicalsafeguarding.org/) protects vulnerable people though healthcare enhancement and support and advocacy in their encounters with the health care system.

[119] The Queensland Safeguards Project has been working to develop an understanding of the nature and role of safeguards in supporting people with models outside the traditional service model.)Safeguards Project Discussion Paper #1 (n.d.)

[120] The MoH service provider contract includes the statement "you will safeguard service users, staff and visitors from infection" and "you will safeguard service users, employees and visitors from intrusion and associated risks" (p.30). This is in a separate section from the 'Risk Management' requirement.

[121] Kendrick (2000) cited in Kendrick, M. and Hartnett, M. Choosing Values in O'Brien, P. & Sullivan, M. (2005), p.41

their family/whanau identifies an area that may be a risk, then planning may include 'risk management', but risk assessment is not well defined in the NASC process.[122]

> We had a young man come to us who needed residential support and it would have been really good to know about some of his history and some of the things that might get him in trouble and pose some risk to the community but that wasn't shared with us because of the Privacy Act.[123]
> (Former manager of a community residential provider, May 2009)

The value ascribed to assessing and planning for risk is variable among NASC providers. Some reported that they felt that a thorough needs assessment would identify risks, but that there was no direct discussion of risk. Another perspective that was raised included the danger that a focus on risk assessment may bring up too many risks to be considered, and that the planning team (person with ID, family/whanau, needs assessor, other invited participants) might think that a plan to support someone in a flexible way would be 'too hard', resulting in placement in a more restrictive environment. If a thorough risk assessment identified a level or type of support that was not available, this could lead to frustration and dissatisfaction.

> Health is important but I don't bring it up unless the person does. A person's medical diagnosis doesn't make them who they are.
> (NASC Needs Assessor – April 2009)

Risk in Individualised Funding Models

The DSS Service specification includes the following pertinent references:

- The Individualized Funding Agency (IFA) will make sure safe administrative support arrangements are in place to ensure the IF budget holder can manage with as little risk to themselves as possible.

- …training in lifting and handling [for staff] when appropriate.

- The possibility of provision of an 'independent advocate' to monitor situations where a person has their budget managed by somebody else (as may be the case for someone who has intellectual disability).

- The IFA must inform the Ministry of Health of any significant risk such as fraud, inappropriate use of IF money, and safety risks to service users. [124]

There is reportedly no standardised process currently in use to identify and help plan for risks, rather these risks are identified as part of general planning with the NASC and IFA. The Phase One review of the scheme recommended that the "MoH should work with NASCs and providers to improve information and support given to clients about the scheme, and about managing the processes within it, including **mitigating risks**…"[125] In response to concerns about the inappropriate use of 'contract employees' (related to not paying the appropriate tax and insurance levies), the

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[123] The Privacy Act 1993 describes the structure for gathering and maintaining personal information. Rule 11 describes the circumstances in which health information can be released including authorising the release of information "if the release of that information is necessary to prevent or lessen a serious or imminent risk to others" (Rule 11(2)d)
[124] Ministry of Health Individualized Funding Service Specification DSS-IFA
[125] Ministry of Health (2008) Individualized Funding Scheme Interim/Phase one Review Project Report, p. 32

Ministry of Health has issued guidance that this option should be stopped, thereby reducing flexibility.

Residential Provider Perspectives of Risk

Results from the survey of providers and the content of interviews with provider agency staff and executives revealed several themes:

- Attention to health concerns (risks) are variable and depend on the population that the provider serves. Providers who serve adults who have significant behavioural issues are more likely to focus on areas of behaviour management, staff and client safety, than to consider potential or emerging health issues.

- There is great variability in how people in the 'mainstream' provider community approach risk assessment and management.[126] Several providers and self-advocates emphasised the importance of 'taking chances' and the 'dignity of risk' as the primary concern for people they support. Others employ a more systematic approach by establishing processes such as 'environmental risk' checklists, and checklists that must be completed before people are accompanied on community outings.

- Occupational Safety and Health was often the first thing people mention in reference to risk. Additional individual and organisational risks only emerged after clarifying the breadth of the definition of risk.

- Several agency representatives noted that less experienced staff tend to 'take fewer risks', because they may not feel prepared or supported to deal with events that emerge.

- Providers noted that available funding simply does not allow for systems to be put in place that would allow for the analysis of risks system-wide, such as tracking cause of death.

- The organisational risks of negative media exposure (in the case of an 'accident' or 'incident') are perceived as significant and real.

Kia Mataara: A Māori Perspective on Risk

One manager in a Māori service provider agency noted that, "Māori people figured out risk management hundreds of years ago because we had to be vigilant all the time." (kia mataara)

This is a key point in risk management – that all the people in a community are vigilant in order to assure the common good. As our modern society has multiple and competing values regarding the 'common good', it becomes increasingly difficult to consistently define what that is and therefore what we need to watch out for or defend.

In Māori service provider organizations, kaumatua (elders) are employed with the express purpose of ensuring that Māori tikanga (cultural practices) are maintained. For families and people with intellectual disability throughout New Zealand, having good support to achieve the goal of an 'ordinary life' in the community is a common

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[126] NRID Survey (Appendix B) and interviews with providers

desire. Service providers may have this as one goal, but also aim to build a network that supports as many people in their community as possible.

The government funders of support still aim to make sure that people get the supports they need, but they are accountable to their government ministers and the population and must be able to make assurances that supports are effective and a good use of public dollars. In this analysis, vigilance includes a complex set of interrelated priorities that must be monitored.

Perspectives of Risk in ID(CC&R), High and Complex Supports

New Zealand's legislative framework for supporting people with intellectual disability who have demonstrated criminal or dangerous behaviour, the Intellectual Disability (Compulsory Care and Rehabilitation) Act (2003), has a significant focus on assessing and addressing risk. The requirements for specialist assessments of risk and the development and monitoring of risk plans by care managers have drawn together small 'expert nodes' within the system that have a deep understanding of risk, including the value of risk-taking. This should not imply that these experts have risk assessment and planning 'figured out'. Actuarial tools are generally used, together with clinical assessment, to arrive at an assessment of risk and a set of recommendations.[127] Yet the 'high stakes' nature of assessment for risks that could result in serious harm to a person or the people around them can understandably lead to a conservative assessment of risk.

In Otago, the community liaison team developed the IDRAMS: Risk Identification Register which identifies behavioural risks, relative to the person's 'ideal' state. The goal is to complete a risk assessment on all RIDCA clients in the Otago region. Some other (NASC) clients are identified and the process is used with them as well. The risk identification register is reviewed and re-done at least annually. The tool is reportedly very useful to help guide staff in managing a person's behaviour. The tool is not used to collect information for aggregate analysis.

Clinical assessments of risk in this setting must balance safety risks against the risk of imposing inappropriate controls on somebody. This could mean that courts should inquire whether it is absolutely imperative to remand someone to compulsory care, rather than establishing services for them as a 'civil' client.

The structure of the ID(CC&R) provides for a clinician to assess risk and extend the time that a person is required to be a 'care recipient' beyond the term of their original sentence, if clinical assessments identify that there is a high level of risk that cannot be managed in any other setting. The Ministry of Health is currently involved in legal appeals, in which people who were care recipients, and their advocates, are questioning the legal right of the state to continue to 'hold' someone beyond the term applied in the original court order. These questions will be subject to a growing body of case law, including questions regarding the potential for civil liability for harm to others in situations in which the assessment and management of risk was deemed to be inadequate. There is clearly a significant level of pressure and scrutiny, and a need for specialised expertise regarding clinical assessment of risk in this population.[128]

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[127] Edghill, R. (2003)
[128] Wilson, N. (2008)

'Dignity of Risk'

This was referred to by several service providers, as being a concept that is included in staff training. However, as O'Brien et. al pointed out:

> The idea of "the dignity of risk" is a valuable corrective to the tendency to overprotect and overregulate. But it doesn't provide much guidance for knowing when to choose for safety.[129]

Examining the Safety First, Risk-Averse Context

> It is important to recognise the benefits of taking risks, as well as the potential consequences. With risk management, we only look at what might go wrong. (Clinical Psychologist, May 2009)

In the context of an overarching New Zealand Disability Strategy that promotes individual choice (and the opportunity to take risks), there are multiple pressures on the system that supports people with disability.[130] These include:

- Conservative clinical interpretation of risk,

- Accountability and quality reporting demands,

- Occupational health and safety requirements,

- Contractual obligations to 'manage risk',

- Service frameworks designed to manage financial risk, and

- A range of values relating to risk, including a public that expects the government to 'protect' people with intellectual disability and keep them 'safe'.

The findings in this study suggest that these pressures generally impose a risk-averse bias in service delivery, one that is concerned primarily with 'safety', above other concerns. It seems safety should be paramount, particularly in the provision of publicly funded supports, but a blanket emphasis on safety without consideration of other factors regarding a person's welfare and satisfaction can create barriers to achieving the human rights inspired vision of choice-making and autonomy.

Titterton (2005) describes the dangers of a 'safety first' approach that:

- Denies the right to choice and self-determination,

- Can lead to loss of self-esteem,

- Supports a form of institutionalisation with the loss of individuality, volition, and an increase in dependence, and

- At its worst… can lead to the abuse of vulnerable people.[131]

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[129] O'Brien, et al. (2004), p. 43.
[130] Titterton (2005), p. 13

Taking risks in a risk-averse environment: moving from 'safety first' to 'risk taking'

In ordinary life settings, people balance opportunities against risks all the time. A system that supports people with intellectual disability must be able to achieve this as well.

This is referred to by Titterton (2005) as a 'risk-taking' approach which:

- Celebrates the taking of risks as a way to enhance people's lives,

- Recognises the importance of psychological and emotional needs, as well as physical needs,

- Promotes choice and autonomy for the person and their family, and

- Promotes the rights of vulnerable people and their carers, **while accepting that these will sometimes be in conflict**.[132]

The following quote from a member of the whanau of a young person with intellectual disability provides one example of such conflict:

> It's a matter of partnership – the people who do the choosing need to be the professionals, the parents, the person who is concerned, the community. I think there has to be a partnership between all those groups of people, and eventually it is decided whether the person should receive these special services. There will be conflict, tension between the groups but ultimately for the benefit of the child. O.K, sometimes it will be recognized that they must agree to disagree but there will common areas where they will forge ahead.[133]

Conflicts that Arise from Different Perspectives on Risk

During the course of this study, people with intellectual disability and their support providers were able to offer multiple examples of conflict, or 'sticking points' where the rights and interests of an individual and their support providers may be at odds.

Example 1: Occupational Safety and Health
The Health and Safety in Employment (HSE) Act 1992, and the HSE Regulations 1995 require employers to take all practicable steps to ensure the safety and health of employees and others while at work. The workplace definition includes any place where a person works, so all home and community settings where people receive supports are included. Provider agencies, as well as people who are 'employers' with IF funding, must comply with these regulations and employees also have responsibility to comply.

Two recent initiatives by the Department of Labour – Occupational Health and Safety have increased the pressure on providers to consider risks to employees.

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[131] Titterton (2005) p. 15. As discussed in chapter 1 in relation to institutional models of care, a closed system of supports has the potential for the unchecked development of abusive or neglectful situations.
[132] Titterton (2005) p. 16. Author's emphasis.
[133] Ballard (1994), p. 222

1. The "Managing the Risk of Workplace Violence to Healthcare and Community Service Workers: Good Practice Guide" [134] was developed in response to several extreme incidents of violence between patients or clients and their caregivers that resulted in the death of at least one health care worker. The guidelines focus on managing the risk of violence in every situation, provide specific strategies for diffusing aggressive behaviour, and imply a no-tolerance level for workplace violence. Providers and the Ministry of Health responded that this guidance does not take into consideration the settings that support people with significant behavioural issues. While the risk of violence should certainly be considered and managed, physical aggression by some people who receive supports is a fact of life. Limited ability to communicate may mean that someone uses a violent way to express themselves. To completely eliminate the risk of violence would likely require inappropriate use of physical or chemical restraints, thereby creating a significant risk to the rights of a person.

2. The "Code of practice for manual handling" provides Occupational Safety and Health guidance on lifting. Depending on the worker, some providers have interpreted the risk assessment guidelines as suggesting that there should not be any one person lifts over 14kg (31lbs). [135] These guidelines impose restrictions that limit flexibility for people who need help with transfers and prefer (or feel safer) with transfers that involve only one person. If a support provider is willing to transfer a person, then they may not be meeting their own responsibilities as employees under HSE Act.

The conflict in New Zealand between health and safety and the ability to live a life that supports risk-taking is not at all unique. Commenting on supports in the United States, French and Swain (2008) note:

> As health and safety legislation has tightened over the years, disabled people have found them more and more restricted and, paradoxically, prevented from undertaking 'normal' tasks. [136]

Example 2: Individualized Budget holder
Mike[137] lives on his own in Canterbury, with home support that he employs using Individualised Funding. Living on his own involves risk sometimes, since he has a balance disorder that increases his likelihood of falls. He likes to put posters up on his ceiling and does this by climbing up on chairs. His friend Marilyn has never seen him do this, but knows he will usually do his home decorating when nobody is home.

