Promoting a National Vision for People with Disabilities

Successful Policies and Enduring Barriers

Prepared by
Paul Saucier

August 2002

With funding from the sponsors of the Ian Axford (New Zealand) Fellowships in Public Policy

ACKNOWLEDGEMENTS

This report is the product of my Ian Axford (New Zealand) Fellowship in Public Policy. The New Zealand Government in partnership with the private sector sponsors the Fellowship. Government sponsors for 2002 were Department of Prime Minister and Cabinet, Treasury, Department of Labour, State Services Commission, Department of Internal Affairs, New Zealand Police, Ministry of Social Policy, Ministry of Foreign Affairs and Trade, Ministry of Education, Ministry of Research, Science and Technology, Ministry of Health, Ministry for the Environment, Ministry of Justice and Environmental Risk Management Authority. Corporate sponsors in 2002 were the National Bank of New Zealand, Air New Zealand and Ericsson. The Commonwealth Fund of New York administers the selection process in the United States. I am extremely grateful to the sponsors, The Commonwealth Fund of New York, the Selection Committee, and the Board of the Ian Axford (New Zealand) Fellowship for providing me with this exceptional opportunity.

The Fellowship is ably administered in New Zealand by Fulbright New Zealand. A visitor to New Zealand could not hope for better professional and personal support than what was provided to my family and me by Jennifer Gill, Melanie Smyth, Lisa Docherty and the rest of the Fulbright team. We are truly grateful.

I am indebted to my host organization, the Ministry of Health. My mentor, Carol Searle, provided free and open access to people, information and other resources within and outside of the Ministry and ensured my professional and social integration within the Disability Services Directorate. Senior locality managers and staff provided invaluable assistance with my field visits around the country. Carol and all of the Ministry staff I talked with were consistently candid in responding to my questions and open to hearing my numerous suggestions.

I was also fortunate to have Bob Stephens as my academic mentor at Victoria University of Wellington. Bob did his best to help me narrow my very broad scope of inquiry. He also provided invaluable perspective on New Zealand's policy process in general, and recent reforms of health and social policy in particular.

In the course of my stay, I spoke to over 150 people throughout the country about New Zealand's disability and ageing sectors. They included consumers, family members, national and local government officials, service providers, advocates, educators and researchers. I truly appreciate the time, materials and insights that were so generously provided to me by those listed in Appendix A.

My colleagues at the Muskie School of Public Service, University of Southern Maine, made this project possible by supporting my leave-of-absence, picking up the work I left behind, responding to my numerous e-mail requests, and encouraging me to make the most of my time here.

Finally, my deep affection and thanks go to Myrna, Nate and Hannah for so willingly embarking on this journey with me.

Wellington
August, 2002

ABBREVIATIONS

ACC	Accident Compensation Corporation
AHB	Area Health Board
ATR	Assessment, Treatment and Rehabilitation
DHB	District Health Board
DHHS	U.S. Department of Health and Human Services
DOL	Department of Labour
DPCWA	Disabled Persons Community Welfare Act 1975
DPEPA	Disabled Persons Employment Promotion Act 1960
DRG	Diagnosis-Related Group (referring to a hospital payment methodology)
DSD	Disability Services Directorate, Ministry of Health (formerly the Disability Issues Directorate)
DSS	Disability Support Services
DSW	Department of Social Welfare (precursor to the Ministry of Social Development)
GDP	Gross Domestic Product
GP	General Practitioner
HFA	Health Funding Authority
HOPS	Health of Older People Strategy
HRA	Human Rights Act 1993
MOH	Ministry of Health
MORST	Ministry of Research, Science and Technology
MSD	Ministry of Social Development
NASC	Needs Assessment and Service Coordination
NHC	National Health Committee
NZDS	New Zealand Disability Strategy
NZPHDA	New Zealand Public Health and Disability Act 2000
ODI	Office for Disability Issues, Ministry of Social Development
SNF	Skilled Nursing Facility
WINZ	Work and Income New Zealand, Ministry of Social Development

EXECUTIVE SUMMARY

The Government launched the *New Zealand Disability Strategy* in April 2001. The *Strategy* calls for a fully inclusive society for people with disabilities. This report examines certain aspects of New Zealand's disability system and concludes that substantial progress has been made over the past decade, but many challenges remain to be addressed before New Zealand can claim to be a fully inclusive society.

Consumers, multiple government agencies and some providers have accepted the NZ Disability Strategy as a broad framework for future disability policy and programs. However, if the *Strategy* is to transform New Zealand into a fully inclusive society, its concepts must now be further articulated, and concrete policy and program changes must follow across government agencies.

Policy and program recommendations are offered throughout the report and compiled in Chapter 7. Most fall into one of the following categories.

- *Promoting Independence*. Largely due to resource constraints, many disability services can only help people maintain their current status, as opposed to actively promoting independence. The disability system needs to be infused with greater expectations of habilitation and rehabilitation. Consumers need more opportunities to express their aspirations and participate in the development of flexible service packages that enable increasing participation in society.
- *Improving Effectiveness*. The effectiveness of disability services is seldom evaluated. More effort should go into identifying weak services and either improving or eliminating them. Work force development is a key component to increasing effectiveness, most visibly in home care. Many existing services could also be made more effective through greater coordination with other services.
- *Simplifying Access to Comprehensive Services*. Entry to services is quite complex, with many individual services requiring separate eligibility and assessment processes. New Zealand has some exciting opportunities to streamline processes by developing cross-departmental assessment and service coordination pilots. It also could re-focus its assessment processes to provide more comprehensive assessment for people with complex needs, and a simpler screening process for people with relatively low needs.

These changes will require both new thinking and new resources. New Zealand will gain some efficiency if it can promote better cross-departmental collaboration, but it belies common sense to believe that New Zealand's disability system can move from one that maintains the status quo to one that promotes full inclusion in society without dedicating more resources to the effort.

Two challenges cut across all the rest.

- *Improving and Using Information*. With some exceptions, disability information systems are very poor. Many major policy and program decisions are made on the basis of anecdotal information, and once in place, programs are rarely evaluated for effectiveness. Cross-departmental collaboration is hampered by the inability to link and analyse data across services.

- *Making All of Government Work as One.* People with disabilities need supports that span the breadth of government. Policy and program development should be more closely coordinated to ensure that one arm of government does not inadvertently create obstacles to the objectives of another arm. This is the fundamental challenge of the new Office for Disability Issues.

New Zealand's health system is undergoing the latest in a decade-long series of structural changes. Disability services have been swept into the current devolution debate because the Ministry of Health administers a substantial disability program through its Disability Services Directorate. However, devolution to District Health Boards will not address the structural challenges that many people with disabilities face. Devolution could improve coordination of health and disability services, but it would do nothing to address the fragmentation of other critical supports, including education, vocational services, income supports, housing, transport, etc. If local control is favoured as a general principal of government, models specific to disability should be developed and tested. These would include many services that extend beyond the mission and experience of District Health Boards.

Specific to older people, devolution may result in positive changes if primary care is included and integrated with secondary care and disability supports. A major rationale for devolving disability supports for older people is that older people are more comfortable with the health system and go to their general practitioners with most of their health and disability concerns. The role of Primary Health Organizations should be specifically addressed as New Zealand develops its integrated continuum of care for older people.

Finally, New Zealand finds itself at a cross roads regarding the human rights approach to disability. The *NZ Disability Strategy* embraces the social model, which views disability not as a personal characteristic, but rather as a set of discriminatory social barriers. New Zealand's Human Rights Act is showing signs of weakness and could be strengthened in a number of ways, but in order to pursue a more aggressive human rights approach, New Zealand will need to be prepared to move away from its tradition of the collective good and toward an approach that emphasizes the rights of individuals.

CHAPTER 1. INTRODUCTION

Purpose

Disability policy is high on the agenda for policy makers in New Zealand and the United States. The countries share an ambitious goal of creating fully inclusive societies, in which people with disabilities enjoy the same opportunities to participate as everyone else. Opportunities include living as independently as possible in communities, receiving education, working, having relationships, enjoying leisure pursuits, leading active lives in retirement, and a host of other life aspirations.

In April 2001, the Government launched the *New Zealand Disability Strategy*, a broad framework to guide disability policy toward full inclusion. The purpose of this project was:

- To assess the degree to which the disability system in New Zealand supports the inclusion and participation in society of people with disabilities;
- To determine whether the *New Zealand Disability Strategy* is an effective tool for achieving a fully inclusive society; and
- To identify remaining barriers to full inclusion and make suggestions for improvement.

The New Zealand Disability Context

Health System Reform
The *NZ Disability Strategy* was mandated by the New Zealand Public Health and Disability Act 2000 (NZPHDA) and launched in an environment of rapidly changing health policy and structures. Twenty-one District Health Boards (DHBs) have been created, and the country's former health and disability purchasing agency, the Health Funding Authority (HFA), has been abolished. The Ministry of Health (MOH) has absorbed the HFA's functions, including the purchase of disability support services (DSS). The MOH has, in turn, devolved many functions to DHBs, but no final decision has been made regarding devolution of funding for DSS. At present, DSS is purchased and monitored by the Disability Services Directorate within the MOH.

Overarching Disability Issues Currently in Play
The latest changes to the health system have created some new issues for the disability sector and caused some perennial challenges to resurface. Major issues include the following:

- *Devolution*. The NZPHDA envisions devolution of health and disability funding to District Health Boards. As the name implies, DHBs are primarily health organizations. They have planning and funding arms that develop local plans with community participation and purchase a mix of services that reflect community needs and priorities. DHBs also have provider arms that own NZ's public hospitals and the constellation of outpatient services operated by them. At issue is whether DSS should devolve and if so, whether DHBs are the appropriate local entities to plan and purchase disability services.
- *Separating DSS for age-related disability.* Currently, DSS is a generic service category that includes a broad range of home-based and residential services to people with disabilities of all ages, including people with

physical, intellectual, sensory and age-related disabilities. A tentative decision has been made to separate funding for age-related DSS from all other DSS funding, in preparation for the expected devolution of age-related DSS to DHBs. This follows several years of advocacy from the ageing sector to develop fully integrated health and disability policy and funding for older people. In April 2002 the MOH released the *Health of Older People Strategy*, the guiding document for development of an integrated system for older New Zealanders. The MOH has created a policy team dedicated to implementing the *Health of Older People Strategy*.

- *Coherency.* People with disabilities often use services from more than one government agency. In response to longstanding concerns about fragmentation of disability policy and services, the new Labour-Alliance Government formed after the 1999 election took a series of actions to make disability policy more coherent across government agencies. First, the Government appointed the country's first Minister for Disability Issues and gave the Minister a cross-departmental portfolio. Secondly, the *NZ Disability Strategy* was issued in fulfillment of the Labour Party's election manifesto pledge to develop a disability plan. Finally, in July 2002, the Government created the Office for Disability Issues (ODI). The ODI is administered by the Ministry of Social Development but has a broad charge of giving advice to the Minister for Disability Issues across all government agencies. It has assumed responsibility for monitoring the *NZ Disability Strategy* from the MOH. The ODI was a compromise with consumer organizations that favored creating a higher profile disability unit within the Office of the Prime Minister.
- *Human Rights.* Disability is one of several protected classes in New Zealand's global anti-discrimination legislation, the Human Rights Act 1993 (HRA). Since its inception, government agencies had been exempted from the HRA, but this exemption was allowed to expire on 31 December 2001. Thus the Government's disability and all other services are now subject to the HRA's provisions. Furthermore, consumer disability organizations are urging the Government to increase the profile of human rights by creating a freestanding NZ disability act, modeled in some respects on the Americans with Disabilities Act. People with disabilities have had mixed success under the HRA, but the human rights approach is thought to have been buttressed by the NZ Disability Strategy, which represents the Government's first formal endorsement of the social model of disability.

Project Approach

The project was conducted between January and August 2002. Following a review of written materials and preliminary meetings with policy makers in Wellington, about 150 semi-structured interviews were conducted with stakeholders across the country. Stakeholders included national and local government officials, consumers, family members, service providers and advocates. Visits to provider organizations typically included a tour of facilities and spontaneous interaction with consumers. Interviews were conducted in urban and rural areas on the North and South Islands. People who were interviewed or otherwise provided assistance are listed in Appendix A. Persons granting interviews were assured that their views would remain confidential.

The project also included a very limited amount of quantitative data analysis. As described later in the report, the Ministry faces significant data issues that made detailed analysis of DSS impossible within the time and resource constraints of this project. This report, therefore, relies heavily on interviews, policy reports and other qualitative data. The primary value of this report is perhaps the outsider perspective it offers.

The project's target population is adults who receive Disability Support Services through the Ministry of Health's Disability Services Directorate (DSD). With some exceptions, DSD is responsible for people with physical, intellectual, sensory and age-related disabilities. People affected by severe mental illness receive services through a separate system administered by the Mental Health Directorate. Devolution of mental health funding is discussed briefly in the report for the lessons it offers to DSS, but no attempt has been made to assess the effectiveness of New Zealand's mental health system. Likewise, the needs of children with disabilities are not addressed in depth, though children's services are discussed in the context of the numerous intersectoral issues that people with disabilities and their families face.

Organization of Report

Chapter 2 provides some background information. A brief comparison of New Zealand and the United States is provided to put some of the later programmatic comparisons in proper context. DSS and other important parts of the disability service system are described, and recent New Zealand health reforms are discussed.

Chapter 3 focuses on the New Zealand Disability Strategy. Its development and subsequent impact on New Zealand's disability system are discussed.

Chapter 4 focuses on current issues that relate specifically to people with physical, intellectual and sensory disabilities. Because age-related disability funding is expected to devolve to DHBs beginning July 2003, age-related disability issues are treated separately in Chapter 5. Chapter 6 addresses issues generally applicable to all DSS populations, regardless of age.

Finally, chapter 7 consolidates all of the recommendations made throughout the report for ease of reference.

CHAPTER 2. BACKGROUND

New Zealand and United States Comparison

New Zealand and the United States have similar visions for people with disabilities, but the two countries are quite different, and a few broad comparisons can be made to put the more detailed discussion that follows in proper context.

Per Capita Spending on Health
In both countries, support services to people with disabilities (including personal care, home assistance, residential care, etc.) are financed primarily through health programs. In the US, Medicaid is the major financing program. In New Zealand, DSS are financed through Vote Health, the country's national health program.

Table 1 underscores that the US spends considerably more per capita on health than NZ and the other selected comparison countries. New Zealand spends the least per capita among the comparison countries, but only slightly less than the United Kingdom (UK). However, NZ and the UK experienced the highest rates of growth in per capita expenditures between 1995 and 1999. In NZ and Belgium, public expenditures grew more rapidly than total expenditures, suggesting an increasing role for public financing of health in those countries. The US and the remaining comparison countries experienced the opposite trend, with private expenditures growing more rapidly than public expenditures.

Table 1. Expenditures on Health Per Capita, In US Dollar Purchasing Power Parity

Country	**1995**			**1999**			**% Change 95-99**	
	Public $	Private $	Total $	Public $	Private $	Total $	Public	Total
Belgium	1332	575	1906	1556	625	2181	16.8%	14.4%
Canada	1514	613	2128	1738	725	2463	14.8%	15.7%
Netherlands	1362	529	1891	1547	712	2259	13.6%	19.5%
New Zealand	960	284	1244	1166	339	1505	21.4%	20.9%
United Kingdom	1104	197	1301	1307	262	1569	18.4%	20.0%
United States	1684	2007	3691	1938	2420	4358	15.1%	18.1%

Source: OECD, 2001

Health Expenditures as a Percentage of GDP
Table 2 expresses health expenditures as a percentage of each country's Gross Domestic Product (GDP). When total expenditures are considered, the same general pattern holds. The US spends the highest proportion of GDP among the comparison countries, and NZ's spending is among the lowest. However, NZ and the US spend similar proportions of GDP on public health expenditures, with NZ rising above the US in 1999. This reflects NZ's increasing public expenditures relative to private expenditures during the period, and also reflects that growth in GDP was slower in NZ than in the US.

Table 2. Expenditures on Health As a Percentage of Gross Domestic Product

Country	**1995 Expenditures**		**1999 Expenditures**	
	Public	Total	Public	Total
Belgium	6.1	8.7	6.3	8.8
Canada	6.6	9.3	6.6	9.3
Netherlands	6.4	8.9	6.0	8.7
New Zealand	5.6	7.3	6.3	8.1
United Kingdom	5.9	6.9	5.8	6.9
United States	6.0	13.2	5.7	12.9

Source: OECD, 2001

In summary, the US spends considerably more per capita and a higher portion of GDP on health than NZ. The public-private expenditure mix is very different in the two countries. The US, which does not have a national health program for all population groups, has a much greater and growing proportion of private expenditures, while NZ relies increasingly on public expenditures through the national Vote Health program, which covers all New Zealanders.