Marilyn helps Mike with reading and managing his personal affairs, including managing his individualised funding package. She is the one who Mike calls when he has a problem, and other people call when they are concerned about Mike. Marilyn and Mike do not always agree about things that Mike wants to do. Once Mike was

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[134] Managing the Risk of Workplace Violence to HealthCare and Community Service Workers: Good Practice Guide. Department of Labour (2009)
[135] Code of practice for manual handling. Published jointly by the Occupational Safety and Health Service of the Department of Labour and the Accident Compensation Corporation (June 2001)p.46
[136] French, S., Swain, J. (2008), p. 92
[137] Mike requested that his real name be included in this report. He would like people to know that he likes Americans and America.

hospitalised for a broken toe and the hospital felt that Mike should stay at the hospital to reduce the risk of him falling and hurting himself more badly if he went home. Mike called Marilyn and asked her to pick him up at the hospital. Marilyn was also concerned about Mike's safety so she said she would not do it. Mike checked himself out of the hospital and found his own way home. Later, Marilyn and Mike talked about this and she explained why she did not come and get him. Marilyn said she and Mike have had help to manage the staff Mike hires, but she wished there were some support available for them around managing those tough situations relating to choice and risk.

Effective implementation of policy that supports risk taking must therefore recognise situations of conflict and either support creative ways to address or resolve conflicts. This has been referred to as "dilemma management".[138]

Negotiated Risk Contracts

One solution to managing the conflicts that may arise between and among people who need support, and those who provide it, is negotiated risk agreements or contracts. In recent years, agreements have been used in several states in the United States.[139] Proponents of the idea suggest that these agreements provide a structured way in which to identify the particular choice that is being contested, and what positive and negative outcomes are anticipated from the particular risk. If a person chooses to do something that cannot be approved of, or supported by the provider, this is seen as an adult way to 'agree to disagree', documents the discussions and outcome, supports person-centred approach, and makes people clearly responsible for their own actions.

Opponents argue that people already have a right to choose, and that these agreements may imply a reduced liability for a provider of support in the event of harm to the person or others (the equivalent of somebody checking themself out of a hospital). The person does not actually 'check out' of services though. There is an imbalance of power between provider and individual, so legal arguments would likely render this agreement unenforceable, making it bad public policy.

In a risk-taking model, the recognition and acceptance of conflicting views regarding particular risks is a central theme. While there seems to be potential in the idea of using 'negotiated risk agreements', these must be approached and adopted with caution.

Making informed choices

Supporting an 'ordinary life' means enabling choices both small and large.[140] Many providers may make small choices available such as what to wear, or which magazine to read. These choices typically have only a minor risk associated with them, and are therefore easy for families or service providers to 'give up'. Choices that are more significant, such as where to live, or how to spend a pay check have possible outcomes that are much more significant and present greater challenges, both at the extremes of control and autonomy. In New Zealand, while there is a clear call from

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[138] Bewley, C. (1998), p. 26
[139] Galantowicz, S. et. al. (2005), p. 11
[140] O'Brien, J. cited in Standards Plus (2007), p. 34

people with intellectual disability for increased choice in significant matters, such as where to live, advocates caution against "abandoning people to their choices".[141]

> We watch them make enormous mistakes and say 'Well, it was their choice'. Most of us make mistakes but are given permission to backtrack, but sometimes we say to disabled people, 'That was a bad choice so we'll make choices for you from now on'. Yet people who think more slowly may make more mistakes along the way, particularly if they have not got people who care deeply about them saying, 'I wonder if you have thought about that carefully?[142]

In order to 'think carefully' about choices, relevant information needs to be made available, and people need be able to use the information.

Current best practice models suggest a person-centred process will best support choice-making in people with intellectual disabilities. Including family/whanau and others who are important in people's lives into decision-making is an important feature of this model.[143]

Supporting Choice with a 'Nudge'

In a complex choice-making world, nobody can be expected to be able to make all decisions completely independently. Thaler and Sunstein argue convincingly that all humans are prone to making choices that are sometimes not in their best interests, and that there is a role for others, including government, to provide 'nudges' (that can be ignored) toward 'better' choices.[144] These nudges often involve people structuring choices ('choice architects'), or using an understanding of human motivation to create incentives that make better outcomes more likely.

Examples of two broad New Zealand government initiatives that employ this practice are:

1. HEHA – Healthy Eating, Healthy Action aims to improve the health of the general population through improving access to fruit in schools, supporting recreation options that encourage physical activity, and reducing the sale of fizzy drinks in schools.[145]

2. ACC workplace safety discounts offers employers in 'high risk' industries (e.g. fishing, construction) a 10% discount on insurance levies if they demonstrate good workplace safety practices (including health and safety training), and complete a workplace safety self-assessment.[146] Companies are provided with financial incentives to provide an environment that supports better safety for its workers. The system is 'nudged' in a direction that is in the best interest of the workers.

A full analysis of the implication of providing a 'nudge' when supporting people with intellectual disability to make informed choices is beyond the scope of this paper; this

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[141]Lorna Sullivan, personal communication March 28, 2008
[142] Standards Plus (2007), p.41
[143] Holburn, S. and Veitze, P. (2002), p.32
[144] Thaler, R., Sunstein, C. (2008)
[145] Ministry of Health and Minister of Health (2008), p. 13
[146] ACC Workplace Safety Discount. (n.d.)

reference is offered here to provoke reflection. It suggests to policymakers and service providers that choice making in the general population is something that does not operate with complete freedom, and that 'informed' choice is usually a choice made on the basis of information that is filtered by others. Family/whanau, friends, and caring support workers are entitled to provide information to help 'nudge' a person towards a decision that may be in their best interest, while asserting and recognising their rights to choose another path. What is important is that the best interests of the individual are kept as the primary focus, and that competing interests (such as family reticence to 'let go', or limitations in service availability) be honestly identified.

An honest analysis of choice-making recognises that there may be a role for others in structuring choice, particularly in areas in which many people are typically bad at making good decisions, including those:

1. That require self control: benefits now – costs later. (e.g. junk food, credit cards)'

2. That have a high degree of difficulty (e.g. choosing a mortgage, choosing between two options for medical care),

3. That are low frequency and don't allow for much 'practice' (e.g. plan of study, where to live, which service provider),

4. That don't provide immediate feedback,

   We usually get feedback only on the options we select, not the ones we reject. Unless people go out of their way to experiment, they may never learn about alternatives to the familiar ones. … Long-term processes rarely provide good feedback. Someone can eat a high-fat diet for years without having any warning signs until the heart attack. When feedback doesn't work, we may benefit from a nudge.[147]

5. That are beyond someone's experience ('How will I know what I will like?')

   When people have a hard time predicting how their choices will end up affecting their lives, they have less to gain by numerous options and perhaps even by choosing for themselves. A nudge might we welcomed.[148]

This discussion is provided as a perspective to add to the understanding of choice-making in people with intellectual disability. It does not intend to justify control over a person's decision making, rather to demonstrate that assertions that people should have 'choice' must be accompanied with deep thinking about what that really means.

The author is aware of research that suggests that people with intellectual disability can be highly influenced by their desire to 'please' or to give the 'right answer', in addition to the influence of additional factors that must be considered such as:

- anxiety and the choice-making context,[149]

- socialisation to accept choices of others,

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[147] Thaler and Sunstein (2008), p. 76
[148] Thaler and Sunstein (2008), p. 77
[149] French, S., Swain, J. (2008)

- legal issues of welfare guardianship[150] and competence, and

- the need to consider how people who are non-verbal or who have very significant cognitive impairment can express and exercise choice.[151]

Negligence and Duty of Care: knowing 'when to step in'

The law imposes a duty of care on everyone (support providers, clinicians, general public), to take reasonable care and avoid injury to a person or damage to property as a result of action or inaction.[152] Conflicting interpretations of this concept were reported several times during the interviews for this study. In the current New Zealand disability support environment, there is little formal definition of how this is to be applied, although this concept was referred to several times in discussions with key informants.

> He was agitated, they (the provider) knew it, and he went out and assaulted someone in the community. What about duty of care?
> (MoH Advisor – May 2009)

> 'Duty of care' includes recognizing what is important to the person because he is Māori. We are always thinking about that.
> (Service provider executive – April 2009)

Negligence, the failure to exercise reasonable care, is the legal concept that applies to duty of care.[153] Establishing negligence in a setting in which someone is in control of their supports and has made a choice may be difficult, and bears further investigation in legal circles.

Risk Taking in 'High Risk' Settings -- the ID(CC&R): Bridging the Gap between 'high and complex' and 'mainstream' approaches to risk

The high level of structure (specialist assessors, care managers, district inspectors) provides a 'checks' and balances system that does not typically exist in general community residential settings.

> Timata Hou has a much more structured environment that includes supervision, review, and monitoring of what is happening for the person. The services include a Care Manager who is responsible for making sure the person is getting services. The Team Manager is there to manage staff. These two people must operate in a coordinated way to ensure the program functions. In this situation, the Care Manager's role is clearly to ensure and advocate for a person's needs to be met.
> (IHC Executive – March 2009)

> It sometimes seems like there is a big jump for people to get from being supported in a highly structured secure setting to a more open setting in the community. It seems like we offer greater choice right at the same time as we

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[150] The PPPR Act codifies the legal process for how welfare guardianship is assigned. Whitireia Community Law Centre (2007), p.5
[151] Schloss et. al. (1993)
[152] Ellison, C. (undated), p.1
[153] Ellison, C. (undated), p.1

reduce the level of supports around someone – and that can lead to problems. (Care Manager – April 2009)

If New Zealand is going to move towards the goal of being a fully inclusive society, as outlined in the NZDS, then the government should be prepared to provide appropriate safeguards (not just accessibility) for all. In the case of people with high support needs, or for those whose behaviour may place others at risk of harm, it is easier to convince the public and politicians of this need, as in the case of ID(CC&R).

For those whose risks are less overt, the necessary support is less clearly defined, may be transient, and there is less of an imperative to create assurances that people are being supported with the necessary risk management or safeguards. Several interviewees commented that 'mainstream' support had variable capacity to help someone who needs behavioural support for either short or long term to live in the community. Long wait times (sometimes over 12 months), combined with variable access and quality of supports were common themes.[154]

The RIDCA acceptance criteria keep getting higher and higher, so NASCs are being left to find supports for people who have really quite high needs. (Behaviour Support Team member – April 2009)

People with pretty high needs can be well supported through NASCs in the community – but it really depends on the individual, and where they live. (MoH Advisor April – 2009)

There is much less structure in place to identify and address risks in the community. The Community Services Manager is responsible for staff and for making sure the plans are carried out, and oversight is 'looser'. Plans may be in place but there are less stringent requirements to make sure they're followed up. Planning may have limitations, based on what providers feel is 'affordable' in the community context.

One service provider, IDEA Services, attempted to address this issue with an 'intensive care management' pilot. People living in the community were assigned a person responsible for intensive care management (equivalent to the Care Manager role in the Timata Hou). The findings from the pilot were that the 'intensive care managers' were making up for deficiencies in the workforce, rather than providing a model of enhanced management. Expanding the program would mean placing a patch over a systemic problem so the decision was made not to further promulgate the model.[155]

The Ministry of Health has proposed a response to this need by developing a discussion paper that recommends enhancements to the current community Behaviour Support Services (BSS) though the establishment of:

1. Triage and prioritisation processes,
2. Multidisciplinary assessment teams, and

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[154] Hughes, D. and Daysh, R. (2008), p. 7
[155] Personal Communication, Wendy Rhodes, 16 March 2009

3. A 'centre for excellence' in intellectual disability to strengthen the clinical and research capacity as it relates to behavioural supports.[156]

A Centre for Excellence in Intellectual Disabilities?

The establishment of a 'Centre of Excellence' is a good idea that merits further exploration as a means of strengthening clinical and research capacity in a number of areas. The concept of a 'Centre' suggests focused efforts from a variety of sectors, including policy advisors, researchers and service providers, which would be guided by the community of people with intellectual disabilities and their advocates. Several informants noted that the multiple stakeholders involved in planning for, funding, delivering, evaluating, and accessing intellectual disability supports are active but not well coordinated. As was noted in Chapter 1, there is a vocal advocacy community in New Zealand but there are opportunities for better collaboration between advocates, support providers, researchers, and government. In an era of fiscal constraint and pressure to 'do more with the same resources', it is even more pressing that efforts be coordinated.

The notion of a 'Centre of Excellence in Intellectual Disability' creates challenges in the New Zealand context however. The issue of competing priorities within both the disability and health sectors is real. If government were to consider supporting such a Centre, policymakers would need to be convinced that the establishment of such a centre would yield clear benefits that would outweigh the risks associated with the anticipated demands for a similar approach from other disability groups, among others. Issues of leadership and control of such a centre would also need to be resolved. While the idea holds promise, these and other concerns must be further investigated in order to create a successful case in support of a Centre of Excellence.

Best practices in risk management: is there a way to assess and manage risks without imposing restrictions on choice?

Effective risk management, both at an individual and at a systems level can support someone to exercise choice and to take risks, but this must be done with adequate awareness and preparation for the tensions that are likely to emerge.[157] The discussion in this chapter has touched on several areas in which different values regarding 'right to risk', health and safety concerns, and individual rights come into conflict and can lead to a system of supports that is biased towards risk-aversion.

Best practice in risk management is well-described in clinical and health systems' literature, with a limited number of sources related to risk management in people with intellectual disability.[158] Generally, the themes that must be included in any such risk management approach include:

- An environment where everyone assumes responsibility for managing risk (including the person with intellectual disability and informal supporters as they are able). In the health sector, this is referred to as a 'culture of safety' and can be adapted to community services as well. Leadership must work to

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[156] Hughes and Daysh (2008)
[157] Titterton (2005), p.26
[158] Galanctowicz (2002)

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ensure that staff are guided by values that ensure that a person is able to take appropriate risks, while being prepared to review and apply necessary safeguards.

- Risk management processes (reviewing the context, identifying risk, assessing and treating risks) are embedded in decision making processes.

- Risks are identified and assessed in a consistent way, using as much good information as possible.

- Risks are documented, reviewed, and managed. This includes documentation and review of 'risk dilemmas'.

- Risks are prioritised in a way that includes the values of person-centeredness and support for autonomy. Resources necessary to help manage risks are clearly identified and tied to prioritization process.

Summary

In New Zealand tensions relating to choice, risk and accountability in the provision of supports continue to be played out in the development of policies.

This chapter offers the following considerations:

1. There is very wide range of knowledge and perspectives on the value of risk assessment. At present, it cannot be assumed that NASCs, or service providers will apply risk assessment in any formal or structured way.

2. The system has a bias towards risk-aversion that can lead to restrictions on choice and flexibility.

3. There is a need to spread the expertise that exists within the High and Complex Behaviour supports program regarding risk assessment and management to 'generic' community supports that are accessed through NASC.

4. Risk-taking is a normal part of life and will likely result in situations where there are conflicts between the rights and values of a person who is being supported and those who are supporting him or her. It is important to face these, document, and address them (sometimes by 'agreeing to disagree') as a way to move towards greater choice and influence by people on their own lives.

5. Choice-making should be approached consciously, with a recognition that simply aiming for 'increased choice' does not address the complex processes involved in making decisions.

3 USING INFORMATION TO HELP MAKE THE SHIFT: NECESSARY INFORMATION TO SUPPORT RISK-TAKING

When considering risks in relation to a person, there is a tendency to focus on the individual, their particular risks, and, if the risks are extreme enough, to develop a 'risk plan' that addresses the major risks for that person. This is an essential, core practice, but does not go far enough. In a social model, society should be working to create a structure in which risks that affect a group of people are managed as a whole. This is akin to a public health model and shifts the focus of the 'problem' at the individual level to the responsibility of society (and its 'systems') to establish sensible safeguards and supports for people. This chapter examines the information that should be captured at a systems (population) level in order to better focus services on those that support flexibility while managing real risks to individuals.

In a risk-taking framework, good information is essential for both making good choices, and for assuring effective use of services. Data systems should be positioned to answer questions about quality of service, as well as questions such as:

- Are people with intellectual disability in New Zealand at greater risk for chronic disease? If so, why?

- Do people with intellectual disability die sooner than the general population? If so, why?

- What is the biggest risk factor for loss of independence for a person with intellectual disability?

- What are particular characteristics about a support system or a person that can increase the risk of harm?

An essential feature of the risk-taking approach described in the previous chapter is the development of robust systems to show evidence of successful outcomes and to identify where negative outcomes may indicate a need for change. This can be done at a provider or individual level, but it is also important to be done at a systems level as well. At present, the information that is available across the disability sector in New Zealand is at best variable and in many cases absent, both at the individual and the population level.

Population-based information

The need for population information has been noted earlier in this report and is clearly recognised among stakeholders. Both the "Ordinary Life" report on the lives of people with intellectual disabilities and the Select Committee's review of disability services suggest that data collection, analysis and dissemination could be improved. The lack of good data is noted as a service gap and both reports recommend improved capacity to share data and make it available to service users. Systems and expertise for analysing available data and communicating findings are essential. Information, absent analysis and reporting, serves no practical purpose.

In August 2005 the Ministry of Health launched the Health Information Strategy for New Zealand with the following comments from the Minister of Health:

To meet the challenges we face in achieving better health and disability outcomes for all New Zealanders, we need to focus on working 'smarter'. If we want to work smarter, then better information is our lifeblood. We simply will not continue to effectively manage the health sector at national, regional, or district levels without improving our ability to collect, use, distribute, and share good information. In an increasingly collaborative health and disability sector, it is through coordination and sharing that we realise the true value of information – that it grows more valuable as we give it away.[159]

The Health Information Strategy, while it does include reference to the intended purpose of supporting the New Zealand Disability Strategy, makes only minimal reference to data sets or systems that will improve information that could be captured in relation to service delivery, needs, or outcomes of people who receive disability supports. Rather, it focuses on building infrastructure and partnerships among DHBs with the following statement that:

Community providers, including NGOs, community groups, and residential care providers, need to develop long-term plans for information and technology that are driven by the benefit to consumers through their participation in the continuum of care in their district.[160]

Specific information strategies with a focus on particular population groups have been developed as a follow up to this work, such as the Health of Older People Information Strategy (2005), and the National Mental Health Information Strategy (2005), but no disability or intellectual disability specific strategy exists. This presents both a challenge and an opportunity to the disability sector in New Zealand.

The challenge
As is stated in the Health Information Strategy, "New Zealand does not have the financial resources nor the time to approach information systems challenges from the top down."[161] This is particularly the case in a relatively small disability sector but the need to collect information for analysis of service and to support delivery outputs and outcomes remains.

The opportunity
Advances in the government's capacity to collect population information and link data sets through the NHI (national health indicator) are now setting the stage for integration with disability-specific datasets. With this, there lies a potential to begin to collect baseline and benchmark data in a range of health encounters and outcomes. The disability sector's CCPS (payment system), combined with other national data systems has the potential to identify the population of people with intellectual disability using either diagnosis field (if reliable) or the use of intellectual-disability specific service codes (as proxy for diagnosis).

The Ministry of Health supported the development of the NASC Information System, Socrates, which was rolled out for use in the NASCs, starting in 2007. The aim of the Socrates system was to standardise the information that was being collected regarding

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[159] Excerpted from Letter to Ministry of Health Senior Advisors from Hon Annette King, Minister of Health. 5 August 2005
[160] Health Information Strategy Steering Committee (2005), p.55
[161] Health Information Strategy Steering Committee (2005), p.10

client characteristics, needs, and outcomes (of Needs Assessment and Service Coordination), and to provide the basis for a more transparent model of funding supports.

The Socrates system is now in use by all NASCs but there is limited aggregate information that is currently being accessed or used by MoH policymakers regarding the population being served by the NASCs. The data captured within the system appears to be primarily focused on collecting accurate information regarding service need and cost, with a description of the population as a secondary goal that has not yet been realised. 'Reports training' is due to begin in June or July 2009 within NASCs and there is some hope that the information from Socrates will allow NASCs and the MoH to better understand the demographics of the population that is being served. Discussions with data analysts within the Ministry suggest that deeper questions, such as achievement of quality of life outcomes, behaviour management needs or health issues will not be captured in this system.

Existing population level data analyses to identify risks to health and safety

While there does not exist any overarching strategy, the disability sector has made advances in research that can begin to form some baseline data regarding approaches to manage risks to people's health and safety.

Interview subjects referred to several initiatives that aimed to better describe the national population of people with intellectual disabilities, even in the absence of a guiding information framework. It was beyond the scope of this project to identify the complete set of indicators that can and should be tracked in this population in New Zealand.[162] The following section presents selected findings that relate to two significant health and safety measures: mortality (as a population health marker), and falls (as a significant incident category). It does not attempt to deliver a comprehensive overview, rather it describes pilot work in the identification of baseline indicators that have been identified as significant in terms of services and population health for people with intellectual disability.

Mortality Analysis

Mortality is a direct indicator of the overall health of a population,[163] and although the rates do not measure the *quality* of life, a review of deaths can create one aspect of the overall picture of the quality of supports the population receives. The 2007 report from the UK, *Death by Indifference*[164] suggests there is widespread ignorance and indifference throughout healthcare services towards people with a learning disability.[165] Anecdotally, several informants for this study wondered whether there may be a higher tolerance for premature death among people with intellectual

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[162] The most significant recent project that has addressed health measures for people with intellectual disabilities is the Ponoma project that developed 15 health indicators for people with intellectual disabilities in Europe. The Ponoma Project's final report is available at www.pomonaproject.org. The National Core Indicators Project (http://www.hsri.org/nci/) has developed a robust set of indicators for tracking individual and system outcomes for people with developmental disabilities.

[163] Ministry of Health (2003b), p.38

[164] Mencap (2007)

[165] Learning Disability is the term used in the United Kingdom to describe the impairment referred to as intellectual disability in New Zealand and throughout this report.

disability in New Zealand, although there is no clear evidence to date that bears this out.

Overall, mortality rates in the general New Zealand population have declined dramatically over the last half century with average life expectancy at birth reaching 80.2 years in 2006.[166] Based on international data, mortality rates for people with intellectual disability have followed this trend. For example, the average life expectancy for someone with Down Syndrome almost doubled from 1982 to 1997, the average age at death increasing from 25 to 49 years.[167] In a report prepared for the Massachusetts Department of Mental Retardation (DMR)[168], the trends in annual mortality rates and average age of death have been tracked since 2000 as shown in the figures below.[169]

Figure 4: Average age at death for the Massachusetts population receiving intellectual disability supports

Average Age at Death per Year
2000-2006

2000	2001	2002	2003	2004	2005	2006
60.2	60.7	61.5	61.7	62.1	60.8	61.6
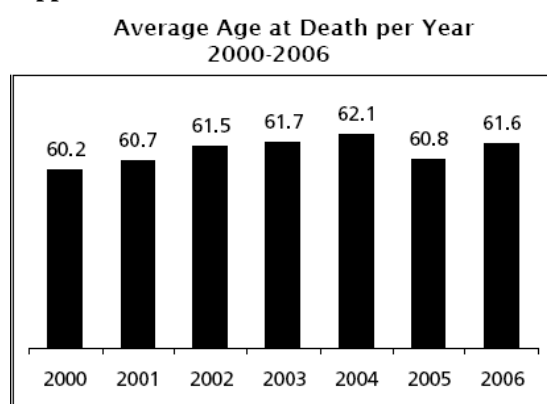
Source: 2006 Massachusetts DMR Mortality Report.[170]

Could the sector provide better information about health status indicators, including mortality?

Several key informants in the provider sector indicated that collection or population analysis of health indicators was not seen as an important part of their role and that resource limitations made them prioritise service delivery over any comprehensive analysis of data. The data systems that were developed by the Regional Health Authorities prior to the restructuring around 1999 were seen as being much more developed than those that currently exist.

When a person who receives intellectual disability support dies, the death will be reported and recorded, to a variety of agencies and for various purposes, yet there is no comprehensive way to examine deaths in this population in New Zealand. In 2006, in response to a concern about a number of deaths among people receiving supports,

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[166] OECD (2006) http://stats.oecd.org/WBOS/Index.aspx?DataSetCode=CSP2009
[167] Yang, Q. et al (2002)
[168] Massachusetts state legislature enacted legislation in 2008 to change the department name to the Massachusetts Department of Developmental Services (DDS). The change will go into effect July 1, 2009.
[169] The upwards trend in mortality rates (2000-2003) has been attributed to improved reporting by support providers in the first years of the implementation of a robust mortality review system.
[170] Massachusetts DMR (2006)

DSS asked providers to begin to inform the DSS office of the details of the death beyond just reporting it to the payment system. An analysis of one year of reported deaths indicated that:

- Of all the deaths that were reported in the DSS payment system (CCPS) for 2008, approximately 11% were reported by providers to the interim manager-DSS.

- Deaths that were reported appeared to be more often those that had coroner or police involvement, which is not surprising, from an organisational risk-management perspective.

- Cause of death was not consistently reported or the cause of death was not validated by a certifying official such as a coroner or funeral director.

- The current system can be used to inform the Ministry of the most high-profile deaths but it is not likely to yield enough useful information regarding mortality for aggregate analysis. The additional resources and structural changes that would be necessary to collect this information from the provider community suggest that the provider community should not be the primary source of health outcomes data.

The following figure shows a very preliminary analysis of mortality patterns for people with intellectual disability compared to the general population based on a merged dataset of people who receive intellectual disability support from DSS and people who have a diagnosis code of 'mental retardation'.[171] A visual comparison to the general population may suggest a disparity but it is important to note that this data has not been age-adjusted and there are multiple population characteristics that may be influencing this data. Direct comparisons cannot necessarily yield an accurate picture. Further investigation is merited to elucidate the pattern that is apparent below.

These preliminary analyses are a good beginning and demonstrate that such analyses are possible with current data systems within the Ministry of Health.

Figure 5: Preliminary analysis of Mortality Patterns in New Zealand 2005 - 2008
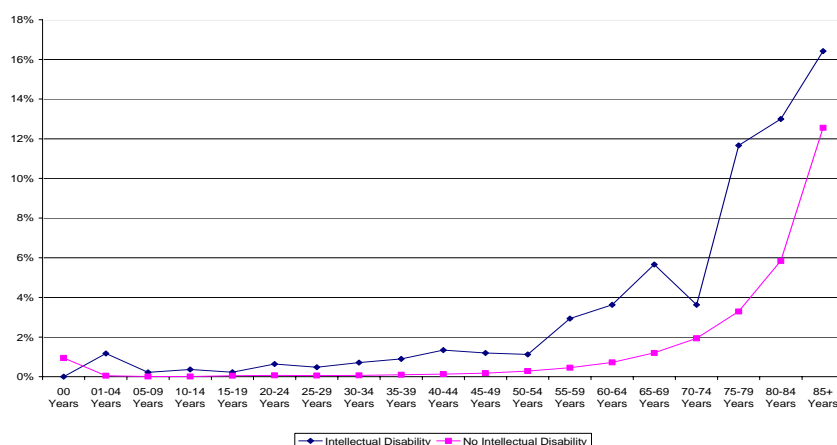
[171] While the data sets have been carefully collected and reviewed, this must be considered to be very preliminary. The author is aware that Ministry of Health analysts and demographers are investigating data issues, such as the puzzling 'dip' in the 70-74 age band that consistently appears in data analyses. See appendix E for identification of the databases and definitions used to develop this figure.

Benchmarking

Benchmarking to a comparable population allows for an enhanced understanding of the issues. Figure 4 presents an example of mortality trends for people with intellectual disability in two states in the United States.[172] Many factors may be debated regarding the direct comparability of the New Zealand population to the population in either state. Again, these are presented here as a means to begin discussion of the possibilities for developing enhanced information about people with intellectual disabilities who receive supports.