Government Structures

New Zealand and the US also have different forms of government. The US is a constitutional republic with an elected head of state (the President), who leads the executive branch of government, which is constitutionally separate from the legislative and judicial branches. The President is often of a different party than one or both houses of Congress, making federal legislation slow to enact.

New Zealand is an independent sovereign nation with a parliamentary government using the Westminster system. Queen Elizabeth II is Head of State, and the Governor-General is the Queen's personal representative in New Zealand. The Prime Minister and Cabinet lead the executive branch. New Zealand's Parliament has only one chamber, the House of Representatives. New Zealand's unicameral legislature and parliamentary system can result in rapid policy change once agreement is reached in Cabinet.

In the US, disability policy is a shared responsibility between the federal government and state governments. In general, the federal Americans with Disabilities Act governs protection against discrimination on the basis of disability, while services to people with disabilities are shaped by policy and program decisions made by states. Financing of disability services is shared between the federal and state governments. The largest single source of financing is the Medicaid program, through which matching federal funds are made available to states.

In New Zealand 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 NZ's national health program, Vote Health.

Current Scope of and Access to Disability Support Services

Disability support services (DSS) describes a wide range of supports provided through the Ministry of Health's Disability Services Directorate (DSD) to people with physical, intellectual, sensory and age-related disabilities.[1] In order to qualify for DSS, a person's disability must be likely to continue for six months or more and require ongoing support. Persons requesting DSS are assessed by a designated Needs Assessment and Service Coordination (NASC) agency, which allocates services based on the assessed level of need. Types of support available include information and advice, personal care, assistance with household management, home-delivered meals, respite care and other carer support, rehabilitation (provided primarily through hospital-based Assessment, Treatment and Rehabilitation units), equipment, environmental and vehicle modification, grants for vehicle purchase, some day and vocational services and residential care (group homes, rest homes and continuing care hospitals).

DSS are provided under New Zealand's national health program (Vote Health), financed through general government revenues. At first blush, DSS look like a universal entitlement to disability and long-term care not found in the US, but the system operates under a capped budget, and individuals are not personally entitled to services. Some services are subject to waiting lists and prioritisation criteria. In some areas, NASC agency capacity cannot keep up with the demand for assessments, and the wait for an assessment can be six months or more. (NASC agencies have a triage process that allows them to prioritise requests for assessments when their capacity is stretched.) Without an assessment, services cannot be authorized. Once an assessment has been conducted, most services appear to be available within a reasonable time frame, with the exception of equipment and environmental and vehicle modifications, which can take several months or years to receive.

Most services are provided without regard to one's ability to pay, with some exceptions. Residential care for older people (rest homes and continuing care hospitals) is subject to both income and asset tests. Once assets have been depleted below maximums, resident contributions are capped at $636 per week and the government pays the remainder through a "top up" subsidy.[2] Household management services (meal preparation, cleaning, shopping) are subject to an income test. Home modification costing more than $7,900 is subject to income and asset tests.

The DSD purchases DSS through roughly 3,000 contractual agreements with providers. Most are for-profit or non-profit private agencies, with the exception of public hospitals, from which the Ministry purchases in-patient assessment, treatment and rehabilitation (ATR) services, mostly for older people but also for children and adults with disabilities. The Ministry also purchases Needs Assessment and Service Coordination (NASC) services from several District Health Boards (DHBs).

---

[1] Psychiatric disability is also included in the list of qualifying conditions for DSS, but funding for services to people with a primary diagnosis of serious mental illness is overseen by the Ministry of Health's Mental Health Directorate and has been devolved to DHBs.

[2] New Zealand's "top up" mechanism is very similar to the Medicaid "spend down" mechanism used in most US states.

Other Important Government Organizations and Services

DSD is the single largest funder of disability services, but New Zealand's disability system includes several other important components, as follows:

- *Office for Disability Issues (ODI).* The ODI was created on 1 July, 2002 for the purpose of providing cross-departmental advice to the Minister for Disability Issues. It is administratively located within the Ministry of Social Development, but is expected to focus on disability issues across government agencies. For example, it has assumed from the MOH responsibility for monitoring the *NZ Disability Strategy*, and is also developing a project that is expected to look at the coherence and equity of disability services across government.
- *Ministry of Social Development (MSD).* Through Work and Income NZ (WINZ), the MSD administers New Zealand's income support programs. These include the Invalid and Sickness Benefits, often accessed by people with disabilities. It also includes government superannuation (retirement benefits), residential care subsidies, and certain other disability allowances. WINZ also administers contracts for a range of vocational services, including sheltered workshops, and mainstream employment programs (e.g., apprenticeship and job service programs). MSD's policy arm develops the policy in all of these areas except vocational and employment services.
- *Other Ministry of Health Directorates.* In addition to DSD, the Ministry has other directorates that are important to people with disabilities. These include the Mental Health Directorate, which provides funding (through DHBs) for the 3% of New Zealanders affected by the most severe mental illness at any given time, and the DHB Funding and Performance Directorate, which has overseen the devolution of personal health and other health funding to DHBs.
- *Department of Labour (DOL).* The DOL's Labour Market Policy Group provides policy advice on vocational and employment programs for people with disabilities.
- *Ministry of Education.* The Ministry of education is responsible for the education of children with disabilities. Specialist Education Services was a separate government unit until February 2002, when it was integrated into the Ministry.
- *Housing New Zealand Corporation.* Housing New Zealand Corporation collaborates with government agencies and community groups to develop group homes and other housing for people with disabilities. For example, funding has been provided to Housing NZ to adapt or construct housing for people with intellectual disabilities leaving institutions. Housing New Zealand Corporation also administers State Housing, which is often the only affordable housing that can be accessed by people with physical disabilities.
- *Accident Compensation Corporation (ACC).* New Zealand's Accident Compensation Corporation provides no-fault compensation and rehabilitation to New Zealanders and visitors injured through medical misadventure or accidents, regardless of location. ACC protects people in the workplace, at home, in automobiles, while playing sports, etc. People who have acquired disabilities under the ACC system receive ongoing support through ACC. This has created two parallel systems for people with disabilities. The ACC system is generally thought to be more generous than the DSS system. This

stems in part from ACC's clear legislative goal, which is to restore functioning to pre-accident levels and/or to compensate people for loss of function. The charge of DSS, on the other hand, is to promote inclusion and participation in society to the extent that resources are available.

- *Human Rights Commission*. The Human Rights Commission is responsible for enforcing the Human Rights Act, which prohibits discrimination on the basis of several categories, including disability. In the past few years, disability-related enquiries have comprised the single largest category of work for the Commission.

Other important government agencies include the Office of the Health and Disability Commissioner, the Ministry of Transport, the State Services Commission, and the Lottery Grants Board. Local authorities also provide services and make decisions that impact on people with disabilities. For example, local authorities fund transport systems, create and maintain public spaces and council housing, and administer local building regulations.

The extent to which people with disabilities use services from several agencies simultaneously is not known, but anecdotal evidence suggests that most of these agencies have many common clients. The greatest overlap is thought to be between MSD and DSD, because many people who receive DSS depend on income support programs as well, particularly if they are in residential care.

Recent History of Disability Support Services

The roots of today's DSS can be traced at least as far back as 1971 when the Department of Social Welfare (DSW) was created to bring together many services that had evolved over the previous decades. The new Department inherited the programs of the Department of Social Security, which it replaced, including its home help program for "the elderly and infirm." (Royal Commission of Inquiry, 1972) This was consolidated with a separate home help program that had been operated by the Department of Labour. The new Department of Social Welfare also assumed responsibility for subsidies paid to voluntary organizations for people with intellectual disabilities, which had been paid previously by the Department of Health. (Ministerial Task Force on Social Welfare Services, 1986) Income support programs important to people with disabilities, such as the Sickness Benefit and Invalids Benefit, were also inherited from Social Security and located in the new department.

In 1975, the Disabled Persons Community Welfare Act (DPCWA) established a new entitlement to a range of social supports for community living. The new program was also administered by the DSW. By this time, the DSW had assembled a variety of community-based services for people with disabilities. The Department of Health, in the meantime, continued to fund institutions throughout the country, either directly or through public hospitals. It also funded a number of other services for people with all types of disabilities, including home nursing, home help, continuing care hospital subsidies and prosthetic devices.

Increasing costs and poor performance (e.g., increasing waiting lists for surgery) of the publicly funded health system became an increasing concern in the 1970s. Pressure for reform mounted, and between 1983 and 1989, the Government implemented the Area Health Board (AHB) system, under which public financing for hospital care and certain other health services was devolved to AHBs.

Following the 1990 election, market-oriented health reforms were implemented to split the purchaser and provider roles. Under the reforms (operational between 1993-1996), four Regional Health Authorities (RHAs), not tied to public hospitals or any other providers of care, assumed responsibility for purchasing health services in a competitive market. (Gauld, 2001) Although these reforms were designed primarily for health services, similar concerns were also being expressed about the growing disability sector: that expenditures were growing too fast and that lack of competition was resulting in poor performance and inefficiency. Despite considerable consolidation of disability-related services within DSW, the Department of Health was also providing a growing amount of community-based services and, because of its ongoing role in funding institutions, the lion's share of funding for services overall (not including income support). In 1990-91, the Department of Health provided $754 million in disability-related funding, as compared to $239 million provided through the Department of Social Welfare. (Shipley and Upton (a), 1992) Citing fragmentation of disability services as a major problem, the Government decided to consolidate Health and DSW funding for most disability-related services within the Regional Health Athorities and make them responsible for purchasing Disability Support Services. (Shipley and Upton (b), 1992) Included in the transfer was funding for day activities and social rehabilitation. Consideration was given to transferring vocational services for people with disabilities to the RHAs as well, but following consultation, a decision was made to leave those services in DSW. Income support programs also remained at DSW. Under the RHAs, DSS services were accessed following an individual assessment to establish functional need, replacing the entitlement approach of the DPCWA. The new DSS services were ringfenced and capped at 25% of the Vote Health budget.[3]

A key accomplishment of the RHAs and their successor agency, the Health Funding Authority (HFA), was the transformation of New Zealand's disability system from one with a large institutional component (particularly for people with intellectual disabilities) to one based almost entirely in community services. The Government endorsed the policy of deinstitutionalization in 1990 and by June 1998, sufficient progress had been made to establish a strategic goal of full deinstitutionalization by 30 June 1999. (Ministry of Health and Health Funding Authority, 1998) Though it will take a bit longer than planned to complete the goal, plans are in place and funding secured to move approximately 360 people who remain at Kimberley and 80 who remain at Braemar as of August 2002. The move to community-based services, combined with the competitive contracting approach of the 1990s reforms, greatly expanded the infrastructure of community-based providers.

The New Zealand Public Health and Disability Act 2000 (NZPHDA)

The 1999 change in Government ushered in the latest major structural change to New Zealand's health system. Rejecting the competitive purchasing approach of the 1990s, the new Government abolished the Health Funding Authority (HFA) and

---

[3] The 25% cap includes funding for mental health services, which is administered separately by the Mental Health Directorate. DSS expenditures exclusive of mental health currently represent about 19.5% of the Vote Health budget.

returned to a scheme reminiscent of the Area Health Board system of the 1980s. Twenty-one District Health Boards (DHBs) have been created, with the intention of devolving health and disability funding to the local level. DHBs have planning and funding arms, and provider arms that include local public hospitals and some other services. DHBs include locally elected and nationally appointed members, and are meant to be accountable to their communities and to the Minister of Health.

The HFA was merged into the Ministry of Health, which became the funder for all health and disability support services (DSS) during the transition period. To date, most personal health and mental health funding and some Mäori health agreements have been devolved to DHBs. Funding for age-related DSS is expected to devolve by July 2003, subject to final Cabinet approval and demonstrated capability by DHBs. No decision will be made regarding devolution of DSS for physical, intellectual and sensory disabilities before July 2004.

The portions of the NZPHDA that establish the legislative charge for DSS are as follows:

> The purpose of this Act is to provide for the public funding and provision of personal health services, public health services, *and disability support services*, and to establish new publicly-owned health and disability organizations…(§3(1), emphasis added)
>
> …to achieve for New Zealanders…the promotion of the inclusion and participation in society and independence of people with disabilities…(§3(1)(a)(ii))
>
> …to provide a community voice in matters relating to personal health services, public health services, and disability support services…(§3(1)(c))
>
> The objectives stated in subsection (1) are to be pursued to the extent that they are reasonably achievable within the funding provided. (§3(2))

The NZPHDA also directed the Minister responsible for disability issues[4] to develop a Disability Strategy "to provide the framework for the Government's overall direction of the disability sector in improving disability support services." (§8(2))

---

[4] The Minister for Disability Issues was a new position created by the Labour-Alliance Government following the 1999 election. The Minister provides leadership on disability issues across the several agencies that are involved with disability.

CHAPTER 3. THE NEW ZEALAND DISABILITY STRATEGY

Adoption of the Strategy

Prior to the legislative change contained in the NZPHDA, the Government had already begun developing a Disability Strategy in keeping with the Labour Party's election manifesto pledge to develop a disability plan. Early drafts of the NZPHDA included a requirement to develop a Health Strategy. The requirement to develop a Disability Strategy was added in later drafts of the bill, giving the Disability Strategy par status with the Health Strategy.

Hon Ruth Dyson, New Zealand's first Minister for Disability Issues, appointed a sector reference group with majority representation by consumers. The group also included providers, and some of the consumers on the group also worked for provider agencies. An officials group, comprised of government officials from the Ministry of Health, Health Funding Authority, Ministry of Education, Ministry of Social Policy, Department of Labour, Work and Income NZ, State Services Commission, Specialist Education Services, Accident Compensation Corporation, Ministry of Transport, and others met separately. The Ministry of Health provided staff support to both groups and in September 2000, the Minister for Disability Issues sent a discussion document out for broader public consultation, including 68 meetings, resulting in 632 formal submissions, a high number. (Ministry of Health, 2001a) As the sector reference group waded through the submissions and approached its final recommendations, a debate arose as to the appropriate level of detail that should be reflected in the strategy. A number of sector reference group members favoured including detailed references to specific service gaps, the need for new resources and time frames for achieving certain outcomes, but it had limited time to develop the strategy to that level of detail. Officials, however, considered that the Strategy needed to be a framework document to ensure its applicability across all of Government and continuing relevance over time. A compromise was arrived at, in which the draft was written as a broad strategic framework including actions to be taken but with no timeframes, and the sector reference group communicated some of its more specific recommendations in a cover letter to Hon Lianne Dalziel, who had assumed the Disability Issues portfolio during the course of the group's work. The letter included both process recommendations (e.g., enlisting support from the Opposition and including consumers in monitoring) and specific content (e.g., phasing out segregated schools by 2010 and providing new funding to implement the strategy). The Minister decided to condense the draft document submitted by the sector reference group to form the Government's *New Zealand Disability Strategy*.

The result was a very broad document, published in April, 2001, that established an ambitious vision: that New Zealand will become a "fully inclusive society." (Ministry of Health, 2001b) The *NZ Disability Strategy* includes the following fifteen objectives:

1. Encourage and educate for a non-disabling society.
2. Ensure rights for disabled people.
3. Provide the best education for disabled people.
4. Provide opportunities in employment and economic development for disabled people.
5. Foster leadership by disabled people.

6. Foster an aware and responsive public service.
7. Create long-term support systems centred on the individual.
8. Support quality living in the community for disabled people.
9. Support lifestyle choices, recreation and culture for disabled people.
10. Collect and use relevant information about disabled people and disability issues.
11. Promote participation of disabled Mäori.
12. Promote participation of disabled Pacific peoples.
13. Enable disabled children and youth to lead full and active lives.
14. Promote participation of disabled women in order to improve their quality of life.
15. Value families, whänau and people providing ongoing support.

The document makes the claim that these objectives are "underpinned by detailed Actions," but it is important to note that the actions are quite broadly stated, without reference to specific governmental actions or indicators of success. For example, the Actions listed under Objective 1 (Encourage and educate for a non-disabling society) are:

1.1 Develop national and locally-based anti-discrimination programmes.
1.2 Recognise that it is disabled people who are experts on their own experience.
1.3 Recognise and honour the achievements of disabled people.
1.4 Include the perspectives of disabled people in ethical and bioethical debates.
1.5 Encourage ongoing debate on disability issues.

How effective has the *NZ Disability Strategy* been to date? What are its chances of influencing the direction of policy in the future? These questions were put to the individuals interviewed for this project. Their responses are reflected in the following analysis of perceived strengths and limitations.

Perceived Strengths

- *The Disability Strategy is widely recognized in the disability sector as the Government's guiding document for disability policy and programs.* With very few exceptions, the consumers, providers, public officials, and others interviewed knew about the *Strategy* and had an opinion about it. This undoubtedly reflects the extensive public consultation that occurred during development, and the continuing promotion of the *Strategy* by the Minister for Disability Issues, the Disabled Persons Assembly (DPA), the Disability Services Directorate, and other individuals and organizations. It also reflects relatively good accessibility to the document via alternative formats, a dedicated web site, and broad distribution of implementation reports.
- *Consumers are generally enthusiastic about the Disability Strategy.* While many consumers observed that the document was very broad and lacked resources for implementation, they nonetheless felt that it was a huge step forward for New Zealand. Many noted that the *Strategy* is the first formal government document to endorse full inclusion and a social model of disability. Several consumers indicated that the document was personally validating of them as individuals with the same rights and responsibilities as other members of society.
- *The disability sector applauds the effort to hold all of government accountable to the Strategy.* To date, monitoring of the *Strategy* has focused on government agencies. Each agency was asked to develop an implementation plan. Service providers in particular are pleased with the focus on government agencies. Too

often in the past, they reported, providers have been held accountable while government exempted itself. *Strategy* monitoring has been an exception.

- *The NZ Disability Strategy is being used as a tool by Ministry staff, providers, advocacy groups and others.* Many of the individuals interviewed were able to cite specific examples of how they had used the strategy in their work. For example, the DSD includes references to the *Strategy* in Requests for Proposals (RFPs) and requires that bidders address *Strategy* objectives. Many providers said they cited the *Strategy* in their negotiations with Ministry officials to get contracts for new or enhanced services. The 2001 Annual Report of Alzheimer's New Zealand cites Objective 7 (creation of long-term support systems centred on the individual) as particularly important to the organisation.
- *The NZ Disability Strategy has given a high profile to disability issues at a time when they could easily have been overshadowed by the latest set of health reforms.* If, as has been reported, the *Strategy* was inserted into the NZPHDA to ensure an appropriate level of attention for disability issues, it has clearly achieved that purpose. The proposed devolution of DSS under the NZPHDA remains an important issue to resolve, but rather than focusing exclusively on that structural issue, the disability sector has been able to develop its own objectives. Presumably, the decision regarding devolution can now be made according to whether or not it advances the objectives of the *Strategy*.

Limitations

- *In general, providers are much less enthusiastic about the Strategy than consumers.* This in part reflects unhappiness with the development process, which included only a few providers on the sector reference group. A few providers also expressed concern that the *Strategy* does not address the needs of people with significant disabilities. Many providers expressed cynicism about the Government's commitment, given that no new resources have been allocated directly to *Strategy* implementation. Nonetheless, most of the providers interviewed said they were familiar with the Strategy and cited it when advocating for their programs.
- *There is widespread confusion as to whether or not the NZ Disability Strategy applies to older persons with disabilities.* This is in part due to longstanding tensions between the younger and older sectors in New Zealand, but it also results from the decision to separate DSS funding for age-related disability from DSS funding for physical, intellectual and sensory disabilities. Some in the ageing sector identify exclusively with the *New Zealand Positive Ageing Strategy* (Ministry of Social Policy, 2001) and the *Health of Older People Strategy* (Ministry of Health, 2002), and do not view the *NZ Disability Strategy* as providing policy guidance for services to older people.
- *The NZ Disability Strategy has failed to attract significant new resources.* No new resources have been earmarked for strategy implementation. Some have argued that the strategy requires only a change in public attitudes, but it seems clear that most of the objectives have significant resource implications.
- *The NZ Disability Strategy is vulnerable if the Government or the Minister should change.* New Zealand is littered with strategies from the past that have been abandoned with a change in Government. Many persons interviewed expressed concern about the *Strategy's* viability over time, particularly since its impact has in part stemmed from the strong advocacy of the incumbent Minister for Disability Issues. Fears about the future may be self-fulfilling if Ministry staff,

providers and others take a wait-and-see attitude about the *Strategy*. Cutting against this concern, however, is the very strong support that the *Strategy* enjoys among consumers. To the extent that consumer advocates continue to champion the Strategy, it may be able to survive political changes.

- *The Disability Strategy provides little guidance on development priorities.* Almost all parties interviewed felt that the Strategy is too vague to provide useful guidance for service development. In fact, many observed that the strategy gives wide enough berth to justify almost any type of development. The Strategy may not have been intended as a guide to program planners, but could probably serve that function if it were developed to the next level of detail.
- *Successful implementation of the Strategy has not been defined and will be very difficult to assess.* The Strategy does not include objective, measurable indicators of success. Full progress reports are scheduled to be completed after five and ten years, but to date, given the lack of new resources, monitoring has been limited to holding government agencies accountable to their own implementation plans. This approach has undoubtedly raised awareness and created some change within government agencies, but no attention has been paid to broader social indicators of "a fully inclusive society." For example, if one government agency hires a person with a disability, a positive change has occurred. But the one new hire will not impact the overall employment rate of all New Zealanders with disabilities.

Recommendations: Disability Strategy

- The Office for Disability Issues should work with the disability sector to develop *NZ Disability Strategy* success indicators. What does it mean, in objective terms, to have "a fully inclusive society?" A set of indicators should be established as soon as possible, and baseline measures taken. The five and ten year reviews could then be based on these indicators. The disability sector should be engaged in creating the indicators. One possible approach would be to have separate consumer and provider groups develop one or two measures for each objective, and then bring the two groups together to work out a final list. To avoid frustration, efforts should remain modest and focus on areas where data already exists. For example, in the area of employment, one indicator could be employment rates among people with disabilities, as reported by the New Zealand Disability Survey (Statistics New Zealand, 2001). Another could be the employment rate of people receiving DSS. An indicator related to community living could be the number of people living in each of the settings of care supported by DSS (e.g., rest homes, community group homes, own home, flat). Overall attitude toward disability (which is commonly cited as a major problem) might be captured by adding a few questions to the Census or Disability survey.
- Develop policy designed to impact the selected indicators. The *NZ Disability Strategy* provides a direction for disability policy that is broad enough to include the efforts of multiple agencies, but it does not, by itself, provide specific policy guidance. Whether or not DSS funding devolves to DHBs, a key role of the new Office for Disability Issues will be to coordinate implementing policy across government agencies.

CHAPTER 4. ISSUES SPECIFIC TO PHYSICAL, INTELLECTUAL AND SENSORY DISABILITIES (NON AGE-RELATED)

This chapter addresses issues primarily associated with non age-related disability.

Overall Impressions

Within a decade, New Zealand's DSS system for non age-related disability has been transformed from one that had a substantial institutional component in 1990 (particularly for people with intellectual disability) to one that is now almost entirely community-based. Funding has been secured to move the approximately 360 adults with intellectual disability who remain at Kimberley Centre and the 80 who live at Braemar. This places New Zealand well ahead of many states in the US, which continue to be challenged by running dual community and institutional systems. New Zealand's community system is quite fragile, however, and has several challenges to address before it meets the *New Zealand Disability Strategy*'s high standard of a "fully inclusive society."

- The DSS system is primarily focused on maintaining people's current situations, rather than promoting full inclusion and independence. The home support system is particularly vulnerable, depending on a work force that is poorly paid, often not trained, and accustomed to "doing for" rather than promoting independence.
- New Zealand's residential options for younger people (particularly those with intellectual disability) are based heavily on group homes and other "models" of care. Development of group home infrastructure was effective in closing New Zealand's institutions, but it is rigid and may now be acting as a barrier to independence for some individuals who are able and willing to move on.
- DSS is largely a "stand alone" system. It is poorly integrated with vocational, educational and health systems. The main purpose cited for the New Deal DSS reforms of 1993 to 1996 was to reduce fragmentation, but the "system" for people with disabilities remains a set of free-standing sub-systems, each of which must be navigated separately by people with disabilities and their families.
- Adaptive technology and home modifications are major challenges for the DSS system. Though often critical to greater inclusion in society, resource constraints have required these often expensive supports to be limited. Rapid emergence of new technology and lack of a satisfactory body of research on effectiveness makes policy development extremely challenging in this area.

Being nearly free of the resource demands of large institutions, the DSD, in partnership with other government and private agencies, is now in a position to focus on improvements to the community system, transforming it from one that maintains people's current levels of inclusion to one that works toward the *NZ Disability Strategy*'s vision of a fully inclusive society.

Greater Focus on Habilitation

An important element of moving New Zealand's DSS system from one that maintains to one that promotes inclusion is a greater emphasis on habilitation. In recent history, habilitation has been cited as a need in DSS since the New Deal reforms of the early 1990s. (Shipley and Upton, 1992; Ministry of Health, 1994)

Habilitation is a concept similar to rehabilitation, except that it applies to gaining function, health, skills, and experiences for the first time, as opposed to recovering something that has been lost. People who are born with physical impairments, for example, often need physio and occupational therapies to gain motion that develops naturally in others. People who spent their early years in institutions may never have learned fundamental life skills such as cooking, housekeeping and using the public transport system. Habilitation potentially includes a broad range of services designed to promote greater independence.

- *Comprehensive Assessment and Service Coordination.* The first step in developing a habilitative system is performing a comprehensive assessment that focuses on people's goals and coordinating habilitative services from an array of service systems. This issue applies to all DSS population groups and is addressed in Chapter 6.
- *Skilled Therapies.* Physio-, occupational, speech and language, and psycho-therapies can all be critical to promoting function and independence. Though theoretically available to people, access can be a problem, particularly for the many people who get caught between service systems. Boundary issues exist between DSS and the personal health and mental health systems, for example, which can result in significant obstacles to obtaining therapies. In primary and secondary schools, therapies are generally available only on a consultative basis to staff.
- *Vocational Services.* Many people in the DSS system have little or no employment experience and require pre-vocational and vocational services. This topic is addressed below.
- *Equipment, Technology and Environmental Modification.* For many, new technologies and equipment offer opportunities to increase function and independence, but this is an area that challenges the DSS system. New products are often very expensive, and the Ministry must balance access and cost issues as it develops policy in this area. With a greater emphasis on habilitation, it may become possible to link funding of equipment to clear habilitation goals.

Employment and Vocational Services

Overview

Objective 4 of the NZ Disability Strategy is to "provide opportunities in employment and economic development for disabled people." Shortly after the release of the *NZ Disability Strategy*, the Government released its complementary vocational strategy for people with disabilities, *Pathways to Inclusion* (Department of Labour, 2001).

New Zealand supports in this area can be divided roughly into three distinct groups of services, administered by three agencies. The Disability Services Directorate and the Ministry of Social Development, both provide funding for community participation. Community participation captures a range of daytime activities for people who are neither employed nor engaged in vocational services. Examples include life skills training, recreation and leisure activities, and arts programs. Through WINZ, MSD also administers contracts for vocational services. These include contracts to sheltered workshops and other agencies that help people prepare for and enter employment. WINZ also administers the contract with Workbridge, a national vocational services agency that evolved from the post-World War I Soldiers' Civil Reestablishment League (later renamed the Rehabilitation League to reflect its broadening mission). Finally, WINZ administers a number of mainstream employment services for people who are seeking work. These include apprenticeship programs and job placement services.

Labour Force Participation Among People with Disabilities
The NZ Disability Survey shows employment rates among adults with disabilities to be only slightly lower than employment rates among adults without disabilities. (Table 3) However, the employment rate is calculated by dividing the number of people employed by *the number in the labour force*. In other words, only people who are working or actively looking for work are included in the denominator. Those who are not seeking work are not captured in the statistic.

Table 3. Employment Rate* of New Zealanders with and without Disabilities, 1996 and 2001

	1996 Employment Rate	**2001 Employment Rate**
Adults (15+) with Disability	92.3%	90.8%
Adults (15+) without Disability	94.1%	94.1%

Source: Statistics New Zealand. Calculated from Table 4.02 on 1996 and 2001 Disability Surveys

*Employment rate is derived by dividing the number of people working by the number who are in the labour force.

Table 4 shows that the percentage of adults with disabilities in the labour force is much lower than the percentage of adults without disabilities in the labour force. The lower rate of people with disabilities actively seeking work probably reflects a variety of factors, including higher levels of disability among older people (who tend to be out of the labour force), people with disability enrolled in community participation programs (and therefore not actively seeking work), and discouragement among people who were not able to find employment in the past and are no longer seeking work.

Table 4. Percent of New Zealanders with and without Disabilities in Labour Force*, 1996 and 2001

	1996 % in Labour Force	**2001% in Labour Force**
Adults (15+) with Disability	39.9%	43.6%
Adults (15+) without Disability	70.0%	69.8%

Source: Statistics New Zealand. Calculated from Table 4.02 on 1996 and 2001 Disability Surveys

*Those working or actively looking for work.

Changes from the 1996 survey to the 2001 survey are interesting when the employment rate and labour force participation are considered together. The employment rate dropped slightly for adults with disabilities (from 92.3% to 90.8%), but the percentage in the labour force increased (from 39.9% to 43.6%), suggesting that the decreasing employment rate is at least in part due to an increasing denominator (people working or actively seeking work).

Disincentives for Consumers, Families, and Agencies

The low rate of labour force participation among people with disabilities is reinforced by the rules governing income support programs (invalid benefit and sickness benefit), which create disincentives to employment. The income support programs are available to people whom, because of sickness or disability, are unable to work full-time. People receiving benefit are generally allowed to work up to fifteen hours per week. If they exceed fifteen hours, the income benefit is jeopardized. Several people interviewed reported that consumers are well aware of the limits and avoid increasing hours of work for fear of losing the benefit. Loss of benefit can also be a concern to family members when a person with a disability lives at home, and it can affect provider income when the benefit is used to pay part of a residential fee. In some districts, WINZ staff reportedly discourage people on benefit from seeking employment, and are not likely to encourage referrals to vocational services agencies nor mainstream employment services. Thus, several forces act to discourage a person who is receiving income support from expanding employment beyond the maximum allowed under WINZ rules.

Similar disincentives exist in the US. Earnings affect eligibility for income support programs such as Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). Because the US does not have a national health program, means-tested health benefits (Medicaid) and health benefits tied to disability (Medicare) can also be jeopardized by employment. The US Social Security Administration and the federal Department of Health and Human Services have launched a series of demonstration programs designed to reduce income and health coverage disincentives while increasing access to employment services. The Social Security Administration will be testing a gradual and even reduction of income supports that will reduce benefits by $1 for every $2 earned by a beneficiary. Rather than losing all benefits when a maximum amount is earned, beneficiaries will continue to receive a diminishing benefit until earnings equal twice the original benefit amount.

In NZ, the MSD has developed demonstration programs to test the impact of providing different types of employment support to increase competitive employment among people on sickness and invalid benefits. The demonstration projects were developed in response to increasing numbers of people receiving benefit, particularly among people with mental illness. Planning for the demonstration programs identified benefit loss as a disincentive,[5] but a decision was made to proceed with the demonstration "within the existing policy and legislative framework," which means that benefit-related disincentives will not be addressed by the demonstration. (Ministry of Social Development, 2002) The projects began in June of this year and will run for two years. An evaluation is planned. Although the demonstration projects do address income disincentives currently, program designers may have an opportunity to improve income incentives if early evaluation results find that the programs do not attract a sufficient number of volunteers in their current form.

---

[5] In general, income from $81 to $180 per week results in a reduction in benefit of 30¢ per dollar earned, and income from $181 per week results in a reduction of 70¢ per dollar.

Pathways to Inclusion

Five months after the Disability Strategy was released the Government issued *Pathways to Inclusion* (Department of Labour, 2001), its complementary vocational services strategy for people with disabilities. A central objective is repeal of New Zealand's sheltered workshop legislation, the Disabled Persons Employment Promotion Act 1960 (DPEPA). In May, the Government announced a five-year, $27 million funding package to implement *Pathways*. (Dyson, 2002)

The DPEPA, like similar laws in the US, exempts operators of sheltered workshops from minimum wage and holidays legislation. Such laws, progressive in their time, are seen as discriminatory in today's human rights context. The DPEPA is also thought to have resulted in provider "capture" of people with disabilities. Rather than functioning as pre-employment training sites, the sheltered workshops have become long-term vocational services for many.