Figure 6: Connecticut and Massachusetts Intellectual Disability Mortality rates[173]

Connecticut DMR and Massachusetts DMR Mortality Rates by Age
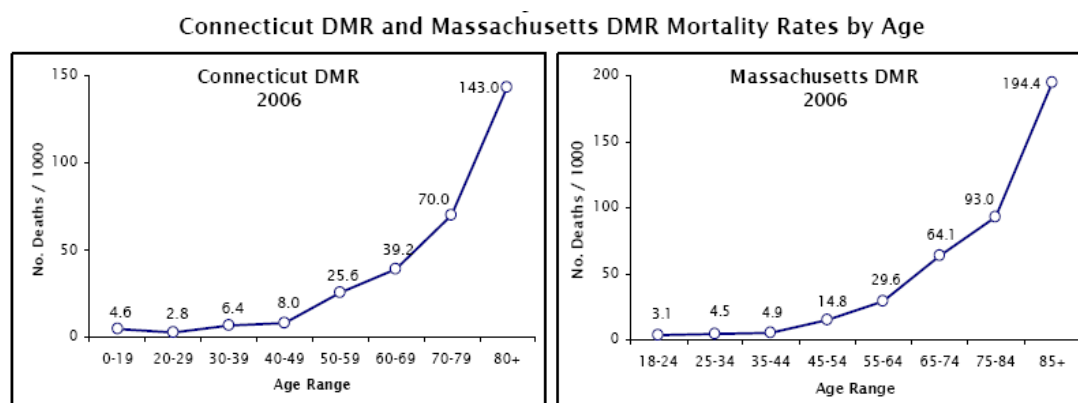
Using the same data set that was used to track mortality, the Ministry of Health has recently begun to develop the capacity to analyse health characteristics of this population. Preliminary analyses of indicators for chronic diseases and mental health disorders suggest what has previously been anecdotally reported, that there is a burden of chronic disease and mental health disorders in this population. These analyses informed the recent Ministry of Health report to the Minister on options to improve the health status of people with intellectual disability.

In a fully inclusive society, people living with intellectual disability must be supported by a system that is able to understand health risks and address population health disparities. Effectively gathering population information is an essential first step, followed by establishing targets for improvement.

There is a clear opportunity for the Ministry of Health to collaborate with researchers to establish baseline or benchmark mortality and population health measures for people with intellectual disability in New Zealand.

Incident reporting and review: Learning from mistakes

Honest reporting and learning from adverse incidents is essential in a support structure that values both risk-taking and safety.

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[172] Benchmark populations are those with similar features and can be used to compare outcomes and trends in data. Mortality trends from the states of Connecticut and Massachusetts are presented here as an example for broad comparison. Further analyses of population characteristics in New Zealand and potential benchmark populations would be necessary to better establish the comparability of given populations.

[173] Massachusetts DMR (2006).

Leadership should create an environment where recognising mistakes is valued and mistakes can be viewed as opportunities for improvement. Structured responses to critical incidents such as Root Cause Analysis and Failure Modes Effects Analysis provide useful information to organisations as part of organisational learning. None of the providers interviewed for this project were very experienced with these approaches, although some were familiar with the terms and had some experience with addressing critical incidents as part of organisational learning. [174]

Aggregate information regarding incidents is sometimes analysed within agencies but is not regularly done across intellectual disability providers. This was discussed by several providers in key informant interviews.

New Zealand's largest provider agency for people with intellectual disability, the IHC, has internal reporting databases and tracking systems. In early 2009, the system was not providing useful reports due to technical problems, although these are anticipated to be resolved and allow managers to track occurrences and trends in incidents. The organisation has established an internal incident review process that was due to begin reviewing significant internal incidents in April 2009.

The Ministry of Health receives reports of incidents in the regular six monthly report, as well as typically receiving telephone notification from provider agencies in the case of any incident that is serious or may be reported in the media. Serious incidents are also reported to Health Cert, which oversees provider agency audits.

Providers who responded to the survey distributed for this review all reported that their agency collected information about incidents, because systems to record injuries and accidents are required by Occupational Safety and Health regulation. Most reported using internal databases in which the data was recorded, but there was limited review or analysis of incidents on an aggregate basis. During interviews, providers indicated that resource limitations and a focus on providing direct service prevented much attention to this level of quality assurance.

In a study of 21 providers in New Zealand, Bray et al (2002)[175] found that all providers had a systematic way of recording client injuries, although the definitions varied, and some providers recorded 'near misses', while others did not. Ten agencies stated that they summarised or analysed their information on incidents, while eleven did not. Of the agencies that did review their incidents data on an aggregate basis, the reviews were mostly to look for patterns involving individual clients.

Providers who support people under the IDCCR record and report incidents in variable fashion as well. Reports of serious incidents are sent to the Ministry of Health, and RIDCAs collect and track incidents as well. There is however no regular analysis of incidents across RIDCAs.

Events are clearly being 'recorded', but there is little information that can currently be collected or analysed at a system-wide level regarding risk management. As has been

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[174] A useful review of these specific approaches in the services that support people with intellectual disability is available in Staugaitis (2002)
[175] Bray, A. (2002)

noted earlier in this report, several respondents suggested that the data systems that were in place in the early days of the Disability Strategy, under the Regional Health Authorities were better organised and more useful than what currently exists.

Falls

Falls are a significant category of incidents that need to be monitored. Injuries from falls comprise a significant portion of the total injury burden in the general population. The University of Otago's Injury Prevention Research Unit has calculated that 43% of all hospitalisations for unintentional injury between 1993 and 2002 were the result of falls.[176]

In New Zealand, a review of incident reports from 13 intellectual disability service provider agencies (residential and day programmes) indicated that a fall contributed to 31% of all injuries reported and 45% of those that required medical attention.[177]

In Massachusetts, a review of the state-wide incident's database revealed a similar pattern, with 35% (n=1505) of all reported injuries across a year being related to a fall.

Among elderly people, falls are recognised as a significant risk. The costs, both in terms of loss of independence, as well as for necessary medical and rehabilitative support can be enormous following a fall. This, combined with the fact that many falls are preventable, suggests a focused initiative that targets falls prevention.

Indeed, this was the conclusion of the researchers in both Massachusetts and New Zealand. Based on population level findings of the incidence of injuries related to falls, the Massachusetts Department of Developmental Services moved to support a targeted falls prevention pilot which:

1. Asks participating provider agencies to collect enhanced information on falls and 'near misses' throughout the course of the study.

2. Provides training to agency support staff on fall prevention strategies; raising awareness of the risks of falls and suggesting best practice on how to minimise those risks.

As follow up to the initial findings, New Zealand's Donald Beasley Institute proposed a national prospective study of injuries among adults with intellectual disability, as well as a falls prevention pilot study. The prospective study has not received funding support to date. Work to prevent falls has been ongoing through a partnership between the Donald Beasley Institute and the University of Otago, with an application for additional investigation of falls in people with intellectual disability submitted to the Health Research Council of New Zealand in 2009. There is a small number of researchers internationally working in this important area of falls prevention in intellectual disability.

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[176] Preventing Injury from Falls (2005)
[177] Based on a 12 month retrospective review of 594 injury reports, Bray, A. (2002)

Summary and Recommendations

At present, there is no formal or organised process being used to collect and analyse data regarding health and critical incidents across the population in New Zealand. Pilot work during the course of this project has shown that currently available data sets hold promise to establish benchmark and health outcome indicators yet there is more work to be done.

RECOMMENDATION

Build on the preliminary work being done within the Ministry of Health to establish the ability to use available data systems to identify accurate, ongoing markers of health status for people with intellectual disability.

The Ministry of Health should consider the development of a 'Disability Services Information Strategy' that includes:

- A focus on person centred values by working with service users, families/whanau, provider agency staff and executives, clinicians, researchers, and funders to identify the most important health outcomes, and valid indicators of these outcomes.

- Identification of relevant data sets and indicators that already exist and any issues that may emerge regarding linkages or collection of relevant data. Appendix E includes a list of relevant data sets that the Ministry of Health is currently able to link through NHI.[178]

- A process for review and dissemination of population level information throughout the disability sector.

- Clarity regarding how privacy issues will be handled in the management of data systems concerning the population.[179]

- Sample templates for data-driven reports that are based on simple analyses and that can identify patterns and trends associated with risks.

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[178] Definition of disability varies among ministries, and there are significant issues with accurate collection of data, in part due to a values-based hesitation to assign a 'disability' label, as in the Ministry of Education (Personal Communication, Jan Scown, 20 March 2009).

[179] Issues related to privacy of health information have been addressed by the development of a Privacy Authentication and Security (PAS) guideline for the sector, developed in collaboration between the ACC and the MoH.

4 SUPPORTING RISK TAKING: ORGANISATIONAL SUPPORTS, WORKFORCE DEVELOPMENT AND TRAINING

When promoting a risk-taking approach it is essential to have a broad understanding of risk and risk-taking throughout the system. This chapter describes issues related to workforce development in order to effectively manage both the positive and negative aspects of risk. To be confident supporters of risk-taking, people who provide supports must possess skills beyond basic risk identification and developing a risk plan. They must have developed skills in:

- Multidisciplinary interactions,[180] including a common understanding of risk and the ability to effectively empower, challenge, and support people.

- Negotiation, including the ability to clearly state positions and goals, identify boundaries (i.e. clear issues of personal safety), and be prepared to 'agree to disagree'.

- Facilitation, using empowerment strategies in order to encourage to people "to have more say over their lives, but also to assume responsibility for their decisions in relation to risk".[181]

Workforce Issues

People with intellectual disabilities in New Zealand (and internationally) receive support from a workforce that is varied in skill and experience, is largely non-professional, and is prone to high turnover rates.[182] Several key informants commented on the need for better support to people at the 'front-line' efforts to support and raise the capacity of the current workforce to provide supports are significant and enduring themes both in New Zealand and in the United States.

> Many times, the people with the least training are the ones who have the most responsibility for making sure people are safe.
> (Self-advocate, June 2009)

In many settings, clinical nursing positions must be filled by people trained overseas because of limited training available within New Zealand[183] and competition with other, acute care settings that may offer better compensation or working conditions.

Review of Selected Workforce Training

The Ministry of Health responded to calls for leadership to increase training with development of the 'Disability Support Services Workforce Action Plan'[184] in early

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[180] Referred to as 'interprofessional working' in Titterton (2005), p.114

[181] Titterton (2005), p. 116

[182] Social Services Committee (2008)

[183] When New Zealand had large institutions, psychopaedic nurses were trained specifically in the supports and models of service for people with intellectual disability. This training program was lost during the process of institutionalisation. 'Learning disability' nurses from the UK have filled a small number of the gaps that have emerged in the system.

[184] This planning effort was based on previous projects within the Ministry of Health, 'Quality and Safety Project' that was started in 2003 and included a workforce survey, and development of a national certificate for the sector.

2009. This action plan aims to provide training and career paths for the disability support workforce to allow the system to move toward more choice and community based services. In particular, it highlights the need to develop a trained workforce to help expand use of flexible models of Individualised Funding and Supported Independent Living.

This Action Plan builds Ministry of Health initiatives, including contracting with training developers to create training modules for:

1. Home based support workers. A new foundation skill training for front-line workers was developed for roll-out in early 2009. Modules include 'Applying a risk management plan'[185], and 'Providing supports to a person whose behaviour presents challenges in a health or disability setting'[186]. These modules will generally be used within the work setting, as part of staff development. They provide a well-structured approach to training staff and include several case studies for participatory learning, along with a requirement that the learner apply the knowledge to a risk management plan within their agency and is reviewed by the agencies multidisciplinary team. The balance between choice and control is referenced by asserting that the individual has a right to services that meets their needs, takes into account their choices, and also protects them. The evaluation requires that the trainee "consider feedback from the person" when evaluating a risk management plan. Throughout the training, 'Risks' are defined as the potential for harm. There is no specific reference to the value of taking risks or mention of support for managing risk dilemmas.

In order to ensure a workforce is capable of effectively managing risks, staff should be trained and supported to consider:

- What to do when a person's choice is unsafe?

- What is my responsibility when someone makes a choice that is not safe?

In addition, staff should be trained and supported to learn more about:

- The value in taking risk,

- The support structures that their organization has to support them

- How and when to report and record risk dilemmas

Providers of traditional community residential supports and some supported living providers could use this training but it is unclear how people who are hired to provide support through individualised funding may use this training.

2. NASCs. A tertiary level training programme is being developed in 2009 with support from the Ministry of Health. Training needs were provided by the sector. The author has not been able to review the training materials to date, but conversations with Careerforce staff and Ministry advisors familiar with the process have suggested that risk and risk-taking are not included to any appreciable extent in the training.

3. **Leaders**. No leadership training was directly accessed or reviewed for this project.

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[185] Careerforce (2008)
[186] ibid

Leadership training should include proven strategies for reviewing sentinel events[187] and data to understand current and emerging systems risks and to focus quality improvement efforts. As noted previously, leaders throughout the New Zealand disability support sector have variable knowledge about risk practices and perceptions of the value of creating formalised risk monitoring processes. Leadership will be essential to structure and guide an approach that supports risk-taking, and makes the sector better prepared to provide evidence of quality approaches such as incident reporting and monitoring.

Clinical Training

Specialist Assessment Guidelines

Guidelines for IDCCR specialist assessors were developed in 2003 for the Ministry of Health.[188] These materials include a thorough discussion of research findings that point to the challenge of arriving at a valid assessment of risk of harm, particularly among those with intellectual disability. It recommends a *functional* approach to assessing risk of violent or criminal behaviour that considers the internal and external factors that are responsible for a person acting in a way that is violent or criminal. The collection of as much relevant data is recommended, as this is the only way that the clinician can make qualified statements regarding the probability and severity of challenging behaviour. Specific tools, such as the Risk Factors Form and a recommendation for actuarial tools are offered, yet there remains significant leeway for the clinician to consider additional factors in developing an assessment of risk.