Pathways has two major goals: to increase the participation of people with disabilities in employment; and to increase the participation of people with disabilities in communities. The second goal (increasing community participation) appears to be a response to concerns expressed by families, providers and others regarding the potential loss of the sheltered workshop as a community resource. The concern was that an increasing emphasis on competitive employment would leave behind some people with substantial disabilities who would not become employed, but would no longer have access to workshops. While this concern is valid, the dual goals expressed in *Pathways* weaken the document's employment focus. The danger is that most of the new resources earmarked for implementation will be used to protect providers from loss and preserve existing "slots" by reclassifying consumers from sheltered employment status to community participation status.

One of *Pathways'* stated goals is to "ensure services are responsive to the needs of all groups of people with disabilities." This again reflects a valid concern that not all people will become competitively employed, and resources must be preserved for those who do not. One way of addressing this concern and ensuring a flexible, individual approach would be to allocate an adequate amount of Pathways implementation funding to provide an individual voucher to every person currently employed in a workshop setting.[6] This would encourage consumers and their families and other supporters to select services that promote individual goals.

Access to Employment Services for DSS Consumers

The percentage of people receiving DSS who are employed is not retrievable from existing information systems, but is thought to be lower than the percentage for all people with disabilities. This is explained in part by the relatively high support needs of people receiving DSS, but may also reflect their relatively low access to vocational services. The Ministry of Health's NASC guidelines (Ministry of Health, 2002b) reinforce the sense that vocational services are a low priority in the DSS assessment process. "Educational/ vocational/ voluntary" appears as the 17th heading, following social, leisure, household management, communication and a host of other needs. If

---

[6] This idea is modelled after the US Social Security Administration's Ticket to Work initiative, in which all eligible beneficiaries receive a "ticket" redeemable at a broad range of vocational services agencies. This enables consumers to make choices and "purchase" the services they need, rather than being forced into contracted provider "slots."

vocational needs are indicated, the NASC agency must refer the person to another agency for a vocational services assessment, where he or she is likely to end up on a waiting list. Within the NASC's immediate sphere of influence, however, community participation funding is provided as a component of DSS. Community participation should be available for those who need it, but employment services should be just as easy to access.

This is a classic example of government funding streams creating barriers for consumers. The fact that vocational needs are assessed and funded by a different service system than DSS results in lower access to vocational services for DSS consumers. A promising effort toward inter-agency collaboration is being undertaken in the Waikato. (Intersect Waikato, 2002) Nine agencies have come together to develop joint approaches to increasing employment among people with disabilities. To date, the agencies have completed a stock-take and are developing a local inter-agency strategy within the national framework established by the *NZ Disability Strategy*.

Recommendations: Employment and Vocational Services

- Increase access to vocational services for DSS consumers by improving inter-agency coordination at both national and local levels. Experiment with multi-agency assessment mechanisms that provide easy access to comprehensive services for people. (The MORST has funded a project that offers great potential in this area,[7] and the Intersect Waikato effort offers a possible venue for local pilot testing.)
- Irrespective of progress on inter-agency assessment processes, vocational needs should be addressed more consistently as part of NASC assessments, referrals made to vocational agencies as indicated, and coordination provided to streamline the process for consumers.
- Clarify that the primary goal of *Pathways to Inclusion* is to increase the number of people with disabilities who are employed. Ensure that data systems can track the movement of people from their current sheltered workshop settings into other settings following repeal of DPEPA. Carefully evaluate the extent to which *Pathways* results in greater employment, as opposed to reclassification (but no real change in situation) for people with disabilities.
- Ensure that *Pathways* implementation considers the individual needs of consumers by allocating an adequate amount of *Pathways* funding to provide an individual service voucher to each person currently working in a sheltered workshop. Rather than planning a set number of employment or community participation "slots," enable each consumer to purchase the type of service he or she needs. This approach has a secondary benefit of reducing inter-agency cost shifting concerns, since demand for additional funding in any particular agency's area of responsibility would be accompanied by portable funding.
- Build on current MSD employment pilots to include people with physical and intellectual disabilities in the target group, and to reduce disincentives for

---

[7] "A Model of Co-ordinated Case Management (including assessment) for Disabled People Across Government Departments," funded for three years to the Ministry of Health from the Ministry of Research, Science and Technology's cross-departmental research pool.

people receiving income support benefits by experimenting with gradual reductions of income support (e.g., reduction of support by $1 for each $2 earned) and expedited reinstatement for employed people who are mistakenly removed from income support programs.
- Ensure that people with disabilities who are receiving sickness or invalid benefits are not turned away from mainstream employment services.

Devolution of Non Age-Related DSS

Current Status

The New Zealand Public Health and Disability Act 2000 envisioned that funding for most services overseen by the Ministry of Health would devolve to 21 District Health Boards (DHBs), comprised of locally elected and nationally appointed members who are accountable to their communities and to the Minister of Health. Most personal health and mental health funding and some Mäori health services agreements have already devolved. DSS funding for people with age-related disability is expected to devolve beginning in July 2003, subject to final approval by Cabinet and demonstrated capability by DHBs. (Age-related DSS funding devolution is discussed in Chapter 5) A decision regarding the devolution of non age-related DSS will not be made before 1 July 2004.

Focus on Health

The debate regarding the appropriate balance between central and local control of the health and social services system is as old as the country itself. (For history, see Gauld, 2001; Ministerial Task Force on Social Welfare Services, 1986) The relationship has been subject to numerous legislative changes since 1854, when provinces were initially given responsibility for hospital services and poor relief. (Hay, 1989) The pendulum has swung between central and local authority with each major reform. In recent history, hospital and some other personal health services were devolved to Area Health Boards in the 1983 to 1991 period. Between 1993 and 1999, central government progressively reclaimed control of funding, initially through four Regional Health Authorities (RHAs) and, following the “re-reforms” of 1996, the Transitional Health Authority and, finally, the Health Funding Authority (HFA). With passage of the NZPHDA, the Labour-Alliance Government elected in 1999 effectively abolished the reforms of the 1990s in favour of returning to a devolved system with an emphasis on delivery of health services through District Health Boards. An important difference, however, is that DSS are slated to devolve in this latest iteration (subject to further analysis of options), whereas they were not part of the previous devolution to Area Health Boards. This new situation arises because in the intervening reforms of the 1990s, responsibility for purchasing certain community-based services were transferred from the former Department of Social Welfare to the RHAs and combined with other services previously purchased by the Department of Health, creating the current DSS program.

A common point of view among the people interviewed during this project is that DSS is slated for devolution because it happens to be administered by the Ministry of Health, not because the architects of devolution thought DSS should necessarily be devolved. The NZPHDA was an explicit rejection of the market-based health purchasing reforms of the 1990s, in which public hospitals had been converted to

Crown Health Enterprises and made to compete with private hospitals for health funding. Minister of Health Annette King's speech upon first reading of the New Zealand Public Health and Disability Act 2000 is illustrative of the debate's focus on health:

> "As a new Zealander, I was dismayed by what happened to our *health* system during the 1990s. … But if I was saddened and dismayed by what happened, I was still staggered by the level of disillusionment and the lack of morale I discovered right across the *health* sector when I became Minister...No wonder we have found so much support from the public and *health professionals* for the changes this Bill puts forward. *Health professionals* are in the *health system* to deliver *health*, and most understand this Bill will empower them to do so again." (King, 2000, emphasis added)

A Solution that Fails to Address DSS Problems

Because devolution was designed as a solution to New Zealand's health system challenges, it fails to address the major issues facing DSS. For example, fragmentation of services is a major concern for people with disabilities. Devolution of DSS funding to DHBs could decrease fragmentation between disability supports, mental health services and secondary health services, all of which would be administered by DHBs. However, it would not address the boundaries with numerous other important systems, including primary health care, vocational services, housing, education and transport. There may be models of devolved funding that could integrate several of these components at the local level, but DHBs would not be the obvious locus for such models, particularly since many younger people with disabilities feel alienated by the health system. This view was expressed by the *NZ Disability Strategy* Reference Group in a letter to Hon Lianne Dalziel, then Minister for Disability Issues. The group, a majority of whom were people with disabilities, expressed strong opposition to devolving funding for non age-related DSS. (*New Zealand Disability Strategy* Reference Group, 2000)

Risks

Devolution to DHBs of funding for non age-related DSS carries significant risks, including the following.

- *DSS funding could be diverted to higher priority purposes.* With the creation of a three-year budget for DHBs, a high expectation has been created that deficits will be closed within that timeframe. Disability system needs are not likely to be as visible as closure of deficits, reduction of elective surgery queues, restoration of hospital facilities, etc.
- *DHBs would have little guidance on disability service development.* The *NZ Disability Strategy* is a very high level document that provides little specific direction for service development and no new resources. If devolution were to occur, DHBs would have very wide discretion for further development of the service system. In contrast, the mental health *Blueprint* has provided DHBs with a very specific service development plan, tied to resources that become available if the DHBs follow the plan. (Mental Health Commission, 1998).

- *DHBs have little experience with the provision of community-based disability supports.* They would have a steep learning curve in administering contracts with hundreds of community support agencies, consulting with the sector, and implementing the *NZ Disability Strategy*.
- *The DSS system would undergo another major disruption with no obvious benefits.* Throughout the country, people expressed a strong sense of change fatigue following the reforms and "re-reforms" of the 1993 to 1999 period. The benefits of another major structural reform in the disability sector are unclear.

Recommendations: Devolution of Non-age-related DSS

- Devolution of funding for non age-related DSS should be postponed indefinitely, pending clarification of the specific disability system problems that devolution would address. It would be beneficial for DHBs and the entire disability sector to have greater certainty regarding devolution. Currently, the question hangs over all other decisions and is having a paralysing effect on the disability system.
- If devolution is favoured as a potential solution to fragmentation of services and other disability issues, pilots should be developed to test and evaluate models designed specifically for disability services.

CHAPTER 5. ISSUES SPECIFIC TO AGE-RELATED DISABILITY

Recent History

The 1990s were a decade of significant growth in the older population and change in age-related disability services in New Zealand. Between 1991 and 2001, the number of New Zealanders who were between 75 and 84 years of age grew by nearly 39,000, while the number who were 85 years or older grew by over 19,000. (Chart 1)

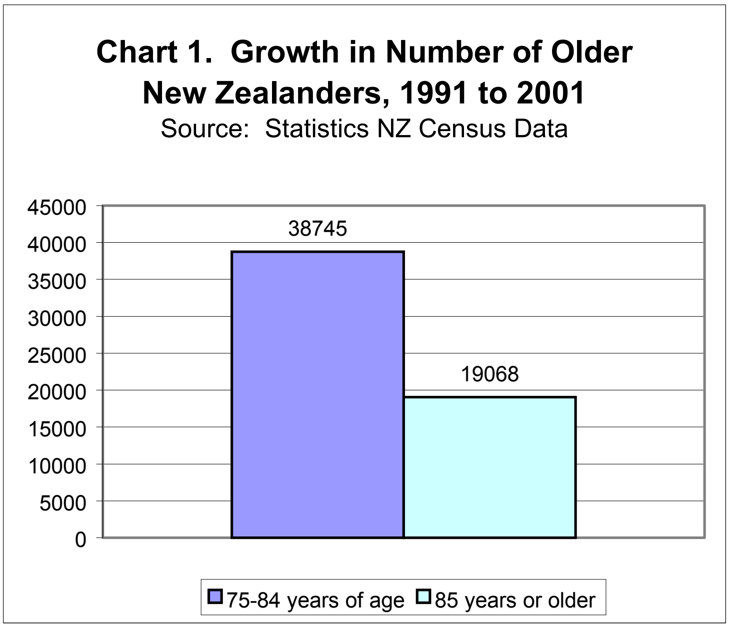


Chart 1. Growth in Number of Older New Zealanders, 1991 to 2001

Source: Statistics NZ Census Data

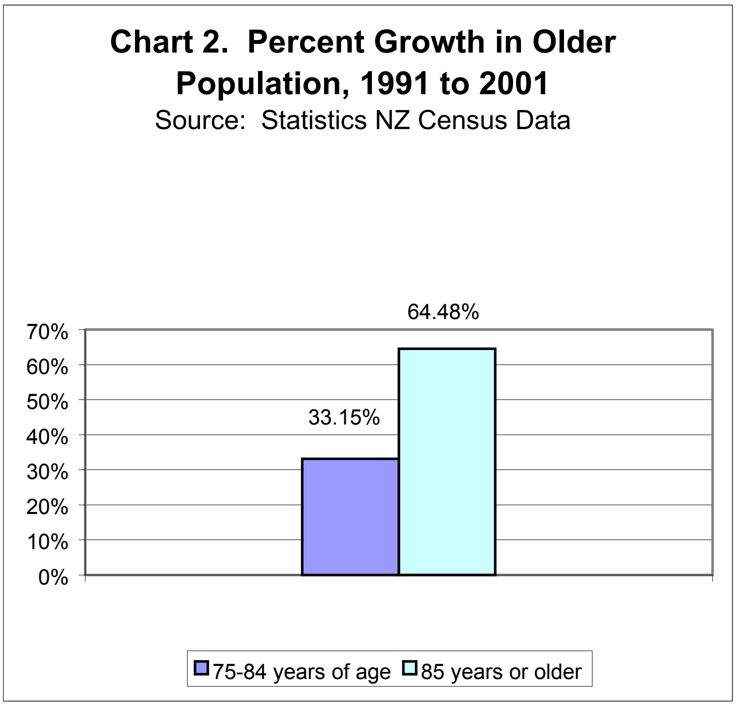
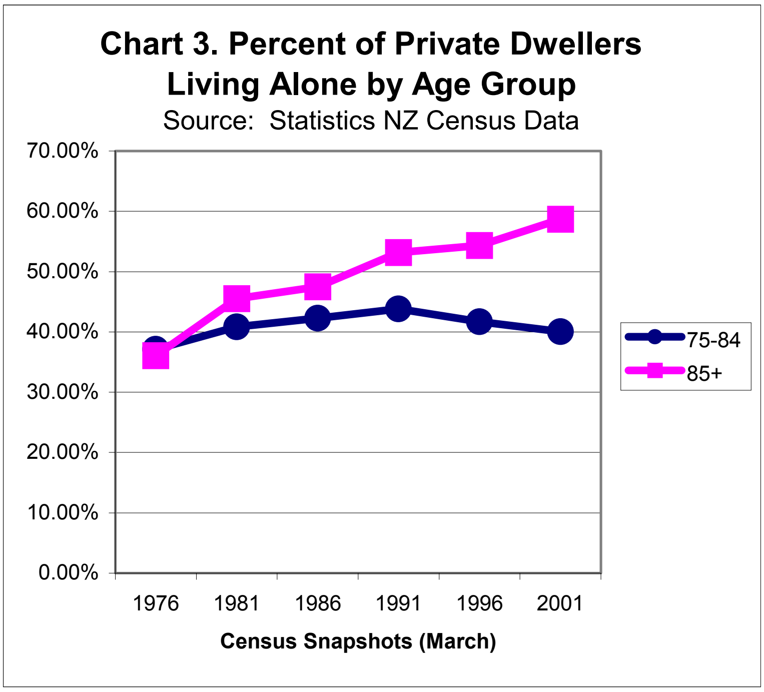


Chart 2. Percent Growth in Older Population, 1991 to 2001

Source: Statistics NZ Census Data

Chart 2 shows that, although the absolute growth of people 75 to 84 years of age was greater than the absolute growth of those 85 and over, the rate of growth was nearly twice as high in the older age category. This is particularly significant because the likelihood of needing residential care increases with age.

As the number of people 85 years of age and older has increased, the percentage of the age group living alone has also increased, from 53% in 1991 to 59% in 2001.



This reflects in part increasing longevity of the population. It may also reflect social trends, including increasing mobility and increasing participation of women in the workforce, both of which could result in fewer older people living with or near their adult children. It may also suggest that the decade's significant expansion of home care has enabled more people to remain in their homes into their later years.

The past decade also saw significant changes in the service delivery system. The NASC system was implemented, home care services were rapidly expanded, retirement villages and national rest home and hospital companies emerged, and public hospitals closed long-term wards where older people had lived. These changes occurred in the context of three significant health system reforms (commencing in 1993, 1996 and 2000). As policy and service delivery changes rippled through the system, acuity levels and lengths of stay changed across providers, blurring roles. Rest homes experienced increasing acuity levels, private continuing care hospitals had less demand for convalescent care and more for end-of-life care, and home care established itself as a viable alternative to institutional care.

The Current System

The current system of age-related DSS reflects the turbulence of the past decade. Individual providers have responded to policy and market changes, but not to their evolving relationships to other levels of care. Many of the persons interviewed for this project painted a picture of a badly fragmented system of care, in which levels of care are not well defined nor interconnected. Common perceptions include the following:

- Home care expanded greatly in the 1990s, and it appears to have made an impact on the use of rest home and continuing care hospital placement among older people.
- The role and effectiveness of inpatient ATR services are unclear. DSS spends about 14% of its budget on ATR based on the hypothesis that ATR services reduce utilization of residential care, but there has not been any recent outcomes analysis.
- Community- and home-based rehabilitation is rare.
- Rest homes and continuing care hospitals are considered terminal points. Once in residential care, there is little or no expectation that people will receive rehabilitation and return home. With the rise in home care availability, acuity levels have reportedly risen in both rest homes and continuing care hospitals, blurring the distinctions between them.
- For those who are discharged to their homes, there is little coordination between hospital discharge workers and community DSS providers. Community providers routinely receive referrals after or immediately before a person has been discharged. General practitioners might be a logical point of coordination when older people undergo transitions, but the historical split between New Zealand’s primary care and hospital sectors makes it difficult for GPs to manage discharges from hospital. Related to this issue, district nursing services and home care are rarely coordinated. When both are delivered to an older person, for example, no attempt is made to divide tasks or coordinate the schedule of visits to the home.

Fortunately, these and other challenges have been recognized for some time. Recent pieces by Ashton (2000) and the National Health Committee (2000) are only the latest in a long series of New Zealand papers and reports that characterize care for older people as fragmented and rife with cost shifting. The *Health of Older People Strategy* (HOPS) refers to the earlier work of the NHC and repeats the call for integrated services to older people. With the development and launch of HOPS, the Ministry of Health has embraced the need to view older people as a discrete population and has created a team of analysts dedicated to older people’s issues.

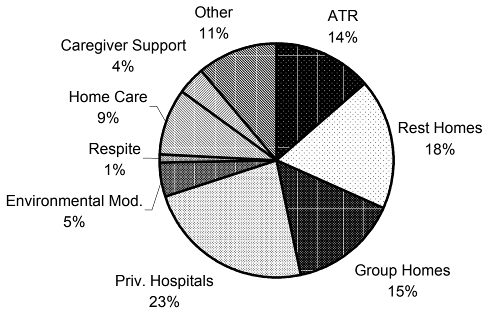
The Role of Public Hospitals in Age-Related DSS

In the 1980s, most public hospitals in New Zealand completed their exit from long-term geriatric care, complementing a parallel effort to close psychopaedic wards that provided institutional care to younger people with intellectual disability. This ended an historical role dating back to the mid-1800s, when provinces had been made explicitly responsible for hospital and charitable care and had combined the two roles in their local hospitals. Many settlers (mostly men) had come to New Zealand without family and turned to the local hospital when they could no longer care for themselves. The tradition of free long-term wards more or less persevered for nearly 150 years before finally being laid to rest in 1993, by which time the service had evolved from one created for poor people who lacked family support to one that served people of various means and family situations. In that year, patients of long-term public hospital wards were subjected to income and asset tests, levelling the playing field with private residential care and removing the incentive to choose public hospitals. By that time, the policy was somewhat moot, since public hospitals had largely stopped providing the service.

The closure of long-term wards reduced but did not eliminate the role of public hospitals in long-term care. Geriatrics, like most medical specialties, remains a hospital-based service in New Zealand. Many public hospitals provide geriatric services through Assessment, Treatment and Rehabilitation (ATR) units[8], which are thought to promote restoration of function and independence among older people. Secondly, NZ provider response to diagnosis-related group (DRG) hospital payments has been very different than the response among US providers. A DRG payment is based on the diagnosis of the patient (as opposed to a per-day payment, which is based on length of stay) and provides hospitals with an incentive to minimize length of stay. In the US, which is much more market-based than NZ, a post-acute industry sprang up among skilled nursing-level facilities (SNFs) to accommodate the earlier discharges of sicker people. The resulting pattern in the US is for many patients to move from hospital to a SNF to home or other long-term setting. In New Zealand, which has a greater tradition of public solutions, ATR units appear to be playing this post-acute function. Analysis of data in at least one New Zealand community suggests that reduced length of stay in acute hospital wards may simply have been shifted onto separate DSS contracts for ATR by discharging patients from acute and admitting them into ATR beds on the same day. (Eschenbach, 2002) This may or may not be an appropriate role for ATR, but it suggests that the role of the service is unclear, despite its claim to a very significant portion of the annual DSS budget. As Chart 4 illustrates, ATR accounted for 14% of the budget in 2000-2001, only 4% less than the rest home budget.

Chart 4. DSS Budget by Service Type, FY 2000-01

Source: Ministry of Health



Given the high unit cost, even a modest increase in ATR bed days can consume all of the new resources available for system development. Before any additional investments are made in such a high-cost service, its role should be clarified in the context of the integrated continuum of care called for in HOPS, and its effectiveness should be evaluated. Given ACC's strong interest in the rehabilitation of older people

---

[8] Levels of ATR vary across the country. Some hospitals have reduced capacity significantly in the past decade.

who suffer accidents, and DHBs' expected responsibility for age-related DSS, this is an area in which a jointly sponsored evaluation by the Ministry of Health, ACC and DHBs would be beneficial to all parties. The parties should also consider restructuring ATR payments to provide an incentive for successful rehabilitation. Currently, the Ministry of Health's ATR contracts pay for a set number of days, whether or not they are used by the hospital. Once the goals of ATR are clarified, consideration should be given to a payment methodology based in part on patient outcomes.

Another aspect of hospital care that would benefit from careful review is discharge planning. Throughout the country, community DSS agencies reported that they are regularly subjected to the "Friday afternoon dump," in which public hospitals make urgent referrals on Friday or the day before a holiday to decrease hospital census leading into a weekend or holiday. What is startling about this practice is not so much that it occurs, but that it is accepted as standard practice across the country. If the urgency occurs every Friday, one would expect the system to adapt eventually by beginning the discharge planning earlier (on Wednesday, for example), to give community agencies time to prepare.

Residential Care for Older Persons

After at least fifteen years of increasing rates of rest home use among older people (1976 to 1991), the rate dropped in the first half of the 1990s (Chart 5), suggesting that rapid expansion of home care options and implementation of needs-based assessments successfully encouraged the use of home care as an alternative to rest home care.

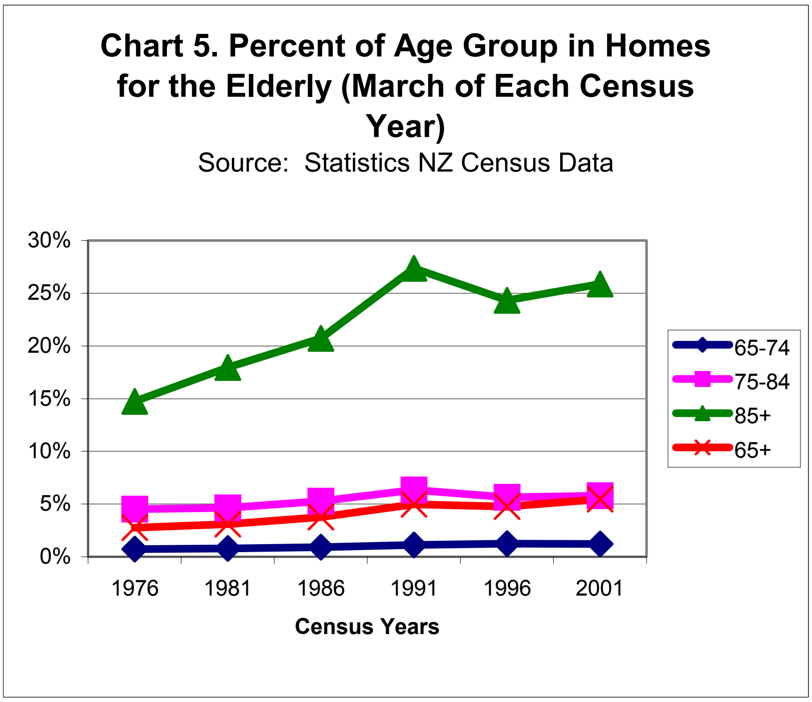


Chart 5. Percent of Age Group in Homes for the Elderly (March of Each Census Year)

Source: Statistics NZ Census Data

Rates of institutionalisation rose again between 1996 and 2001. This recent trend should be examined closely for explanations, as it has serious implications for continued development of the aged care system in New Zealand. Given the rapidly growing number of New Zealanders who are 85 years and older, even a small increase in the rate of institutionalisation can have large budget implications. Unfortunately, the DSS NASC process has not been producing reliable aggregate data for analysis, so it is impossible to study the characteristics of people in rest home, private hospitals and home care over time to see if increasing use of institutional care can be explained by increasing levels of need among New Zealand's older people.

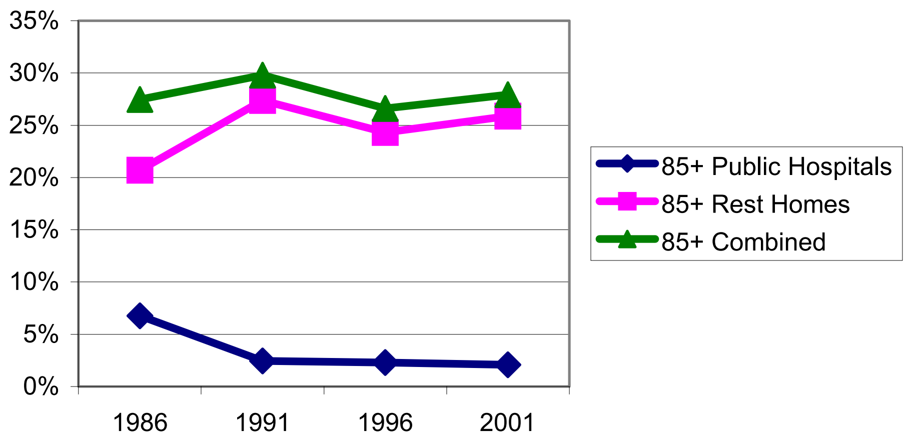
The recent increase in residential care utilization can be explained by policy changes to income and asset tests for residential care. In 1998, the asset exemption was doubled for single persons (from \$7,500 to \$15,000) and couples in care (\$15,000 to \$30,000), and more than doubled for couples in which one of the partners is in care (from \$20,000 plus house, car and personal effects to \$45,000 plus house, car, and personal effects). The 1998 policy changes also added a \$10,000 funeral expense exemption for each person in care. A number of income exemptions were added as well, including allowances from NZ superannuation, 50% of a person's private superannuation, and portions of spousal income. The increases in asset exemptions are of particular interest, given the current proposal to eliminate asset testing altogether. More detailed analysis of post-1998 residential care utilization should be undertaken for lessons applicable to the current debate.

A possible related service delivery factor is the recent increase in retirement villages and multi-level care schemes for older people. It may be that retirement villas and flats are becoming patient "feeders" for rest homes and private hospitals operated by the same companies, but there is currently no reliable data to test this hypothesis. A concern for policy makers in NZ and the US alike is that retirement villages, which market themselves to relatively affluent older people, deplete people's assets before referring them to residential care and government subsidies. The recent growth in retirement villages suggests that they will have an increasing impact on New Zealand's publicly funded age-related care in the future, and should be a priority for policy research.

Another service delivery factor could be an unidentified change in public hospital services. As Chart 6 illustrates, the use of public hospitals and rest homes have been closely related in the past.

Chart 6. Percent of Population 85 Years or Older in Public Hospitals and Rest Homes Over Time

Source: Statistics NZ Census Data



Between 1986 and 1991, the percentage of people 85 years or older in public hospitals dropped dramatically (bottom line), but the percentage in rest homes correspondingly increased correspondingly (middle line). When the percentages for both settings are combined, the (top) line flattens considerably, suggesting a substitution effect between the two levels of care. The drop in public hospital care to older people from 1986 to 1991 can be explained by the intentional decrease in public hospital-based long-term geriatric wards, many of which were hold-overs from earlier times when public hospitals provided long-term charitable care. The more recent and much slighter drop in the percentage of people 85 years or older in public hospitals (from 1996 to 2001) is not easily explained by an obvious systemic change in the capacity of public hospitals, but may instead be related to increasing capacity among private continuing care hospitals.

Another important service delivery component influencing the use of residential care is home care. The rapid increase of home care in the 1990s appears to have absorbed a large portion of the growing older population, enabling New Zealand to decrease the percentage of older people who were entering residential care between 1991 and 1996, but the system may have reached its limits as currently configured. This is discussed further in the next subsection.

The increasing role played by home care and increasing availability of retirement village options have reportedly increased the level of need of older people entering residential care. (This view was universal among the persons interviewed for this project, but reliable assessment data are not available to confirm it.) Given that residential care is among the most expensive resources in the age-related DSS system, it makes good policy sense to reserve it for older people with the greatest needs. However, the nature of residential care may not have kept up with its changing clientele. The car ports built into some of New Zealand's older rest homes are remnants of a bygone era when older people would move to rest homes when they were still able to drive. They were then retirement homes, where people could go for private living quarters with housekeeping and congregate meals, much the same services offered by today's retirement villages, but in more modest facilities with less private space. People tended to stay a long time, and if they developed ongoing nursing needs, they moved to a continuing care hospital. Today, the distinctions between rest homes and continuing care hospitals have been blurred as both are serving people with higher needs for shorter lengths of stay. Yet staffing distinctions remain based on old assumptions about resident needs. Rest homes are not required to have nursing-level staff, despite increasing acuity levels.

With the *Health of Older People Strategy* calling for an integrated continuum of care, this is a perfect moment in time to review the changing role of traditional providers in New Zealand's age-related DSS system. Public hospitals, rest homes and continuing care hospitals have all changed their roles in the past decade, and they have also changed the way they interact with one another. Home care has its roots in small home help programs started in the 1940s and 50s to help older people with housekeeping, but was transformed in the 1990s into a substantial alternative to residential care. For New Zealanders with means, retirement villages offer an upscale alternative to retirement homes of the past, but the interaction of this new, private alternative with the publicly subsidized system is not well understood. Community-based rehabilitation and post-acute care are being discussed as important potential additions to the system. In short, the system has undergone a huge amount of change stimulated by a combination of policy and market changes in the 1990s, and it is now time to review all levels of care as New Zealand reassesses its needs for the future. As the Ministry, consumers, DHBs, providers and other stakeholders implement the *Health of Older People Strategy*, an important early outcome will be a clear re-conceptualization of New Zealand's age-related care system, with gaps (notably community-based rehabilitation) clearly identified and addressed.

Home Care

As discussed in the previous section, home care expanded greatly in the 1990s, enabling NZ to decrease the percentage of older people entering residential care between 1991 and 1996. Unfortunately, data is not available from the DSS assessment system to analyse the characteristics of older people who use home care services, so it is difficult to describe precisely the role that home care has played in the evolving age-related DSS system. As in the US, providers tend to disagree about the level of care being provided in the home. NZ home care agency managers generally believe that they are serving people with very high needs who would otherwise be in residential care, but residential care managers tend to believe that home care has siphoned off only the "easy" clients, leaving residential care to serve people with very high needs.

It is quite unclear, for example, the extent to which people requiring intrusive procedures are served at home. Some home care agencies report doing some procedures but not others. Other agencies do not provide any at all, making a distinction between home care, which does not include any intrusive procedures, and district nursing, which may. District nursing is generally deployed through the DHB provider arm, and home care, which includes household management and personal care services, is provided through separate community home care agencies.[9] Home health and home care are also assessed and ordered through separate systems. Home health tends to be ordered by GPs (to change bandages or provide other home nursing services following an office visit, for example) or hospital-based physicians following an acute or ATR admission. These same providers may make a simultaneous referral to a NASC agency for home care. People who need both do not have the benefit of a coordinated plan of care that considers both needs and schedules them to provide the best support for the older person. For example, if a person needs two nursing visits and three personal care visits each week, the two services could together provide five days of home visiting. If the visits are not coordinated (as is generally true), a person could end up with all five visits happening on three days, and no visits on the other four.