Interviews across the sector indicated that there remain significant challenges in the area of assessing and predicting risk in people with intellectual disability. Follow-up training has attempted to raise the standard of risk assessment and reporting in this group by suggesting that actuarial assessments[189] must serve as the 'anchor' for risk assessments. If a clinician feels that the risk that is predicted by the use of the actuarial tools should be modified, this should only be done by pointing to objective factors that support the modification.[190] There remains limited information in the literature regarding the utility of actuarial assessments in people with intellectual disability.[191]

Assessment and Management of Risk to Others

In 2005/2006, the Ministry of Health funded the development of a Toolkit for the Assessment and Management of Risk to Others.[192] This was developed for the mental health supports professionals with extensive input from the mental health sector. It is a simple framework based on an iterative model that focuses on:

1. Accurate, specific information about a person, and their behaviour.

2. Pathways to violence (pattern recognition).

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[187] Guidance for reviewing sentinel events is included in Staugaitis (2002)
[188] Edghill, R. (2003)
[189] Actuarial assessments are those that have been developed to identify the likelihood of an event based on data from studies of the behaviour of people who have similar characteristics.
[190] Wilson, N. (2008)
[191] Johnston, S. J. (2002)
[192] Evans, C. et. al. (2006)

3. Pathways to safety (recovery).

While this Toolkit was developed for the mental health population, several salient and promising features are highlighted below:

- One of the challenges in the mental health sector that led to the development of the toolkit was a perception that risk assessment and management was the domain of forensic clinicians. This is analogous to the situation in intellectual disability supports, in which expertise is perceived to lie primarily within the IDCC&R and High and Complex Behavioural supports. As a remedy to this situation, the toolkit was developed with a conceptual framework that asserts that risk assessment and management is a central task for *all* mental health professionals. The framework provides for a 'common language' regarding the process in general terms.

- The framework includes recognition of the individual as central to the process and includes their participation in as much of the process as possible. Professionals who have worked through the assessment process have noted that the people they work with learned to use the 'pathways to violence' terminology themselves, as a way to better understand their own risk.

- The toolkit does not specifically address issues concerning management of risk in people with intellectual disabilities. Issues such as a greater influence on behavioural approaches and observation over cognitive and self-reporting approaches were thought to deserve attention that was beyond the scope of the project. Several features of the framework were highlighted however that would make the approach applicable to addressing risk in people with intellectual disability:

  - The model is designed to be adaptable to different service settings and organisational contexts.

  - The model provides a framework for a common language regarding risk among staff of varying levels of competency.

  - The process of collecting accurate information at an individual level, considering their personal context, and building an understanding of risk based on experience is consistent with the model used in needs assessment and service planning processes that already exist.

- The toolkit was disseminated through a series of train-the-trainer workshops. Providers and services were encouraged to take on the tools and implement them in their own service context. While the toolkit was received positively, there is little information as to the uptake in the support community or an evaluation of its ongoing effectiveness and applicability. This point is noted as a caution: evaluation of the implementation phase is an essential yet often neglected step following the development of such tools.

Supporting learning by Sharing Information Regarding Risk

Organisations can learn from internal and shared reporting of challenging risk situations. In the UK, a newsletter called *The Risk Factor* is circulated by a

community social care agency.[193] It presents case studies that review 'risk dilemmas', such as balancing a person's wish to stay in her home with her risk of falling, or weighing the risks of persuading a first time young offender to apologize to his victim. The positive aspect of risk is regularly highlighted and discussed throughout these publications.

In the United States, the Commission on Quality of Care and Advocacy for Persons with Disabilities has another format for disseminating information about risks. Through a quarterly series of stories called "Could this Happen in Your Progam?", the Commission presents examples of adverse events as way to heighten awareness regarding risks.[194]

These examples are provided as low cost ways of supporting the system's capacity to learn about risk and risk-taking that could be potentially adapted for use in New Zealand.

Summary and Recommendations

Training is a key element in enhancing the system's ability to effectively balance choice and flexibility with necessary safeguards in a risk-taking model, but it is not the only answer. The discussion in chapters 2 and 3 has demonstrated that there are multiple factors that must combine to drive the system towards greater choice, and that do not put vulnerable people at unacceptable risk of harm.

1. Review provider-driven home-based support worker NASC guidelines and work to ensure providers are training on the positive aspects of risk, as well as on building competencies in multidisciplinary work negotiation, and facilitation related to risk.

2. Consider the development a toolkit for risk assessment in services for people with intellectual disability to better support and build understanding of risk assessment. This would help bridge the 'knowledge gap' between specialised and 'generic' support, facilitate interdisciplinary communication regarding risk, and apply a structured approach to identifying and communicating about risk. Essential elements of such a toolkit include:

    a) The use of multiple scenarios ('cases') for training that allow for trainees to practice applying their knowledge in situations that they will likely encounter.

    b) An assumption that the person who receives supports will be an active participant in identifying, analysing, prioritising, and mitigating risks in their own life.

3. Consider supporting the development of a semi-annual newsletter, along the lines of 'The Risk Factor' in the UK. This could be shared among providers and used as a way to promote ongoing discussion regarding risks, rights, and safety in services for people with intellectual disability. The source would likely be submissions by providers, but it could be collated or administered

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[193] Community Care (1 May, 2009)
[194] Could This Happen in Your Program? (n.d.) New York State Commission on Quality of Care & Advocacy for Persons with Disabilities

either by a provider initiative or through the Ministry of Health. This should include NASCs, and DHBs as a way to increase cross-agency consideration of risk.

5   SUMMARY AND CONCLUSION

Setting the Stage to Manage Risk

In order to move toward an increase in choice and flexibility, the system will need to accept a shift towards a risk-taking approach. This does not mean that there is an expectation of more negative outcomes from risk-taking. Rather, there should be more attention paid to the safeguards that need to be in place, both at an individual and at a system level. Identifying risks, and their meaning for a system is an inexact and challenging discipline but it is an essential component of good service planning.

A robust risk management system of supports for people with intellectual disability includes a series of necessary building blocks. These are:

- Identifying and planning to mitigate risk for individuals;
- Monitoring and mediating individual risk;
- Providing training and resources for staff to support individuals; and
- Addressing risk system-wide.[195]

New Zealand's support system for people with intellectual disability has developed areas of the system that know and understand risk well. In other areas, risks are not considered relevant to a person-centred service approach. There are numerous areas in which the system might improve upon current service planning efforts by examining and carefully documenting risk and risk management activities, especially the negotiations around risk and individual choice.

Building on this information, New Zealand could then add to the evidence base regarding effective current practice and move toward the goal of system-level, evidence-based improvements.

Starting with the Values Base and Moving to Risk-Taking

The single theme that consistently emerged in each interview and interaction throughout the course of this study was the desire to ensure that all people with intellectual disability live the best life possible. Many people also expressed frustration at how difficult this was to achieve and agreed that a 'risk-averse' system of support limits choices and impedes people's ability to feel satisfied with the life they are living.

What would it take to shift to a risk-taking approach?

> Something of a cultural revolution will be needed for policymakers,.., and practitioners to embrace the full implication of the 'risk society' in relation to policy and practice.[196]

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[195] Galanctowicz (2002)
[196] Titterton (2005), p. 122

There are many factors that drive the system toward a 'safety first' approach, but that approach can, if not properly managed, place restrictions on choice and flexibility. Pushing the system to understand and support 'risk-taking' and applying effective risk management are ways to enhance flexibility, if the right supports are in place. Leadership must support the development of an organisational culture that promotes safety, while respecting and supporting individual preferences.

In the current economic climate, concerns about resource constraints are real and expected to endure. Safeguards or support needs that may be identified through a risk assessment may not necessarily be funded. As community and flexible funding models grow and evolve, informal and natural supports will continue to provide an essential level of safeguards. Family, whanau, and community organisations are all key players in providing supports in a society that understands and supports risk-taking. New Zealand's exploration of Local Area Coordination-type models must include consideration of how risks will be addressed as part of service planning and delivery. Individual risks must be considered, as well as factors, such as regulatory demands, that may serve to reduce the flexibility that is promised in this model.

Partnerships in making the shift

The framework presented in 'Better Connected Services for Kiwis'[197] offers useful strategies for effecting positive change in complex systems. The framework's application to support a move towards risk-taking follows:

1. **Manage for Outcomes**. A clear focus on the desired outcomes (and regular reminders) will help identify barriers and regulation that may be impeding progress towards greater choice-making.

2. **Identify and support creative, passionate and values driven people** who are positioned 'in the middle'. These people do not generally see rules as fixed, so are willing to approach situations with a can-do attitude, rather than being constrained by regulation or paralysed by 'the system'. The author met several of these people throughout New Zealand, many of whom commented on their desire for better collaboration.

3. **Leadership must recognise that a 'safety first' approach can limit** choice and work to support collaboration and develop organisational structures and processes that support risk-taking, while recognising where safeguards are necessary.

4. **Partner with people with intellectual disability** in the work toward identifying and supporting risk and risk-taking. This may require a process of empowerment to help people to participate as drivers of change towards a service model that consistently supports choice and risk-taking.

5. **Evaluate policy and be prepared to consider modifications** when there is evidence that supports are not helping people to exercise choice and control in their lives, or that outcomes (such as health) are not meeting the targets.

6. **Promote diffusion of successful approaches** across the system through multiple networks. Innovation and successful approaches need to be celebrated and promoted to encourage 'spread' of best practices. Policy initiatives should support innovation and collaboration.

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[197] Institute of Policy Studies (2008)

7. **Commit to the hard work of collaboration**, 'taking risks', and 'working on the edge'. Promoting risk-taking in a system that naturally leans towards risk-aversion and greater control will require a shared commitment to face and address issues over the long term.

From a subjective analysis of the content of interviews and interactions during this study, New Zealand's disability support system must first begin by building better collaboration and trust, asserting the common desire: to ensure that all people with intellectual disability live the best life possible.

Summary of Recommendations

Chapter 1
The Ministry of Health should commission an external evaluation of the ID(CC&R). An evaluation of this new programme that includes the experience of care recipients will add to the body of evidence, and provide valuable programmatic information.

Chapter 2
The Ministry of Health, the research, and the support sector should further consider the establishment of a 'Centre of Excellence' with a focus on people with intellectual disability. The idea holds promise, and could be used as a way to focus efforts to establish implement, and evaluate new models of practice.

Chapter 3
Build on the preliminary work being done within the Ministry of Health to establish the ability to use available data systems to identify accurate, ongoing markers of health status for people with intellectual disability.

- The Ministry of Health should consider the development of Development a 'Disability Services Information Strategy'.

Chapter 4

- Review training and evaluation plans to identify how the materials will be used to support staff who are hired through IF.

- Consider the need to incorporate risk-taking and safeguarding training into NASC training materials.

- Review home-based support worker NASC guidelines and work to ensure providers are training on the positive aspects of risk, as well as on building competencies in multidisciplinary work negotiation, and facilitation related to risk.

- Consider the development of a toolkit for risk assessment in people with intellectual disability to better support and build understanding of risk assessment. This would help bridge the 'knowledge gap' between specialised and 'generic' supports, facilitate interdisciplinary communication regarding risk, and apply a standardised approach to identifying and communicating about risk.

- Consider supporting the development of a semi-annual newsletter, along the lines of 'The Risk Factor' in the UK. This could be shared among providers

and used as a way to promote ongoing discussion regarding risks, rights, and safety in services for people with intellectual disability.

Summary of recommendations by stakeholder group

Stakeholders across the service delivery spectrum each have a part to play. What follows is a summary of specific suggestions, targeted at selected specific stakeholder groups.

Policymakers and the Ministry of Health

- Ensure that legislation and regulation are consistent with the rights to choice that are codified in the UN Convention on People with Disability and the New Zealand Disability Strategy

- Prioritise good information, on an individual and system basis as a key to developing effective services

- Consider how choice and 'risk-taking' will be supported and addressed in new flexible funding models that are being proposed, such as in Local Area Coordination, and in expansion of Individualised Funding models.

- Support innovation across the system, not just with top-down approaches but by supporting networks of committed and passionate individuals across the service delivery sector.

- Support the development of training specifically on risk, risk assessment, and risk-taking approaches for use across the entire sector.

- Ensure that quality assurance systems work towards effective analysis of sentinel events across the system, in order to learn more about risks and suggest system improvements. Review current reporting systems to ensure that information that is provided is consistent and useful, and enhance guidance as necessary.

- Work proactively with media to enhance understanding of risk and choice.

- Work directly with researchers to enhance the evidence base regarding risk-taking and it's relation with quality of life.

Support provider managers

- Collaborate among service provider agencies to share issues of risk, successful approaches, and approaches to manage 'risk dilemmas.'

- Build internal risk management systems with an eye to supporting risk-taking rather than simply meeting regulatory and quality assurance requirements.

- Ensure that negative outcomes of risk-taking choices are used as learning opportunities for the person (and their family/whanau) as well as the organisation. In the absence of negative outcomes, reflect on what safeguards could be in place to allow people with intellectual disabilities make good decisions in risky situations.

- Work collaboratively with other organisations towards a system that aggregates important risk events across the sector.

Needs Assessment Service Coordination Agencies

- Consider risk and risk-taking as an integral part of needs assessment and service planning.

- Build discussions of risk into communications among NASCs and with service providers.

- Build relationships with clinical teams to help inform needs assessment and planning.

High and Complex Behaviour Support Teams
- Collaborate with NASCs and community teams in the development of training specifically on risk, risk assessment, and risk-taking.