Many of the home care agency managers interviewed expressed concern that their services are being stretched too thinly. This stems in part from an assessment process that is very budget conscious and authorizes the least number of hours possible (as it is charged with doing), and in part by a low unit price ($14 per hour for household management; $15 per hour for personal care). Home care workers in most agencies start at just above minimum wage and work part-time. Larger agencies conduct their own orientation and in-service training, and some have created internal career ladders, but most workers do not have any hope of advancement. There is very little worker

---

[9] Nurse Maude in Canterbury is an exception. It provides both district nursing and home care services.

interest in human services certificate programs offered through polytechnics or universities, because few agencies can afford to reimburse employees for tuition or time at university, and completion of the certificate generally does not result in job advancement or significant pay increases. Agencies reported that flexibility in scheduling and number of hours is the most important benefit they offer employees, since they cannot compete for full-time, career oriented workers. Typical home care workers include: a woman who is a second earner in her family and wants to be home when her children return from school; a woman receiving a domestic benefit who may not work more than twelve to fifteen hours per week without jeopardizing her benefit, but who could not afford to pay child care and other expenses if she worked full-time; and a person who has become employed by the agency for the express purpose of caring for a family member.

These factors (work force development challenges, limited scope of service, and low reimbursement) are limiting the ability of home care to increase its effectiveness and serve people with increasingly complex needs in the community. The Ministry of Health has recognized the need for a stock-take of home care and is embarking on a comprehensive review to strengthen the service and ensure that it will be able to grow and meet the needs of increasing numbers of older people in the future. In a related effort, the Ministry and ACC are working on joint home care standards that will clarify and standardize government expectations of home care agencies. Finally, the Ministry is working with home care agencies to identify critical capacity needed to deliver quality home care services. These three efforts should be very closely coordinated with each other, and with the system development work being undertaken to implement the HOPS.

Need for Greater Community Rehabilitation Focus
Illness and hospitalisation are associated with loss of function in older persons, which in turn can lead to greater dependence. Effective rehabilitation following an acute event (stroke or hip fracture, for example) can mean the difference between remaining home and being readmitted to hospital or admitted to long-term residential care. A recent study by Tinetti et al. (2002) found that older persons receiving restorative home care services (based on principles from geriatric medicine, nursing, rehabilitation and goal attainment) had better outcomes than older persons receiving usual home care. Those receiving restorative care were more likely to remain at home and less likely to use the emergency department, and had better mean scores in self-care, home management and mobility.

As discussed above, New Zealand spends a significant portion of its DSS budget on hospital-based ATR services, but very little on community-based rehabilitation. This should be considered as HOPS implementation proceeds. For some, a discharge directly from acute care to home may be feasible if good home-based rehabilitation is available and well integrated with home care services. Others might need an intermediate level of facility-based care that provides intensive rehabilitation in preparation for a home discharge. Important considerations include the following:

- If more community rehabilitation is made available, who should receive it? If it becomes an add-on service that all older people receive, it is likely to add costs to the system. On the other hand, if clinicians carefully select patients likely to benefit from rehabilitation, greater quality of life and reduced costs from residential care placement could offset the costs of service expansion.

- What role should rehabilitation play in New Zealand's new continuum of care? How will it be integrated with GP services, hospital services, residential care and home care?
- Where both exist, what is the relationship between community rehabilitation and ATR units?
- What is the role of personal health in funding the components of rehabilitation, such as physiotherapy, speech and language therapy and occupational therapy? Why are these services not already being provided as part of a community package of care?
- If community rehabilitation is developed as a new bundled service, how should it be reimbursed? How can incentives for effective rehabilitation be built into the payment methodology?

The Ministry of Health has initiated activity in this area. The Central Locality office is piloting a community rehabilitation service in Levin, for example. This pilot should be carefully evaluated for effectiveness and its place in the continuum of care should be determined.

Recommendations: Service Delivery System

- Identify the levels of care needed to ensure maximum independence for older New Zealanders. Specifically, develop and evaluate community-based rehabilitation options, including post-acute facility-based care (for those who require a step-down from hospital) and home-based rehabilitation. Consider adding an intermediate level of residential support (commonly referred to as Assisted Living or Supported Living in the US) for people who cannot live alone, do not require rest home or hospital level of care, but cannot afford retirement village options.
- Review the roles played by existing providers:
    - ATR. Evaluate the effectiveness of ATR services. What role has it been playing? When is hospital-based ATR needed rather than (or in addition to) community-based rehabilitation? How can the expertise of geriatricians be extended to community-based settings?
    - Rest homes and continuing care hospitals. What are the key differences between the groups of older people served in these two settings? Have the groups become more and more similar over time? If so, do the different staffing requirements continue to make sense?
    - Retirement villages. Who lives in retirement villages? How and when do they intersect with the public aged-care system? What are the opportunities for public-private partnerships?
    - Home care. Who is receiving home care? How is it different from district nurse services? How do the characteristics of people receiving home care compare to the characteristics of people in residential care? What are the opportunities for enhancing home care to make it increasingly effective for people with complex needs? How can home care and home health be coordinated?

- Plans for an integrated continuum of care should pay particular attention to enhancing coordination between primary care and secondary care; between hospitals and community providers, and between district nursing and home care.

Asset Testing

Currently, older people seeking a government subsidy for residential care in a rest home or private continuing care hospitals must meet an asset test before receiving a residential care subsidy.[10] If they exceed asset limits, they must spend their excess assets for care before any subsidy applies. The current asset limits are $15,000 for a single or widowed person, $30,000 for a couple when both are in care, and $45,000 for a couple when one is in care. An additional $10,000 per person in care may be exempted from the test for funeral expenses. When only one person in a couple is in care, the remaining spouse's home, car and personal effects are also exempted from the test.

The Government's Proposal

Removal of the asset test has been a goal of the current government. Promised in the 1999 election, it is considered a piece of unfinished business to be addressed by the new Government formed following the July 2002 election. The issue has been framed as a matter of equity, because asset tests are not applied when people under 65 seek subsidies for non-age related residential care.

Equity is an extremely powerful argument in political debate, and the Government's proposal is extremely popular among older people and their heirs, but the risks of the proposal are substantial and deserve thorough debate. In public policy debates, equity (or fairness) is considered a fundamental principal that is met when similar people are treated similarly. Conversely, fairness may call for treating people differently because their circumstances are different. This is generally the case with taxation, for example, where we consider it fair to assess people with higher incomes at higher tax rates. It may be that older people are sufficiently different from younger people to justify a different asset testing policy.

Older people entering residential care are at a different life stage than younger people. Assets accumulated over a lifetime may be contributed to the cost of care without compromising other needs that came earlier in life, such as attending University, buying a car, buying a home, and raising children. Younger people with disabilities, may have all of those expenses ahead of them, and may need to make critical investments in order to achieve the "fully inclusive society" called for in the *NZ Disability Strategy*. Their expenses may be higher than average if they need an adapted vehicle or modified home. Once an older person enters residential care, she is unlikely to have any large expenses before her other than health and long-term care. Preserved assets will pass on to heirs. Thus, a policy ostensibly proposed to benefit older people will actually represent a governmental transfer from taxpayers to the heirs of middle and upper class New Zealanders.

---

[10] An income test also applies. NZ superannuation (minus a personal exemption), 50% of private superannuation, insurance/endowment payments, and income from ACC lump sum payments after one year, are all contributed to the cost of care, up to a maximum contribution of $636 per week.

Incentive to Institutionalise

New Zealand's recent experience supports the argument that removing the asset test will increase the rate of institutionalisation of older people. As previously discussed, the asset test for residential care was liberalized in 1998. Asset limits were doubled in two categories (single, couple in care) and more than doubled when one partner is in care and the other is in the community. The funeral expenses exemption ($10,000 per person in care) was also added in 1998. The number of people in subsidized care began rising in 1998 and continued into 2001. If the asset test were removed altogether, New Zealand could expect an even greater rise in the use of residential care, contrary to the goals of continuing independence and ageing in place expressed in the *NZ Disability Strategy* and the *Health of Older People Strategy*. Whereas current policy encourages family members to support ageing in place, a complete removal of the asset test would encourage them to place their parents in residential care.

Cost Trade-offs

Current estimates for removing the asset test are reported to be over $200 million in the first year, rising in subsequent years as the population ages. This is a conservative estimate, as it does not include an increase in the rate of institutionalisation. To put this figure in perspective, it can be expressed as a percentage of DSS expenditures in the fiscal year 2000-2001 (Table 5).

Table 5. Estimated Cost of Asset Test Removal Expressed as a Percentage of DSS Expenditures in 2000-01.

DSS Category	00-01 Expenditures	Estimated Asset Test Cost	Asset Test Cost as % of DSS in 00-01
Total Expenditures (excluding Mental Health)	$1,167,773,000	$200,000,000	17%
Rest Homes and Continuing Care Hospitals	$496,500,000	$200,000,000	40%
Home Support	$110,740,000	$200,000,000	181%
Caregiver Support	$44,140,000	$200,000,000	453%
Respite Care	$12,510,000	$200,000,000	1600%

Source for DSS Expenditures: Ministry of Health
Source for Asset Test Cost Estimate: Evening Post (13 June 2002)

In the first year alone, removing the asset test would increase the cost of residential care by an estimated 40%. It would represent almost twice the amount spent on home care in 2000-01. Perhaps the greatest irony of the proposed policy is that the Ministry has been extremely challenged by the complexities involved in developing family support policy. The Ministry's policy is to provide support but not direct payments to family members. Yet removal of the asset test would result in potential annual transfers to families (via inheritance) equivalent to 453% of the caregiver support budget in 2000-2001.

Sustainability

Given the very high cost of the policy, careful consideration should be given to its sustainability over time. In an international review of long-term care, Merlis (2000) found that most countries use some form of means testing or cost sharing for institutional long-term care that is much greater than that required for medical services. Experience in other countries suggests that once removed, an asset test would be difficult to re-establish. In the US, it took the economic recession of the early 1990s and the threat of significant cuts in Medicaid long-term care benefits to establish a national policy of estate recovery.[11] In the province of New Brunswick, Canada, a recent proposal to impose an asset spend-down requirement was defeated in the face of strong opposition. (Merlis, 2000)

In Search of Complementary Policy

If asset removal should go forward, risks notwithstanding, consideration should be given to implementing it in a way that supports implementation of the *Health of Older People Strategy* and the *NZ Disability Strategy*. One way to achieve this is to use an asset waiver to create an incentive for rehabilitation. Currently, if an older person is discharged from hospital to a rest home or continuing care hospital, the asset test requires them to begin depleting their assets immediately. Instead, a post-acute period should be created, during which asset testing would be waived. (In the US, Medicare reimburses post-acute care in a skilled nursing facility for 90 days, for example.) During that period, rehabilitation could be conducted without jeopardizing assets. Family members would have an incentive to push for effective rehabilitation within the specified time frame. Expectations of residential care would change, from places where people go to live out their final days, to places where people go to restore function before returning home. Expanding effective community rehabilitation options would be a key component of this policy.

Regardless of what New Zealand ultimately decides, it should carefully evaluate any changes it makes in asset policy. Many countries are reviewing how they finance long-term care costs in the face of an ageing population, and New Zealand's experience will be instructive.

Finally, in conjunction with any change in asset testing, consumer decision making procedures should be reviewed and, if necessary, augmented to ensure that older people are making informed decisions about residential care free from coercion by family members or others who may have a vested interest in removing them from their homes.

Recommendations: Asset Testing

- Changes to asset testing policy should be considered in the context of improvements to the system of care for older people. Specifically, a time-limited waiver of asset testing in combination with development of community rehabilitation options should be considered.

---

[11] Estate recovery is similar to New Zealand's caveat scheme. Non-liquid assets, such as real estate, remain the property of the consumer until death, at which time a state may recover long-term care costs from the estate. Assets (homes, for example) are not recovered for as long as a surviving spouse or other dependant continues to use them.

- The effects of any change in asset testing policy should be carefully evaluated, with particular attention to the rate of admissions and length of stay in residential care post-policy against current benchmark to see the impact.
- Safeguards should be created to ensure that older people make informed decisions about residential care, free from pressure by family members.

Devolving Age-Related DSS

The Current Plan

One of the outcomes of the development of the *New Zealand Disability Strategy* was a tentative Government decision to implement a recommendation that emerged from the sector reference group to separate and devolve DSS funding for age-related disability to DHBs. Nominal separation of funding (within the Ministry's budget) began July 2002, and funding for age-related DSS is expected to devolve to DHBs beginning 1 July 2003, pending a final decision by Cabinet and demonstrated capability by DHBs. This outcome was a win-win for the constituencies of age-related and non age-related DSS. For those involved with age-related care, devolution of age-related DSS, the development of the *Health of Older People Strategy* and the Ministry of Health's creation of a policy team dedicated to older people were the realization of a longstanding goal to bring greater focus to health and disability services for older people. For those involved with non age-related DSS, the decision to separate and devolve age-related DSS has removed the pressure to devolve all of DSS to DHBs. Younger people generally oppose devolution to DHBs, fearing the "medicalization" of disability supports.

The rationale for the separation is that people with age-related disability are more likely to have chronic medical conditions than younger people with other types of disabilities, and are more likely to go to their GPs for care as they develop disability in their later years.

Risks

As New Zealand prepares to devolve DSS funding for age-related disability, a number of risks and challenges should be considered. Ashton (2000) suggested that the consolidation of financing within the Regional Health Authorities by 1996 had finally provided an opportunity to integrate services for older people in New Zealand, but that opportunity was not realized. At about the same time as Ashton was writing, the National Health Committee (2000) was issuing its latest in a long series of papers and reports that characterized care for older people as fragmented and rife with cost shifting. The *Health of Older People Strategy* (2002) refers to the earlier work of the NHC and repeats the call to integrate services for older people. Clearly, consolidation of financing in one central agency was not sufficient to integrate services for older people in New Zealand. This is entirely consistent with the US experience. The central lesson of the Social HMO demonstration was that integrated financing is a necessary but not sufficient condition for integrated service delivery. (Finch et al., 1991) This lesson is an important one as New Zealand now looks to DHBs to integrate services for older people, on the theory that devolved funding will make this possible at the local level. When a closer look is taken, very few DSS are currently purchased from the provider arms of DHBs. With the exception of ATR and NASC services, most DSS are purchased centrally by the Ministry of Health from home care agencies, private residential care providers and other community agencies. These agencies and providers have largely replaced the long-term geriatric wards that had historically been provided by public hospitals, but they are not particularly well integrated with hospitals. In other words, integrated care will not naturally follow integrated financing.

Related to the first point, GPs are not integrated with DHBs. Simply devolving DSS funding to DHBs will not make them any more accessible nor well integrated with primary care unless primary and secondary care become more integrated. The evaluation of integration efforts across the country (such as Kaipara Care and Elder Care Canterbury) produced mixed results, suggesting that more work needs to be done on this issue. (Health Services Research Centre, 2001) On a national policy level, the *Health of Older People Strategy* needs to be carefully coordinated with the *Primary Care Strategy* to ensure that GPs play a significant role in the devolved system. Older people's relationships with GPs were cited as a rationale for devolution, but GPs could easily be left out of the loop because of their traditional separation from public hospitals (the provider arm of DHBs).

Early drafts of DHB capacity criteria (upon which the Ministry will make devolution decisions regarding individual DHBs) provide only very weak accountability to the Ministry and the *Health of Older People Strategy*. The criteria contain no consumer outcome indicators nor do they require demonstrated expertise in the continuum of age-related services. In order to be deemed capable, a DHB must make a series of process commitments, such as being willing to work with sector representatives to develop local service plans. In its current form, the *Health of Older People Strategy* provides insufficient guidance, because key concepts such as "integrated continuum of care" and "ageing in place" are not defined with any specificity. When asked to describe what ageing in place meant to them, people interviewed for this project offered a range of definitions that included: support to live where people want to live; living at home for as long as possible; and living in a facility that provides different levels of care over time as needs change. One DHB is already discussing a facility-based ageing in place initiative, when it is not at all clear that the policy supports development of new facilities.

There is a perception in some districts that the NASC process will be discontinued for older people and each DHB will be free to assess in the manner it deems best. If this is allowed to occur, the Ministry will give up its ability to establish nationally consistent policy regarding the level of need required to trigger various levels of DSS. Furthermore, it will be impossible for the Ministry to compare what is happening across districts. While it may be advisable to pilot and evaluate the effectiveness of different assessment tools, the Ministry should continue to play a lead role and move toward a minimum data set (MDS) of assessment data that every DHB would be required to submit. The Ministry has established the New Zealand Guidelines Group to develop assessment processes for older people with the expectation that assessment requirements will be incorporated into the National Service Framework.

Finally, and perhaps most significantly, there is widespread confusion as to whether or not the *NZ Disability Strategy* applies to older people with disability. The danger is that *NZ Disability Strategy* themes focusing on independence and social supports will be lost in the broader health themes of the *Health of Older People Strategy*, which addresses the needs of all older people.

Recommendations: Devolution

- DHBs need clearer guidance from the Ministry regarding the goals of devolution and expectations of integrated care. Concepts such as "integrated continuum of care" and "ageing in place" should be articulated in greater detail. While DHBs must be given some flexibility in a devolved system, the desired outcomes for consumers should be clear and DHBs should be accountable for them.
- In keeping with a key rationale of devolution (that older people with disability see their doctors for care) Primary Health Organisations (PHOs) should play an important role in a devolved age care system. For example, the Ministry should consider piloting an integrated care model in which a PHO is the central coordination point for older people. Other opportunities to integrate implementation of the *Health of Older People Strategy* and the *Primary Care Strategy* should be identified.
- The Ministry should maintain an ongoing interest in facilitating a nationally consistent and comparable assessment process for older people with disability support needs. While some experimentation with alternative tools may be beneficial, the Ministry should develop a minimum data set (MDS) that all DHBs would collect and submit. In addition to demographic data, the MDS should collect social needs and include considerably more information about functional and health status than is currently collected through the NASC process.
- The applicability of the *NZ Disability Strategy* to older people should be clarified to ensure that its focus on maximizing independence is not lost.

CHAPTER 6. GENERAL ISSUES APPLICABLE TO ALL DSS GROUPS

Consumer Centeredness and Service Flexibility

A key principal underlying the *NZ Disability Strategy* is that service delivery systems should be more responsive to the needs and preferences of consumers. This assumes that systems will provide multiple opportunities for consumer input, and that services will be flexible enough to respond to the input.

Consumer Involvement in Policy and Program Development

At the level of system development, the *NZ Disability Strategy* calls for greater leadership among consumers in staffing, governing, managing, planning and evaluating services. New Zealand appears to be a leader in this area, particularly within the Ministry of Health's Disability Services Directorate. People with disabilities hold both staff and management positions within the DSD, and although greater participation is certainly possible and desirable, current levels of participation appear to surpass what is found in a typical state agency in the US. The DSD is also experimenting with multiple forms of consumer involvement in policy and service development that go beyond traditional consultation processes. This includes, for example, contracting with several consumer-based organizations to provide direct input but also to gather further consumer input from the community at large. People with disability are also routinely asked to sit on review panels to score proposals for new services. A consumer participates on at least one of the Ministry's contracted audit teams.

Development of the *NZ Disability Strategy* was itself an example of consumer participation. Unlike traditional sector reference groups, a majority of the reference group for the NZDS were people with disabilities. The NZDS was published in large print and pictoral versions to expand access to people with visual and intellectual disabilities.

Consumer Direction

Consumer direction refers to a continuum of approaches in which individual consumers make decisions about the care they receive. Consumer direction can include selecting, managing and dismissing workers, and deciding what type of services to purchase and what time of day they will be delivered. Stone (2000) has observed that consumer direction assumes that supports are predominantly non-medical, focused primarily on low-tech services that promote independence. Thus, unlike medical services, a highly trained professional is not needed to make appropriate care decisions. Consumers, families, whänau and other supporters are in the best position to know what is needed and what will work.

Consumer direction has been a small part of the US disability system since the 1970s, when consumers active in the Independent Living Movement successfully advocated for consumer directed personal care services in several states. More recently, consumer direction concepts have been applied to intellectual disability through Self Determination initiatives developed in several states with support from The Robert Wood Johnson Foundation. As part of the federal government's effort to implement the *Olmstead* decision, the federal Department of Health and Human Services

(DHHS) is supporting a variety of efforts in several states to enhance consumer options in service delivery. The Cash and Counselling demonstration program, supported by The Robert Wood Johnson Foundation and DHHS in three states, is a consumer directed program that gives personal care consumers the option of taking cash in lieu of agency-provided services. Consumers must receive counselling as to their rights and responsibilities, and purchase their care with the cash received.

New Zealand has had consumer directed services available to limited numbers of DSS consumers for several years under the self-managed contract.[12] Under this option, administered by NASC agencies, consumers are assessed for need as usual, but instead of authorizing services via existing provider contracts, the NASC issues cheques on a regular basis so consumers can purchase their own care. Although there have been no widespread abuses of the system, the Ministry of Health placed a moratorium on self-managed contracts a few years ago, concerned that the risks were not well enough understood. The moratorium is currently being reviewed with an eye toward reopening self-managed options with an appropriate policy framework in place. This offers hope that self direction will soon be expanded in New Zealand, but it also opens the risk that policy will be too rigid. Benjamin (2001) points out that efforts to overlay consumer direction with traditional quality assurance and other policy frameworks run the paradoxical risk of undermining the very concept they are trying to support. If policy makers are uncomfortable with the risks of consumer direction, it will be more advantageous to allow experimentation with minimal policy through an evaluated pilot program than to over-regulate the concept. By definition, self directed services allow consumers to tailor their services in ways that are not possible with traditional, regulated services.

Self-managed contracts appear to be popular with Mäori, offering an additional advantage to further development of the concept in New Zealand. What quickly strikes a visitor with no previous involvement in Mäori issues is the degree to which Mäori concepts of effective support are consistent with the general movement in the field of disability toward greater involvement of consumers in planning, directing and evaluating their care. Mäori concepts articulated by Ratima et al. (1995) include respect for clients, which involves active participation of the client, caregiver and whänau in all levels of decision making.

The flexibility inherent in the approach responds to longstanding requests by Mäori to make DSS more holistic and incorporate whänau. It provides the flexibility to support people in culturally appropriate ways without getting bogged down in much harder questions of service delivery infrastructure.[13]

---

[12] There are much older examples of self direction in New Zealand. In 1952, the Social Security Department first offered a home help scheme to the “elderly and infirm.” As described 20 years later by the Royal Commission, "the home help may be employed privately by the claimant, or by the department, which tries to have a reserve of home helpers recruited from social security beneficiaries and others who are prepared to do such part time work." (Royal Commission of Inquiry, 1972)

[13] The concept may also be welcome by Pacific Islanders and people of other cultures, but application to other cultures was not directly observed during this project.

Consumer direction also creates a base from which multi-agency collaboration becomes easier. If several agencies can offer flexible, consumer directed options, resources are much more easily pooled to create flexible funding for consumers, families and whänau. Even if only a few agencies have flexible options, resources from those agencies can be used as "flex funds" to enhance more traditional services.

Expanding Flexible Service Options

Consumer direction is not for everyone, but service options should be as flexible as possible within traditional services as well. Inflexibility of funding is especially apparent in the residential services area, where people tend to get stuck within a residential care option because their subsidies are not truly portable. Residential subsidies are least flexible for age-related care, where legislative restrictions make the subsidy available only for rest homes and continuing care hospitals.

For younger people living in community group homes, the subsidy is theoretically portable to supported flats, but the Ministry's contracting schemes can make it very challenging to move the funding. Once the Ministry has made a contractual commitment to fund a certain number of beds in a group home, the funds for those beds are encumbered to that contract for the contract period. If a person wants to leave the group home, the Ministry generally has to find additional funds for the transition period. This appears to be particularly problematic for people with intellectual disability, because the predominant service delivery option available is community group homes. Thus consumers tend to face the very limited options of living with family or living in a group homes, with few options in between (such as supported living in flats, for example).

The Ministry is currently undertaking projects[14] to help several younger people move out of rest homes, where they were inappropriately placed for lack of other options. These projects will identify specific barriers that keep people from being mobile and becoming more integrated in the community.

Recommendations: Consumer Centeredness and Service Flexibility

- Self-direction should be promoted by lifting the moratorium on self-managed contracts. Consumers should receive thorough information, understand their responsibilities and give informed consent. Beyond that, government should avoid creating too rigid a policy framework that undermines the concept. If risks are considered too great, an evaluated pilot approach with minimal requirements should be considered.
- Peer counselling and advocacy programs should be developed, in which consumers who live independently or self-manage their care are available to advise and encourage consumers who want to live independently or exercise more control over their care.
- The MOH and the MSD could create a collaborative competitive grants program that promotes greater service flexibility for consumers. Through an RFP process, proposals could be solicited for initiatives that: enhance

---

[14] An example is the Community ReIntegration Project (CRIP), which has identified nearly 400 younger people living in rest homes in the Auckland Locality who meet the criteria for potential community living.

consumer control, have the potential to inform broader system reform, and can be evaluated. Existing government policy could be waived for purposes of demonstrating new models.

- The MOH and MSD should collaborate to make residential care subsidies for people of all ages portable to supported living or independent living arrangements. Ensure that all residents have regular opportunities to review their living arrangements. Consider piloting the Self Determination approach for people with intellectual disabilities. Review contracting procedures and commitments to ensure that funding is truly portable from one setting to another. Evaluate the current community reintegration efforts to identify barriers to transition.
- The MOH and MSD should collaborate to create savings incentives for consumers receiving income support benefits. Consider allowing people to shelter assets in "Independence Accounts" for specified purposes, such as down payments on homes or modified vehicles, without jeopardizing income support benefits. For those increasing their levels of paid employment, consider allowing income support benefits to accumulate in Independence Accounts rather than be subject to abatement.
- Ensure that self direction initiatives are culturally sensitive. Self managed contracts appear to be popular with Mäori, and the flexibility of the approach may make it applicable to other cultures as well.
- Work with Housing NZ Corporation to expand the availability of accessible and affordable mainstream housing options for supported living, such as state houses and flats.

Needs Assessment and Service Coordination (NASC)

During the health purchasing reforms implemented from 1993 to 1996, DSS were converted from an entitlement-based benefit system to one in which resources are allocated according to individual needs, as determined by an assessor. Following an assessment, a service coordinator develops a service plan. Assessors and service coordinators (often both functions are performed by the same person) are employed by NASC agencies, selected by the Ministry of Health to perform the function as free from provider conflict-of-interest as possible. As the gatekeepers of the DSS system, NASC agencies have always been controversial, acting as lightning rods for criticism about the DSS system's shortcomings.

When established, NASC agencies were expected to provide comprehensive assessments addressing all of a person's needs, followed by active service coordination to put multiple services in place. Reassessments were to be performed annually. The NASC process is clearly under-resourced to carry out that level of activity. Assessments have been repeatedly criticised for not being comprehensive or specialized enough for people who have complex or highly specialized needs.[15] Service coordination tends to be a one-time activity, which is perhaps better described

---

[15] NASC agencies vary in the way they address specialized needs. Most have arrangements to provide specialized assessment on an ad hoc basis, but this entails making a referral for a second assessment following the generic one, creating an additional step for consumers. At least one NASC agency has taken a different approach, in which consumers are referred to one of several specialty sub-contractors, based on a telephone screening.

as service planning. Once the original service plan is developed and authorized, very few DSS consumers receive active, ongoing service coordination. The scope of service planning is generally limited to DSS itself. Consumers who need services from other service systems (e.g., vocational, educational, health) must approach those systems separately from the DSS system. Reassessments do not occur unless initiated by consumers, families or providers, typically in the context of increasing needs that require reassessment in order to trigger higher levels of service.

On the other end of the spectrum, the NASC process appears to provide a much higher level of assessment than necessary for people with relatively low needs. An older person requesting a few hours per week of home help is subject to the same assessment process as one with substantial disability requiring residential care.

The assessment process is guided by a set of national guidelines and an assessment form that is largely narrative in format. The process has been criticized for being too subjective, leading to inconsistency in application. Anecdotes abound regarding DSS consumers who move from one part of the country to another, only to find themselves ineligible for services when assessed by a different agency. Although the NASC process has been the subject on ongoing discussions between the Ministry of Health and stakeholders, greater standardization of the process has been resisted on the grounds that it would make the process too inflexible for consumers. Ironically, consumers report that the current process is quite inflexible.

Because the assessment form is largely narrative, very little data from the assessment process can be aggregated for systematic analysis. The fields that are standardized are limited to demographic data, but because of inconsistent submission of data to the Ministry, the demographic data is unreliable. Information about the specific impairments, conditions and function of people are not standardized.

Finally, the assessment process is primarily focused on maintaining current living situations for people, rather than promoting greater degrees of social inclusion, as envisioned by the *NZ Disability Strategy*. The process appears to be quite responsive when a person is at risk of greater dependence. For example, it can respond with home care services if a person can no longer live at home without supports. But a person needing more or different services to attain greater community inclusion is not a priority in a system that can barely keep up with needs. The section of the assessment form that explores the consumer's goals comes nearly at the end of the multi-page form, perhaps reflecting the system's lack of capacity to focus on the individual life goals of each person in the system.

Improving Access by Refocusing the NASC Process

Access to appropriate services might be improved for people at both ends of the need spectrum if the NASC process were refocused toward those with greater or more complicated service needs. People with very low needs (e.g., two hours of home help per week) could be screened out of the assessment process and given the support requested, up to an established maximum, on the basis of a highly expedited process requiring a simple determination of eligibility. If a person were already receiving the Invalid Benefit, for example, he or she could be given presumptive eligibility for DSS. This would allow the NASC to re-deploy resources formerly used to assess low-level needs toward enhancing assessments and service coordination for people with higher-level needs. Enhancements should include: greater focus on individual consumer goals; greater access to specialist assessment; consideration and coordination of needs outside of DSS; ongoing service coordination for those who need it; and regular review of people already in the DSS system.

If the Ministry of Health considers refocusing NASC, it may be beneficial to collaborate with ACC. ACC is piloting an approach that moves away from assessments for certain accidents that are known to require standard levels of support. For example, ACC has developed a standard week-by-week support package that allocates a set amount of home help, shopping, meal preparation, personal care, etc. in the six weeks following a fractured clavicle (shoulder). These packages are based on ACC's analysis of claims data from past ACC claimants. Claimants who believe they need more than the standard package of care have the choice of being assessed in the traditional manner. Application of this approach may be more difficult for DSS (where needs tend to be ongoing, as opposed to recuperative), but the concept is worth exploring for the potential reduction in process for consumers and lower administrative costs for the DSS system.

Consistency and Flexibility

The NASC process, like similar processes in use in the US, is designed to allocate scarce resources in an equitable fashion. When working properly, the system consistently allocates similar resources to people with similar needs. If people perceive the process as producing inconsistent results, it will not enjoy the support it needs to function effectively as a resource allocation tool.

The best way to ensure consistent results is to adopt a valid and reliable assessment tool. The RAI (Resident Assessment Instrument) is an example of a tool that has been extensively tested and validated and is being used extensively in Canada and the US. Originally developed to assess people in nursing homes, it has been modified and extended to home care settings, and modules can be added for specialty needs. The tool is automated, allowing assessments to be entered electronically using a laptop or other portable device to conduct the assessment. This eliminates the costs of separate data entry processes, and ensures timely submission of assessment data to a central database.

Several people interviewed for this project expressed concern that a standardized and automated tool would diminish the flexibility to address individual needs. It is important to note that a standardized assessment is used to consistently establish a level of need. It does not prescribe a service plan, which is where individual flexibility is achieved. In other words, a standardized tool could produce for New Zealand more consistency in regard to the level of resources allocated to DSS applicants. It would then be up to the service coordination process to ensure that individual service plans were individually tailored, up to the maximum resource levels determined by the assessments.

Recommendations: Needs Assessment and Service Coordination

- Re-deploy existing NASC resources to focus on people with significant needs. For those with relatively low and straightforward needs (e.g., a few hours of home help), streamline the process to avoid full assessments in favour of quick screening for eligibility. Use freed-up resources to conduct more comprehensive assessments and to increase service coordination.

- Move toward a nationally consistent and comparable assessment process by piloting a standardized, automated assessment tool. While some experimentation with alternative tools may be beneficial, the Ministry should develop and require electronic submission of a minimum data set (MDS) from the assessment process, allowing comparative analysis of disability needs and associated services across the country.
- Reorient assessments toward people's goals for greater community inclusion. (If the current assessment form continues to be used, for example, move the goal section to the top of the form, and begin the process with a discussion of consumer goals.) Ensure that service planning is flexible enough to address individual goals for greater inclusion.
- Pilot multi-agency assessment and coordination mechanisms that consider and address needs comprehensively for people with disabilities. For example, a single process through which a consumer could access DSS, vocational and health services. (The multi-agency assessment and coordination project funded by the MORST to the Ministry of Health provides a vehicle for developing pilots.) Develop three or more different pilots and evaluate them for effectiveness (e.g., one pilot focused on children's needs that might include the MOH, Education and Children, Youth and Families; another focused on the needs of older people that might include the MOH, a DHB and a PHO).