ID (CC&R)

- Collaborate with researchers to develop and implement an evaluation of the program that includes an analysis of risk assessment and management strategies in relation to care recipient outcomes.

Service users (People with intellectual disabilities/family/whanau)

- Be aware of rights regarding choice and risk-taking.

- Actively participate in training to learn advocacy (risk-taking) skills and to help others learn how to adopt this approach.

- If you need it, get help with understanding your responsibilities when taking risks.

Researchers

- Add to the limited body of both quantitative and qualitative evidence on the relationship of choice, risk, and risk-management to outcomes such as health, quality of life, and safety.

- Expand on limited research regarding the role of the positive concept of risk and risk taking in supporting people to learn and live preferred lives.

- Further consider how the 'Nudge' concept (supporting choice-making that is in someone's best interest) is or is not applicable in effectively supporting people with intellectual disability.

Clinicians

- Extend best-practice through dissemination and peer support.

- Approach risk-assessment in a multidisciplinary way, including direct feedback on the value of taking a particular risk from the person you are assessing.

- Push for better information from the person with intellectual disability (and their family/support providers) in order to assess health risks, behavioural risks.

Educators

- Build an appreciation for risk taking and the necessary skills into training and workforce development programmes.

Limitations of this study

This study focused primarily on services and supports that people receive from the New Zealand Ministry of Health as a way to investigate the role of risk and risk-taking. While this is a large and significant portion, there are other systems, such as the DHB system that was not specifically reviewed as part of this study.

As a conceptual framework, risk-taking merits additional study. The interaction with resource limitations is a particular concern. As was pointed out in this report, it remains important to clearly identify and state the risks (including organisational and fiscal) that are being considered as a way to understand the factors that influence choice.

CONCLUSION

New Zealand possesses a strong values base that asserts the right of people with intellectual disability to be supported in ways that are individualised, allow for choice and provide what is necessary to live an 'ordinary life'. But values have not been enough. Multiple factors, including the complexities related to choice and risk-taking have created pressures that will continue to limit options for some people. This report has presented a broad perspective on the system, and a narrow focus on one major issue: the balance (or tension) between choice (that involves risk), and controls that may be necessary to ensure safety.

Risk is a feature of an ordinary life for any person. If a person with intellectual disability needs support in their life, then there is often a need to help the person (and their family/whanau) manage risks as well. At an individual level, this can be achieved by exploring choice-making, values and perceptions regarding risk, and by ensuring that support staff and caregivers understand the value of risk taking, their role in providing safeguards and how to negotiate 'risk dilemmas'.

Leaders must create an organisational culture that is committed to promoting safety for individuals and support providers while emphasising an individual's right to express and live the life of their choosing. In order to understand and address risks in this population, it is important to collect, analyse, and disseminate good data regarding population health and other outcomes. This includes analysis of sentinel or serious events in order to learn how to prevent similar occurrences, as well as population level analyses of health indicators. Within the Ministry of Health, there is the opportunity to merge and build on analyses of existing data sets in order to contribute to evidence-based support planning and delivery.

Complex issues related to risk taking and risk management exist as an undercurrent in many policy conversations within New Zealand and internationally about what 'is' (restrictive) and what 'should be' (flexible) in the current support situation for people with intellectual disability. Changing the system will require a shift in thinking. Whether this can be achieved depends on the commitment of policymakers, people with intellectual disabilities, and a great many other committed people to assert the necessity and value in taking risks, and to thoughtfully apply risk management principles to both individual and systems level planning.

The final word is expressed in the following whakatauki (proverb):

> Kia pai te whakatere i te waka
> Kei pariparia e te tai
> Ka monenehu te kura nei

> (Steer with skill the canoe lest the outgoing tide endangers the lives of those on board).[198]

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[198] Borrowed, with gratitude, from Tangitu (2004), p. 18

APPENDIX A: PEOPLE WHO PROVIDED INFORMATION FOR THIS REPORT

People who provided interviews or who otherwise provided direct information for this project. Comments and quotes recorded in the context of Ministry Forums, Huis, and numerous other meetings were not attributed to individuals so those names are not included here.

Ann Bell, Development Manager, Ministry of Health, Disability Support Services
Mark Booth, Group Manager, Ministry of Health, Health & Disability Systems
        Strategy Directorate, Strategy Unit
Barney Cooper, General Manager, Community Care Trust
Jackie Cumming, Director, Health Services Research Centre, Victoria University
        School of Government
Trish Davis, Manager, Special Projects Disability, Ministry of Health, Disability
        Support Services
Rachel Daysh, Senior Advisor Complex Support, Ministry of Health, Disability
        Support Services
Brian Emery, Knowledge, Systems, and Quality Manager, Te Roopu Taurima O
        Manukau
Leigh Hale, Associate Dean for Research, University of Otago School of
        Physiotherapy
Adrian Higgins, Specialist Services Manager, Psychologist, Community Care Trust
Amanda Hinkley, Policy Analyst, Ministry of Health, Population Health Directorate
Terri Hollands, Care Manager, Pohutukawa Unit, Waitemata DHB Regional
        Intellectual Disability Secure Services
Rowane Janes Quality Analyst, Ministry of Health, Health & Disability National
        Services Directorate, National Quality
Roger Jolley, Strategic Advisor Māori and Equity, Ministry of Health Disability
        Support Services
Ruth Kibble, Sector Leadership Manager, Careerforce
Rhondda King, Group Manager – Quality, Ministry of Health, Health & Disability
        National Services Directorate, National Quality
Marianne Linton Senior Research Analyst, Ministry of Health, Disability Policy
Sanjeev Malhotra, Principal Specialist Ministry of Health, Health & Disability
        National Services Directorate
Marese McGee, Chief Executive, Community Living Trust
Brian McKenna, Director, Centre for Mental Health Research, Associate Professor,
        School of Nursing, University of Auckland
Louisa Medlicott, Clinical Psychologist, Otago DHB Specialist Intellectual Disability
        Behaviour Support Service
Brigit Mirfin-Veitch, Director, Donald Beasley Institute
Peter Moodie, Service User
Jenny, Moor, Development Manager Ministry of Health, Health & Disability National
        Services Directorate, Disability Support Services\Service Access Team
Lester Mundell, Chief Advisor and Director IDCC&R Disability Services Directorate,
        Ministry of Health Disability Support Services
Dave Nicholl, Manager, Provider Audit South Island Shared Service Agency Limited
Allison Nichols-Dunsmuir, Project Manager, Ministry of Health Training
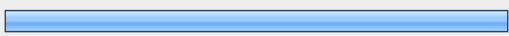   Development

Graeme Parish, Chairperson, MidSouth Region, PeopleFirst New Zealand
Mark Powell, Team Manager, Service Access Team, Ministry of Health, Disability
        Support Services
Marilyn K. Raffensperger, Doctoral candidate, M.Ed(Dist)
Wendy Rhodes, IDEA Services General Manager of Specialist Services
Deborah Roche, Deputy Director General, Ministry of Health, Health & Disability
        Systems Strategy Directorate
Jan Scown Director, Office for Disability Issues
Pam Shanks, Assistant, PeopleFirst New Zealand
Valerie Smith, Senior Advisor Ministry of Health, Disability Policy
Hillary Stace, Research Fellow, Victoria University School of Government
Lorna Sullivan, Chief Executive, Standards Plus
Tuila Tenari, CEO, Te Roopu Taurima O Manukau
Martin Tobias Principal Technical Specialist, Ministry of Health, Health & Disability
        Intelligence Unit
Craig Wright Senior Advisor (Statistics/Epidemiology) Ministry of Health, Health &
        Disability Intelligence Unit
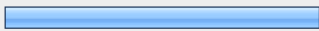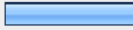
APPENDIX B: SURVEY RESULTS

1. Please consider the following areas of risk and rate their significance in service planning and delivery for the people with intellectual disability.

	Very significant	Major consideration	Moderate consideration	Minimally considered	Response Count
Physical health issues (wellness, chronic illness)	**75.0% (6)**	12.5% (1)	12.5% (1)	0.0% (0)	8
Behavioral risks - danger of harm to self or others	**75.0% (6)**	12.5% (1)	12.5% (1)	0.0% (0)	8
Vulnerability to abuse or exploitation	**62.5% (5)**	25.0% (2)	12.5% (1)	0.0% (0)	8
Denial of human rights	**50.0% (4)**	12.5% (1)	37.5% (3)	0.0% (0)	8
Denial of cultural considerations	**50.0% (4)**	0.0% (0)	**50.0% (4)**	0.0% (0)	8
Not meeting MoH or other audit requirements	**62.5% (5)**	25.0% (2)	12.5% (1)	0.0% (0)	8
Oranizational financial risks (related to budget, costs, payment)	**50.0% (4)**	37.5% (3)	12.5% (1)	0.0% (0)	8
Services provided do not meet the needs of the people in your community	**50.0% (4)**	25.0% (2)	25.0% (2)	0.0% (0)	8
Negative media or public attention	**50.0% (4)**	12.5% (1)	37.5% (3)	0.0% (0)	8
				Other (please specify)	1
				answered question	8
				skipped question	0

2. Who is responsible for risk management within your organization?

	Response Count
	7
answered question	7
skipped question	1

3. Please respond to the following statements regarding services for people with intellectual disability							
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Rating Average	Response Count
Needs assessments regularly include an assessment of risks.	14.3% (1)	14.3% (1)	14.3% (1)	28.6% (2)	28.6% (2)	2.57	7
People with intellectual disabilities are effectively supported to take risks.	12.5% (1)	37.5% (3)	25.0% (2)	25.0% (2)	0.0% (0)	3.38	8
Risk management is an essential part of service planning and delivery.	62.5% (5)	37.5% (3)	0.0% (0)	0.0% (0)	0.0% (0)	4.63	8
Support providers understand their role in managing risk for the people and families/whanau they support.	37.5% (3)	62.5% (5)	0.0% (0)	0.0% (0)	0.0% (0)	4.38	8
The system has found the right balance between supporting individual choice and ensuring health and safety in the people we support.	12.5% (1)	0.0% (0)	37.5% (3)	37.5% (3)	12.5% (1)	2.63	8
Risk assessment and management creates an unnecessary layer of monitoring and documentation.	0.0% (0)	14.3% (1)	14.3% (1)	28.6% (2)	42.9% (3)	2.00	7
Risk management is more about protecting the support organization than the individual.	0.0% (0)	25.0% (2)	0.0% (0)	37.5% (3)	37.5% (3)	2.13	8
					answered question		8
					skipped question		0

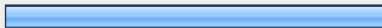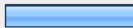| 4. Does your agency collect information on significant incidents that occur while a person is being supported?		Response Percent	Response Count
Yes		100.0%	8
No		0.0%	0
	answered question		8
	skipped question		0

5. Please indicate the information collected and what is done with it. (N/A if the information is not regularly collected)						
	Only recorded on paper in individual's record	Recorded in individual record and collected in agency's database	Collected in agency database and reported to external agency (e.g. MoH, OSH, Coroner)	N/A	Rating Average	Response Count
Unexpected hospital visit	25.0% (2)	**37.5% (3)**	**37.5% (3)**	0.0% (0)	2.13	8
Injuries	12.5% (1)	**87.5% (7)**	0.0% (0)	0.0% (0)	1.88	8
Falls	12.5% (1)	**87.5% (7)**	0.0% (0)	0.0% (0)	1.88	8
Assault victim	12.5% (1)	25.0% (2)	**62.5% (5)**	0.0% (0)	2.50	8
Assault perpetrator	12.5% (1)	37.5% (3)	**50.0% (4)**	0.0% (0)	2.38	8
Restraint	0.0% (0)	**50.0% (4)**	25.0% (2)	25.0% (2)	2.33	8
Medication error	12.5% (1)	**87.5% (7)**	0.0% (0)	0.0% (0)	1.88	8
Absconding	0.0% (0)	**62.5% (5)**	25.0% (2)	12.5% (1)	2.29	8
Choking incident or eating non-food item	12.5% (1)	**62.5% (5)**	12.5% (1)	12.5% (1)	2.00	8
Death	0.0% (0)	0.0% (0)	**100.0% (8)**	0.0% (0)	3.00	8
					Comment	4
					answered question	8
					skipped question	0
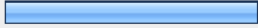
6. Please choose the statement that best describes how data is used in your agency:

		Response Percent	Response Count
Pertinent data is regularly collected, analyzed and reported to the people who need to know.		**62.5%**	**5**
Pertinent data is regularly collected, and analyzed , but not always reported to the people who need to know.		12.5%	1
Data is regularly collected, but not analyzed or reported in a meaningful way.		25.0%	2
Data is irregularly collected analyzed and reported.		0.0%	0
	Other (please specify)		1
		answered question	8
		skipped question	0
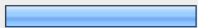
7. Please respond to the following comments regarding serious incidents.

	Always	Usually	Sometimes	Never	Response Count
Staff know who they must report any serious incident to.	**75.0% (6)**	25.0% (2)	0.0% (0)	0.0% (0)	8
Incidents are reviewed by an internal committee to identify whether there are opportunities to improve safety and quality of services.	**50.0% (4)**	25.0% (2)	25.0% (2)	0.0% (0)	8
Incidents are reviewed in order to identify deficiencies or errors by staff at the time of the incident.	**75.0% (6)**	12.5% (1)	12.5% (1)	0.0% (0)	8
				Comment	4
				answered question	8
				skipped question	0

8. Has your agency developed policies regarding the management of individual and organizational risk?

	85	Response Percent	Response Count
Yes		100.0%	8
No		0.0%	0
If yes, please describe the policies			3
	answered question		8
	skipped question		0

9. What staff training does your organization include related to managing risks while supporting people to pursue the life they choose?

	Response Count
	7
answered question	7
skipped question	1

10. Are there specific tools that your staff use to help assess risk when planning for services? Please name or list the tools used.

	Response Percent	Response Count
Yes	75.0%	6
No	25.0%	2
If yes, please describe the tools		5
answered question		8
skipped question		0

11. How would you describe your position?

		Response Percent	Response Count
Chief Executive		50.0%	4
Manager		50.0%	4
Administrator		0.0%	0
Front Line Manager		0.0%	0
Clinician		0.0%	0
Other (please specify)			2
answered question			8
skipped question			0

12. What funded services does your agency provide to support people with intellectual disability?

		Response Percent	Response Count
Community residential support services – Intellectual Disability		75.0%	6
Supported Independent Living – Intellectual Disability		50.0%	4
Home Based Support Services		25.0%	2
Community support teams/services for people with ID		37.5%	3
Behaviour Support Services for People with intellectual disability presenting behaviours that challenge		37.5%	3
Intellectual Disability Supported Accommodation Service (DSSRIDSA)		37.5%	3
Regional Intellectual Disability Secure Service (RIDSS)		12.5%	1
Regional Intellectual Disability Care Agency (RIDCA)		0.0%	0
Needs Assessment and Service Coordination (NASC)		0.0%	0
Other (please specify)			1
answered question			8
skipped question			0

13. How many people with intellectual disabilities does your agency support?			Response Percent	Response Count
Less than 40			25.0%	2
40 - 100			12.5%	1
101 - 300			**37.5%**	**3**
More than 300			25.0%	2
			answered question	8
			skipped question	0

APPENDIX C: OVERVIEW OF THE NEW ZEALAND DISABILITY STRATEGY

The New Zealand Disability Strategy (NZDS) is the key strategic framework for developing and advancing disability services. Underpinning the NZDS is a vision that New Zealand will be inclusive when people with impairments can say they live in, "a society that highly values our lives and continually enhances our full participation"'.[199]

The NZDS outlines 15 objectives to achieve this vision. The objectives that are relevant to the discussion in this paper are included below:

Objective 7: Create a long-term support system centred on the individual.
ACTION
7. 1 Ensure that overarching processes, eligibility criteria, and allocation of resources are nationally consistent, but that individual needs are treated flexibly.

7.9 Ensure that disability services do not perpetuate the myth that disabled people are ill, while recognizing that disabled people do need access to health services without discrimination. *See in particular Chapter 3.*

Objective 8: Support quality living in the community for disabled people.
ACTION
8.1 Increase opportunities for disabled people to live in the community with choice of affordable, quality housing.

8.4 Ensure disabled people are able to access appropriate health services within their community.

Objective 10: Collect and use relevant information about disabled people and disability issues.

ACTION
10.1 Ensure that guidelines for research funding take into account the need for research on disability issues, include disabled people in the development and monitoring of the disability research agenda, and enable disabled people to put forward their own experiences in the context of the research. *See in particular Chapter 3.*

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[199] Ministry of Health (2001)

APPENDIX D: GOVERNMENT AGENCY/ORGANISATIONS THAT FUND AND ADMINISTER SERVICES FOR PEOPLE WITH ID IN NEW ZEALAND

Government Agency/ Organization	Services Funded	Types of services accessed by people with ID.
Ministry of Health (MoH)	• Contracts with NASC agencies for disability assessment and service coordination. • Disability support services for people, mostly under age 65. Over age 65, MoH continues to fund services, until they have been assessed as needing ager-related residential care. • Environmental Support Services (equipment, home and vehicle modifications). • Behaviour support programmes. • Adult day programmes. • Some inpatient Assessment, Treatment, and rehabilitation. • Services provided under the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003.	Needs Assessment Service Coordination Residential Support.[200] Adaptive equipment, home and vehicle modifications. Community behaviour support programmes. Disability Information and Advisory Services People with intellectual disability who have high and complex behavioural needs may receive specialised residential and behavioural support as care recipients under the IDCC&R Act 2003.
District Health Boards	• Disability support services for people over 65, or between 50-65 and have been assessed as having the same service requirements as someone over 65. • Supports for people who experience mental illness. • Public specialist (secondary) and Hospital (tertiary) based care.	Generally, the MoH continues to provide supports to an individual with ID, unless their support needs change to being primarily due to ageing (e.g. needing rest-home level of care). Hospital-based care and some other community programmes.
Ministry of Education	• Special education resources for people with disability. • Professional development programmes for special education workforce.	Special education programmes for children. Special 'independent living' programmes through technical colleges.

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[200] The majority of community residential support that is funded by the MoH is used by people with intellectual disability. This includes group homes, and supports to live independently or with family. The Ministry estimates that 85-90% of the residential support budget for MoH is used by people who have intellectual disability.

Ministry of Social Development	• Work and Income funds a Disability Allowance to people who cannot work because of their disability. • Vocational services • Family and Community services	Disability allowance. (note that in many cases the disability allowance is paid to a residential support provider, with only a small 'living allowance' paid to the individual)
Child Youth and Family Services	• Care and Family Support Services	Family support services. Funding for support of children outside the family home, if necessary.
Accident Compensation Commission (ACC)	• Support services for people who have a disability as a result of an accident.	ACC may fund rehabilitation or support for a person with ID who has been injured as a result of an accident. If a person was not working prior to the accident, the ACC benefit for lost wages would not apply.
Ministry of Transport	• Total Mobility - transportation access.	Discounted taxi services in some areas.
Housing NZ Corporation	• Assistance for people with physical disabilities to access public or privately owned modified housing.	Assistance for physical disability access issues. Community Group Housing provides residential homes to community groups that provide residential services.
Ministry of Economic Development	• Telephone relay service.	Support for using telephone for people with hearing or speech impairments.
State Services Commission	• Established Mainstream Supported Employment Programme (now operated by the Ministry of Social Development)	Employment opportunities for people with "significant disability" in the state sector.
Department of Internal Affairs	• Administers Lottery Grants Board	Grants received by community groups including those that operated by or supporting people with disabilities.

APPENDIX E: ANALYSIS OF MORTALITY OF PEOPLE WITH (INTELLECTUAL) DISABILITY WHO USED SERVICES FUNDED BY MOH NEW ZEALAND

Part of this project included preliminary work to identify data sources that would allow for analysis of mortality of people with **disability** (and **intellectual disability** as a subset) who receive residential supports funded by MoH (YPD).

The data sources were evaluated for their ability to identify the following data:

1. Number of deaths annually
2. Mortality rate (deaths per 1000) [number of deaths / total number of people receiving services]
3. Age distribution
4. Average age of death (year by year) [SUM: age at death / total number of deaths]
5. Cause of death
6. Ethnicity data in the population
7. Mortality rate by ethnicity

Data Element	Source(s)	Confidence A- very good ; B – Good ; C – Fair ; D – not good at all	Comment
Total number of people **with disability** (n)	NZ Disability survey 2006	C- self report	
Total number of people **with intellectual disability** (n)	NZ Disability survey 2001 (ID snapshot)	C – self report	Suspicion of over reporting because of functional definition.
Total number of people with **intellectual disability**	NMDS	B – based on extract from CCPS of all people with ID services	
Number of people receiving funding for (YPD) residential services each year	CCPS Analysis – new extract required.	A – payment system	
Number of people **with disability** who died while receiving residential supports (annually)	CCPS Analysis	A- payment system	
Number of people **with intellectual disability** receiving funding for residential services each year	CCPS Analysis – new extract required.	B- based on residential category as proxy for diagnosis	People with ID may be using services (e.g. IF) that do not have specific ID definition.
Number of people **with intellectual disability** who died while receiving residential supports (annually)	CCPS Analysis	B – based on residential categories as proxy for diagnosis	
Age at death (disability)	CCPS Analysis	A – payment system	
Age at death (intellectual disability)	CCPS Analysis	B- based on residential categories as proxy for diagnosis	
Age distribution of people with intellectual disability	NMDS	B- based on extract from CCPS	

Data Element	Source(s)	Confidence A- very good ; B – Good ; C – Fair ; D – not good at all	Comment
Cause of Death	Reporting to DSS	C-B – depending on degree of follow up possible/ information available from agencies	Incomplete data set at present. Will require follow up with agencies. Reporting will be variable, with input from coroner in some cases, funeral director in others.
Cause of Death	BDM	B – Cause of death entered by clinician, coroner or funeral director	Preliminary analyses suggest a high number of 'neurological syndromes' as causes of death, indicating that there may be more general diagnostic information entered rather than the proximal cause of death for this population.
Ethnicity of people supported by DSS	CCPS Socrates	C-B	
Ethnicity of people with ID	NMDS	B	

Data sets:

1. CCPS – the DSS payment system. DSS identified people receiving intellectual disability (residential and community) support
2. NMDS – National Minimum Data Set
3. DSS report. Based on reports sent from provider agencies when someone has died. Service specification requires the Ministry be notified but this is not always done.
4. BDM – Births Deaths and Marriages. National data set.
5. Socrates – Data entered by Needs Assessment Service Coordination (NASC) agencies at the time of needs assessment/reassessment. This is a relatively new system. Limited national data analysis has been done to date.

APPENDIX F: MOH DATA SETS AVAILABLE FOR ANALYSIS OF MORTALITY IN THE NZ I.D. POPULATION

Definitions[201]

This document contains information about the definitions used for extracting the data reported for Ministry of Health mortality analyses presented in this report.

Intellectual disability definition

In this analysis people are grouped into two main groups: people with and without intellectual disability. Intellectual disability is defined as:

1. DSS known clients with an intellectual disability or attended services specifically for patients with intellectual disability over the last few years (from 2005 to 2008).

2. NMDS patients with a diagnosis code of F70-F73 (Mental retardation) from 1988-2008.

Denominator:

For both prevalence and cost measures, the denominator used is drawn from the population of New Zealand resident healthcare users for the period 1 July 2007 to 30 June 2008, which is defined according to the following conditions:

Each person must:
Have an NHI (National Health Index) number, and
Must not be born after the end of the period, and
Must not be registered as deceased before the start of the period;
and either:

- have had a health service contact (e.g. GP consult, public or private hospital admission, or mental health service) in at least two quarters of the 12-month period prior to the quarter end date; or

- be listed as a New Zealand resident on the NHI and have had a health service contact (e.g. GP consult, public or private hospital admission, or mental health service) in at least one quarter in the 12-month period prior to the quarter end date.

The population identified by the Ministry of Health as New Zealand resident healthcare users is very close to the Statistics New Zealand estimated population. For the period ending 30 June 2008, the resident healthcare user population was 4,293,447 people, which is 100.6 percent of the Statistics New Zealand estimated population for 30 June 2008 (4,268,900 people).

Numerators:

To determine the numerator in the prevalence rate calculations (the number of people with the specific condition) the following criteria were used:

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[201] Sources: Craig Wright – Senior Advisor (Epidemiology); Anna Davies – Advisor (Epidemiology) Ministry of Health

A person is counted having died if their death is reported in the Births, Deaths and Marriages Registry. Data is entered into this system up to 2006.

BIBLIOGRAPHY

ACC Workplace Safety Discount (n.d.), Retrieved 1 June, 2009 from
http://www.acc.co.nz/for-business/self-employed/how-to-pay-less/workplace-safety-
discounts/index.htm

ADA Amendments Act of 2008 (September 25, 2008), Library of Congress. Retrieved
14 June, 2009 from: http://thomas.loc.gov/cgi-
bin/bdquery/z?d110:SN03406:@@@L&summ2=m& Accessed June 21, 2009

American Association of Persons With Disability (2009*), Justice for All blog May 20
2009.* Retrieved 9 June, 2009 at http://jfactivist.typepad.com/jfactivist/2009/05/h-res-
416-submitted-on-may-7-2009-by-congressman-lewis-d-ga-calls-on-the-senate-to-
immediately-ratify-the-un-conve.html

Ashton, Toni (2005), 'Recent developments in the funding and organisation of the
New Zealand Health System'. *Australia and New Zealand Health Policy* 2005:2:9, pp.
2-9

Autism Collaborative (n.d.), Retrieved 9 June, 2009 from: www.autism.org

Ballard, Keith (ed.) (1994), *Disability, Family, Whanau, and Society*. Wellington:
Dunmore Press

Bewley, C. (1998), *Choice and Control: Decision making and people with Learning
Difficulties*, London: Values Into Action

Bray, A. (2002), *Review of Policy Developments in Needs Assessment and Service
Coordination in New Zealand*, Dunedin: Donald Beasley Institute

Bray A. (2003), *Demographics and characteristics of people with an intellectual
disability: Review of the literature prepared for the National Advisory Committee on
Health and Disability to inform its project on services for adults with an intellectual
disability*, Wellington: National Health Committee and Donald Beasley Institute

Careerforce (2008), *Applying a Risk Management Plan.* Intellectual Disability Level
3. Retrieved 30 June, 2009 from:
http://www.careerforce.org.nz/index.cfm/1,126,305,0,html/National-Certificate-in-
Community-Support-Services-Intellectual-Disability-Level-3

Chappell, A. (1992), 'Towards a sociological critique of the normalization principle.'
Disability, Handicap, and Society, 1992:7:1, pp. 35-51

*Code of practice for manual handling. Published jointly by the Occupational Safety
and Health Service of the Department of Labour and the Accident Compensation
Corporation* (June 2001*),* Wellington: Department of Labour and the Accident
Compensation Corporation Accessed 1 June, 2009 from:
http://www.osh.govt.nz/order/catalogue/pdf/manualcode.pdf

Community Care (1 May, 2009), The Risk Factor. Persuading a first-time young offender to say sorry. Retrieved 3 June, 2009 from: http://www.communitycare.co.uk/Articles/2009/05/01/111377/risk-factor-persuading-a-first-time-young-offender-to-say-sorry-to-his-victim.html

Could this Happen in Your Program? (n.d.), New York State Commission on Quality of Care & Advocacy for Persons with Disabilities. Retrieved 1 May 2009 from: http://www.cqcapd.state.ny.us/could_this_happen/casetitl.htm

Davis, P., Ashton, T. (eds) (2001), *Health and Public Policy in New Zealand*, Auckland, Oxford University Press

Daysh, Rachel (2008), *IDCC&R 4 years On: What we know so far*. Presentation for sector consultation, October 2008

Deschamp. P. et al, (2003), *Review of the Local Area Coordination Program in Western Australia*. Retrieved May 18, 2009 from: www.disability.wa.gov.au/dscwr/_assets/main/report/documents/pdf/final_report_lac_review1_(id_369_ver_1.0.2).pdf

Disabled Persons Community Welfare Act (1975) Retrieved 14 June, 2009 from: http://legislation.knowledge-basket.co.nz/gpacts/public/text/1975/se/122se17.html

Edghill, R. (2003), *Specialist Assessment Guidelines Final Draft* Prepared for the Ministry of Health, June 2003

Ellison, C. (n.d.), *Duty of Care, Critical Thinking, and Ethics*. Retrieved 18 May, 2009 from: http://www.restlessdance.org/resources/dot%20to%20dot/dot%20to%20dot%20practice.htm

Evans, C. et. al. (2006), *Assessment and Management of Risk to Others. Guidelines and the Development of a Training Toolkit.* Retrieved 8 July, 2009 from http://www.tepou.co.nz/file/PDF/publications/Risk%20Review%20of%20Assessment%20S.pdf

French, S., Swain, J. (2008), *Understanding Disability: A guide for Health Professionals*, Philadelphia: Churchill Livingstone Elsevier

Galantowicz, S., Selig B., Pell, E., Rowe, J. (2005), *Risk Management and Quality in HCBS: Individual Risk Planning and Prevention, System-Wide Quality Improvement, Centers for Medicare and Medicaid Services*, Retrieved 26 February, 2009 from: http://www.hcbs.org/files/60/2986/Risk_Management_and_Quality_in_HCBS.pdf

Gould, R. (2003), *Continuity Amid Chaos: Health care management and delivery in New Zealand,* Dunedin: University of Otago Press

Government Response to Report of the Social Services Select Committee on its Inquiry into the Quality of Care and Services Provision for People with Disabilities (February 2009) Retrieved 14 February 2009 at http://www.parliament.nz/NR/rdonlyres/8A7D9F6E-E272-41E4-BB27-63A3C4557F07/99832/DBHOH_PAP_17698_6462.pdf

Health and Disability Commissioner (undated), *When you use a health or disability service: YOU HAVE RIGHTS* (Pamphlet)

Health Information Strategy for New Zealand (2005), Health Information Strategy Steering Committee, Wellington: Ministry of Health.

Holburn, S. and Veitze, P. (2002), *Person-Centered Planning. Research, Practice, and Future Directions*, Baltomore: Paul H. Brookes Publishing Co.

Holman, A.(1999), *Funding Freedom 2000*, London: Values Into Action

Hughes, D. and Daysh, R. (2008), *Behaviour Support Discussion Paper for Sector Consultation*. Wellington: Ministry of Health

ID(CC&R) Act (2003), *Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003. Public Act 2003 No. 116.* Retrieved 30 June, 2009 from: http://www.legislation.govt.nz/act/public/2003/0116/latest/DLM224578.html

IHC (November 2008), *Briefing to the Incoming Minister of Health, the Hon Tony Ryall*. Wellington: IHC

Institute of Policy Studies (2008) *Better Connected Services for Kiwis*. Wellington: Victoria University of Wellington, School of Government

Intermediate Care Facilities For the Developmentally Disabled: Meeting the Long Term Care Needs and Maximizing the Potential of Individuals with Mental Retardation and/or Developmental Disabilities (n.d.), American Health Care Association. Retrieved 1 June, 2009 from: http://www.vor.net/ICFMRBackground.html

Johnston, S. J. (2002), 'Risk assessment in offenders with intellectual disability: the evidence base', *Journal of Intellectual Disability Research* 46: supp. 1, pp. 47-56

Kinji, J. and Bray, A. (2001), *Māori concepts of disability*. Dunedin: Donald Beasley Institute.

Label falls short for those with mental retardation (January 22, 2007), NPR Radio All Things Considered. Accessed 14 June, 2009 from: http://www.npr.org/templates/story/story.php?storyId=6943699

Learning about Intellectual Disabilities (n.d.), Retrieved 9 June, 2009 from: www.intellectualdisability.info/diagnosis/autism.htm

Managing the Risk of Workplace Violence to HealthCare and Community Service Workers: Good Practice Guide. (2009), Wellington: Department of Labour. Retrieved 1 June, 2009 from: http://www.osh.govt.nz/publications/booklets/preventing-violence/index.asp

Manawanui InCharge (February 19, 2009) January 2009 Report to the Ministry of Health

Massachusetts DMR (2006), *Massachusetts Department of Mental Retardation Mortality Report*, Prepared by the University of Massachusetts Medical School's Center for Developmental Disabilities Evaluation and Research, Retrieved 1 July, 2009 from http://www.mass.gov/Eeohhs2/docs/dmr/mortalityreport2006.pdf

Mencap (2007), *Death by Indifference: Follow up to the Treat me right! Report*. London: Mencap. Available at www.mencap.org.uk

Milner, P. (2008), *An examination of the outcome of the resettlement of residents from the Kimberly Centre*. Dunedin: Donald Beasley Institute

Ministerial Committee on Disability Issues (2009), Terms of Reference. Retrieved 29 May, 2009 from: http://www.odi.govt.nz/what-we-do/ministerial-committee-on-disability-issues/terms-of-reference.html

Ministry of Health (2001), *The New Zealand Disability Strategy: Making a World of Difference Whakanui Oranga*. Wellington: Ministry of Health

Ministry of Health (n.d.) *Disability Services Directorate Strategic Plan 2008-2010: toward a more flexible disability support system,* Wellington: Ministry of Health

Ministry of Health (n.d.) *Disability Services Directorate Strategic Priorities 2008-2010*, Wellington: Ministry of Health

Ministry of Health and Minister of Health (2008) *Health and Independence Report 2008*, Wellington: Ministry of Health.

Ministry of Health (2003), *Guidelines for the Role and Function of Specialist Assessors Under the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003*

Ministry of Health (2003a), *Procedure Manual Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003*. Wellington: Ministry of Health

Ministry of Health (2003b), *Improving Quality (IQ): A Systems Approach for the New Zealand Health and Disability Sector,* Wellington: Ministry of Health

Ministry of Health (2003), *New Zealand Health and Disability Sector Overview*. Wellington: Ministry of Health Retrieved 6 February, 2009 from: http://www.moh.govt.nz

A guide to the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 (2004), Wellington: Ministry of Health

Ministry of Health (2006) *Discussion Document for the Definition of Secure Service Level Boundaries under High and Complex/IDCC&R Framework (V1-06)*

Ministry of Health (2008), *Individualized Funding Scheme Interim/Phase One Review Project Report (DRAFT),* Planning and Development Disability Services, June 2008

Ministry of Health (n.d), *Guide to the Criminal Procedure (Mentally Impaired Persons) Act 2003* (booklet)

New Zealand Treasury (2009), *Minister's Executive Summary*, Retrieved 21 June at www.treasury.govt.nz/budget 2009/execsum/b09-execsum.pdf

One in Five (March 15, 2009), Interview with Eddie Bartnick Director of Disability Services Commission (Western Australia), One in Five broadcast, New Zealand Public Radio, March 15. Transcribed by author. Audio download available at http://www.radionz.co.nz/national/programmes/oneinfive/20090315

Planning and Development Disability Services (June 2008), *Individualized Funding Scheme Interim/Phase One Review Project Report*, Wellington: Ministry of Health

Ministries of Health and Education (October, 2008), *New Zealand Autism Spectrum Disorder Guideline.* Wellington: Ministry of Health.

Ministry of Social Development (December 2008), *Work in Progress 2008: The annual report from the Minister for Disability Issues to the House of Representatives on implementing the New Zealand Disability Strategy.* Wellington: Office for Disability Issues

National Advisory Committee on Health and Disability (2003), *To Have an 'Ordinary' Life: Community membership for adults with intellectual disability.* A report to the Minister of Health and the Minister for Disability Issues, Wellington: National Health Committee

National Health Committee (2004), *To Have an 'Ordinary' Life. Background papers to inform the National Advisory Committee on Health and Disability*, Wellington: National Health Committee

National Core Indicators Data Brief: Self Determination and Consumer Outcomes, (March 10, 2004). Retrieved 18 May, 2009 from: http://www.hsri.org/docs/786_Core_Report_3.1_Self_Determination.pdf

New Freedom Initiative (2001) Centers for Medicare and Medicaid Services. Retrieved 14 June 2009 from: http://www.cms.hhs.gov/NewFreedomInitiative/

New Zealand Disability Survey (2006) Statistics New Zealand. Retrieved 24 February 2009 from: http://www.stats.govt.nz/people/health/disabilities.htm

OECD (2006) *Country Statistical Profile: New Zealand* Retrieved 7 June from: http://stats.oecd.org/WBOS/Index.aspx?DataSetCode=CSP2009

O'Brien, J., O'Brien, C.L., and Schwartz, D. (2004), *What can we count on to Make and Keep People Safe?: Perspectives on Creating Effective Safeguards for People with Developmental Disabilities.* Retrieved 27 April, 2009 from: http://thechp.syr.edu/CountOn.pdf p.43

O'Brien, P., Sullivan, M. (2005), *Allies in Emancipation: Shifting from Providing Service to Being of Support,* South Melbourne, Victoria: Thomson Dunmore Press

Preventing Injury from Falls (2005), Accident Compensation Commission. Retrieved 1 June from: www.fallsstragety.govt.nz

Safeguards Project Discussion Paper #1 (n.d.), Community Resource Unit Inc., Brisbane, Retrieved 14 June, 2009 from: http://www.cru.org.au/projects/Safeguards/SafeguardsDiscussionPaper1.doc

Saucier, P. (2002), *Promoting a National Vision for People with Disabilities: Successful Policies and Enduring Barriers.* Report from Ian Axford (New Zealand) Fellowships in Public Policy. Retrieved January 4, 2008 from: http://www.fulbright.org.nz/voices/axford/index.html

Schlock, P., Alpers, S., Jayne, D. (1993), 'Self-determination, for persons with disabilities: choice, risk, dignity', *Exceptional Children.* 1993: Decemer 1 pp. 13-17

Statistics New Zealand (2006), *Quick Stats about Culture and Identity* Retrieved February 14, 2009 from: http://www.stats.govt.nz/NR/rdonlyres/5F1F873C-5D36-4E54-9405-34503A2C0AF6/0/quickstatsaboutcultureandidentity.pdf

Statistics New Zealand (2006), *Disabilities* Retrieved 24 February from: http://www.stats.govt.nz/people/health/disabilities.htm

Statistics New Zealand (2007), *"Hot off the Press" 2006 Disability Survey Report*, Retrieved 22 June from http://www.stats.govt.nz/NR/rdonlyres/799A77CC-4DF6-445C-96DA-F5A266538A72/0/2006disabilitysurveyhotp.pdf

Standards and Monitoring Service (2008), *Individualized Funding (IF) in New Zealand: Participants Perspective.* Developed for the Ministry of Health.

Standards Australia and Standards New Zealand (2004), Risk Management AS/NZ 4360:2004, Sydney, NSW: Standards Australia and Standards New Zealand

Standards New Zealand (2008), Health and Disability Service Standards NZS 8134: 2008, Available from Standards New Zealand: www.standards.co.nz

Standards Plus (2007), *Seeking Community – living with a learning disability.* Auckland: People First New Zealand

Staugaitis, S. (2002), *Root Cause Analysis: A Summary of Root Cause Analysis and its use in State Developmental Disabilities Agencies.* Retrieved 1 June, 2009 from http://www.qualitymall.org/products/prod1.asp?prodid=669

Social Services Select Committee (September 2008) *Inquiry into the quality of care and service provision for people with disabilities.* Wellington: Social Services Committee

Tangitu, Phyllis (2004), *Tikanga Whakamua maku ma Te Arawa: Māori Best Practice Model.* Lakes District Health Board.

Te Ara (n.d.), *Pacific Migrations* Retrieved 17 June, 2009 from:
http://www.teara.govt.nz/NewZealanders/MāoriNewZealanders/PacificMigrations/1/en

Thaler, R., Sunstein, C. (2008), *Nudge: Improving Decisions about Health, Wealth, and Happiness*, New York: Caravan Books

Titterton, Mike (2005), Risk and Risk Taking in Social Welfare, London: Jessica Kingsley Publishers

UN Convention on the Rights of People with Disabilities (2008), Office for Disability Issues. Retrieved 9 June, 2009 from: http://www.odi.govt.nz/what-we-do/un-convention/index.html

UN News Center (6 May 2008), Remarks at the Presentation of the Franklin Delano Roosevelt International Disability Award. Retrieved 27 April 2009 from: www.un.org

Whitireia Community Law Centre (2007), A Guide to Making Applications under the PPPR Act. Porirua Community Services Centre. Porirua.

Wilson, N. (2008), Presentation: Accurate and Ethical Communication of Risk in Specialist Reports. Presented at specialist assessor training meeting July 2008

Yang, Q., Rasumussen, S., Friedman, J. (2002), 'Mortality associated with Down's Syndrome in the USA from 1983 to 1997: a population-based study' *The Lancet*, 2002:359:9311, pp. 1019-1025