Intersectoral Opportunities

A theme that runs through this entire report is the need for greater emphasis on intersectoral collaboration. People with disabilities use services from multiple government agencies, and greater emphasis should be placed on making those services work together in a rational and easily accessed manner. The creation of the Office for Disability Issues, with its focus on cross-governmental advice to the Minister for Disability Issues, is an important step in this direction.

Examples of common situations include the following:

- School aged children and their families usually interact with at least three separate systems. The health system is accessed for personal health services, the DSS system for respite, equipment and other services, and the education system for school. Separate assessment processes apply for school-based and DSS services, leading to patently ridiculous situations such as: the school system paying for a chair that cannot leave school premises, which means that government often funds two chairs, one for home and one for school;
- Adults with disabilities receiving DSS who would like to find employment must go through a separate assessment for vocational services, and are not considered likely candidates for those services because they are receiving Invalid Benefits. If they manage to find employment, they put their Invalid Benefits at risk once they exceed fifteen hours of employment per week.
- People who need both nursing and personal care at home need to arrange for each separately, and may not be able to coordinate the days that each is delivered.

There are several examples of intersectoral policy work underway. They include:

- ACC and DSD are jointly developing a home support standard;
- DSD developed a successful proposal to the Ministry of Research, Science and Technology to develop a model of interdepartmental assessment and coordination. Several government agencies endorsed the proposal and are now working with DSD to implement it.
- MSD has undertaken an analysis of the equity and cohesion of disability related services across government agencies.

These developments at the central policy level are very promising, and the cross-governmental perspective of the new Office for Disability Issues will support more efforts in the future. In order to operationalize these efforts for consumers, though, pilots will need to be developed locally to test the practicality of collaboration. An example is the Waikato "All of Government" approach described earlier. (See Employment and Vocational Services in Chapter 4.) The multi-agency assessment and service coordination project funded by MORST provides an opportunity to develop several pilots for testing at the community level.

Information Based Policy Making

Efforts to improve New Zealand's disability services are constrained by poor information systems and insufficient emphasis on evaluation and research. Policy decisions must often be made on the basis of anecdotal evidence alone, and new program initiatives tend to continue indefinitely without scrutiny once they have become part of the baseline budget.

The need for more and better disability data has been well documented. Good information is one of the *NZ Disability Strategy* objectives (#10). Disability data shortcomings have been highlighted in numerous policy reports, strategic plans and evaluations. (see, for example: Shipley and Upton, 1992; Ministry of Health and Health Funding Authority, 1998; Ashton, 2000; Health Services Research Centre, 2001)

Lack of empirical information appears to stem from many factors, including: frequent system restructures that have fragmented data sources over the last several years; a network of financially vulnerable disability services providers who do not have sufficient resources to invest in their data systems infrastructure; bulk purchasing of certain services (resulting in no consumer-specific claims for those services); resistance from various quarters to implementing a standardized assessment instrument; a billing system that continues to pay a significant number of paper claims from providers; lack of strong partnerships with universities and other research organizations; and a culture of practicality that eschews research as a frill given the system's inability to fully fund service needs.

Limitations of DSD Data

The following are examples of analyses or activities that cannot be effectively undertaken given the current state of DSD data:

- The DSD cannot confidently calculate the amount spent for each type of service for people with age-related disability. The impending funding split of age-related DSS has made this a high priority, and work is underway both nationally and locally, with expectations that reliable numbers will be available in advance of the July 2003 deadline. What is remarkable is that a policy decision of such magnitude has driven the information systems work, rather than good information driving the policy decision.
- The split of DSS for age-related disability was based on anecdotal evidence that older people in the DSS system use more health services than younger people, but that has yet to be demonstrated. One way of analysing the question would be to create a linked person-level data file that includes both DSS and personal health claims. The file could be used to describe the combination of health and disability supports used by people, and also to examine whether cost shifting occurs when a policy or program decision is made in one of the two systems. However, a significant portion of DSS claims lack National Health Index (NHI) numbers, the most likely common identifier to use in linking files. Also, because some DSS services are bulk funded, person-specific claims are not available for every service.
- It is not currently possible to aggregate assessment data by setting of care. This information would be extremely beneficial in the implementation of the *Health of Older People Strategy*. One of the goals of HOPS is to create an integrated continuum of care. An excellent starting point would be to analyse the characteristics of people currently served in each of the existing levels of care. Anecdotally, most observers of age-related services believe that acuity levels of people in continuing care hospitals, rest homes and home care have all been rising. It would be useful to confirm that, and to see whether there are explainable differences across settings. It may be, for example, that the distinctions between rest home and continuing care residents have become so small that it no longer makes sense to have two distinct levels of residential care for older people.
- Ethnicity data is considered to be particularly unreliable. This minimizes opportunities to conduct analysis specific to Mäori and Pacific Islanders. Given the sensitivity of ethnic issues, objective information would allow debates to move forward based on what is known, rather than what is believed.
- Detection of fraudulent or erroneous billing is limited because a substantial portion of claims is still processed manually. If both NASC service authorizations and billing against those authorizations were electronic, computers could reject unauthorized or duplicate claims.

Evaluation

Given the increasing numbers of people with disability projected to need services in the future (particularly among older people), evaluation will be even more important than it is currently. The establishment of ongoing research to evaluate the effectiveness of policies regarding older persons was recommended by the Department of Health (Koopman-Boyden, 1975) the Royal Commission on Social Policy (v. IV, 1986) and the National Advisory Committee on Core Health and Disability Support Services (Richmond et al., 1995).

As demands grow, the DSS system will need to make careful program decisions, keeping and expanding programs that are effective and discontinuing those that are not. The political context of publicly funded programs makes discontinuation difficult in the best of circumstances, but without good, objective evaluation data to inform debates, decisions are left entirely to the political process.

The DSD is making efforts to increase its evaluation activities. Examples of new efforts that will be evaluated include the national ageing-in-place initiatives and the Community Re-Integration Project in the Auckland Locality.

Evaluation would be much more affordable if client-level data were already available (such as the assessment data described above). A typical evaluation seeks to measure client-level costs, functional status, health status, setting of care, employment, etc. over time. If all this information has to be collected for each evaluation, it becomes prohibitively expensive. If, on the other hand, this data is collected routinely and exists in a database, evaluators can focus on analysis, rather than collection.

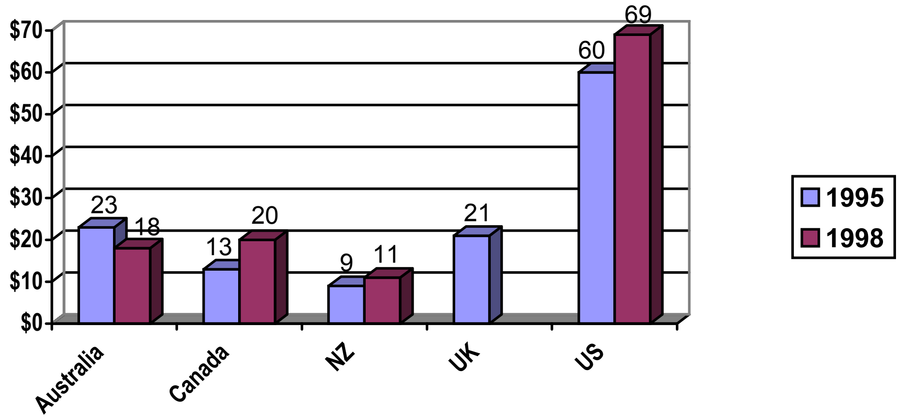
Research

There has been relatively little research conducted on disability in New Zealand, though there is some important work that should be acknowledged.

- The New Zealand Disability Survey, conducted by Statistics New Zealand, has now been conducted twice (1996 and 2001), creating some longitudinal data on New Zealanders with disabilities.
- The Ministry of Research, Science and Technology (MORST) has funded a multi-year project to develop models of multi-agency assessment and service coordination for people with disabilities.
- The Health Research Council and MORST are funding a multi-year research project on Mäori health and disability.
- The National Health Committee has recently undertaken research on adults with intellectual disability.
- The Donald Beasley Institute in Dunedin has conducted a number of research projects, many involving direct interaction with consumers.

International data on health research and development expenditures puts New Zealand on the low end of the spectrum, as shown in Chart 7. [Overleaf]

Chart 7. Public Expenditures on Health Research & Development per Capita, US $ Purchasing Power Parity



Source: OECD 2001 (1998 data for UK not available.)

Recommendations: Information Based Policy Making

- The Disability Services Directorate (DSD) should continue to improve its information systems to enable it to collect reliable, person-level data on service utilization, costs, demographic information and assessed level of need.
- The Office for Disability Issues (ODI) should explore the feasibility of linking data files across agencies to facilitate multi-agency collaboration. Data to target for links include DSS, personal health income support, and vocational services.
- The ODI should consider allocating a portion of its annual administrative budget for evaluation of initiatives throughout government agencies. All new program initiatives should be required to undergo a period of testing and evaluation before being made permanent.
- The ODI, DSD, and other interested agencies should explore the potential for ongoing research partnerships with the University system.
- The DSD should explore the potential for undertaking data analysis in partnership with ACC. An example of a mutually beneficial project that could use data from both agencies is an evaluation of ATR services.

Human Rights

New Zealand has been part of the international human rights movement for people with disabilities. The human rights approach takes form in legislation like New Zealand's Human Rights Act 1993 and the Americans with Disabilities Act (1990). These legal instruments prohibit discrimination on the basis of disability and rely on the social model of disability to function affirmatively for people with disabilities. The social model views disability as a set of barriers constructed by society. Anti-discrimination legislation is used to confront social barriers as discriminatory and call upon society to remove them. Declaring an impairment discriminatory makes no sense; an impairment is usually a permanent feature of a person. However, if disability is something created by society, it can be removed.

Entities that discriminate may be required to make reasonable accommodations for people with disabilities. In other words, they may be required to remove barriers to the extent that such actions are reasonable. A public library would be expected to build a ramp for people with physical disabilities and arrange for inter-library loans of books in Braille for blind people. However, it would probably not be considered reasonable to require the library to translate its entire collection into Braille.

Some in New Zealand have been calling for a disability act to strengthen New Zealand's human rights approach. This raises several important questions.

How is the Human Rights Act 1993 working for people with disabilities? Does it need to be replaced?
Until 1 January 2002, the Human Rights Act protections did not apply to government entities, but the government exemption was allowed to lapse when it expired on 31 December 2001. It is too early to see whether the extension of the HRA will result in a significant number of disability-related cases against government agencies, but if the pattern from the private sector holds, government will see significant activity. In the year ending 30 June 2001, the Human Rights Commission received more disability-related enquiries (21% of over 21,000 received, or nearly 4,500) than any other category, followed closely by sexual harassment (18%). (Human Rights Commission, 2001)

This pattern holds at the complaint level, with disability again leading all other categories. The Commission received 148 complaints (29% of the total) regarding discrimination on the grounds of disability. 2001 was the second consecutive year in which disability-related enquiries and complaints outnumbered all others types, suggesting an emerging trend, rather than a one-off anomaly. (Human Rights Commission, 2000) Partial-year reports for the 2001-2002 year continue the pattern. Between 1 January and 30 April 2002, the Commission received 153 enquiries and informal disputes related to disabilities. This was by far the largest category, with the next highest (race) at 81. (Human Rights Commission, 2002) Unfortunately, the Commission does not report on the resolution of all complaints, so one cannot assess the extent to which the Human Rights Act results in positive outcomes for people with disabilities.

Two recent high profile disability cases hint at weaknesses in the Act. One, involving telecommunications services for deaf people was ultimately resolved in favour of deaf people, but the case took seven years in the human rights process and was ultimately resolved by executive action when the Commission, faced with protracted litigation against the telecommunications industry, successfully appealed to the Prime Minister to take the case to Cabinet for regulatory relief. The Cabinet approved establishment of a relay service via a Telecommunications Service Obligation (TSO), a mechanism available to it under the Telecommunications Act 2001. Had the Government not been willing to act, the case would still not be resolved.

A recent High Court interpretation of the Human Rights Act (*Daniels and Ors v Attorney-General, 2002*) suggests that the Commission may not have the authority to require reasonable accommodation. The case was brought by a group of parents of children with disabilities under both the Education Act 1989 and the Human Rights Act. The plaintiffs prevailed in their argument under the Education Act, but the Court also found that the Human Rights Act requires all people, regardless of need, to be treated the same, not differently. Thus, the fundamental concept of reasonable accommodation that arises from a social model of disability is, under the *Daniels* decision, inoperable under New Zealand's Human Rights Act. (The decision is being appealed.)

What would disability legislation seek beyond the existing provisions of the HRA?
If the *Daniels* decision is upheld, reasonable accommodation will no longer be available as a tool for removing social barriers in New Zealand. Whether new legislation is enacted or the HRA amended, clarification of reasonable accommodation is critical if New Zealand wishes to pursue a human rights approach.

The ADA goes beyond the HRA by establishing standards for publicly funded services to people with disabilities. In federal regulations adopted pursuant to the ADA, public services are considered discriminatory if not delivered in the most integrated setting possible. Thus, if a person lives in an institutional setting but has been assessed as able to live in the community with supports, a public entity can be found in violation of the Act. This standard resulted in the Supreme Court decision *L.C. and E.W. v Olmstead,* ruling that the State of Georgia discriminated against two women with intellectual disability by providing them with institutional services when they were able and wanted to live in community settings. The decision has triggered a massive effort to comply with the Olmstead decision in nearly every state. New Zealand may want to consider setting a similar standard, either as an amendment to the HRA or in freestanding legislation.

How would an ADA-like Act work in New Zealand?
There are some subtle differences between NZ and the US that should be considered as New Zealand looks at legislative options. From the perspective of an American visitor, New Zealand appears to place greater value than the US on consensus solutions to problems. By contrast, the US is very comfortable with individual self-advocacy. A human rights approach is premised on the exercise of individual rights. It moves away from utilitarian philosophy of the collective good. Is New Zealand prepared to value the rights of individuals above the collective utility of society?

Furthermore, it takes aggressive advocacy to make a human rights approach work. The high numbers of disability-based complaints taken to the Human Rights Commission suggests that advocacy is alive and well in New Zealand's disability community. But would the resources be available if the law needed to be pushed to its limits? Had the Government not acted in the telecommunications case, would the Commission have continued to pursue the case?

These are questions that New Zealand must answer for itself.

CHAPTER 7. SUMMARY OF RECOMMENDATIONS

Recommendations made in earlier chapters are restated here in abbreviated form for ease of reference.

Disability Strategy (Chapter 3)

- ODI should work with the disability sector to develop *NZ Disability Strategy* success indicators.
- ODI should work with all relevant agencies to develop coordinated policy that puts the *NZ Disability Strategy* into practice.

Employment and Vocational Services (Chapter 4)

- Increase access to vocational services for DSS consumers by improving inter-agency coordination at both national and local levels.
- Irrespective of progress on inter-agency assessment processes, vocational needs should be addressed more consistently as part of NASC assessments, referrals made to vocational agencies as indicated, and coordination provided to streamline the process for consumers.
- Clarify that the primary goal of *Pathways to Inclusion* is to increase the number of people with disabilities who are employed. Ensure that data systems can track the movement of people from their current sheltered workshop settings into other settings following repeal of DPEPA.
- Ensure that *Pathways* implementation considers the individual needs of consumers by allocating an adequate amount of *Pathways* funding to provide an individual service voucher to each person currently working in a sheltered workshop.
- Build on current MSD employment pilots to include people with physical and intellectual disabilities in the target group, and to reduce disincentives for people receiving income support benefits by experimenting with gradual reductions of income support (e.g., reduction of support by $1 for each $2 earned) and expedited reinstatement for employed people who are mistakenly removed from income support programs.
- Ensure that people with disabilities who are receiving sickness or invalid benefits are not turned away from mainstream employment services.

Devolution of Non Age-related DSS (Chapter 4)

- Devolution of funding for non age-related DSS should be postponed indefinitely, pending clarification of the specific disability system problems that devolution would address.
- If devolution is favoured as a potential solution to fragmentation of services and other disability issues, pilots should be developed to test and evaluate models designed specifically for disability services.

Service Delivery System for Older People (Chapter 5)

- Identify the levels of care needed to ensure maximum independence for older New Zealanders. Specifically, develop and evaluate community-based rehabilitation options. Consider adding an intermediate level of residential support for people who cannot live alone, do not require rest home or hospital level of care, but cannot afford retirement village options.

- Review the roles played by existing providers, including ATR, rest homes, continuing care hospitals and home care.
- Plans for an integrated continuum of care should pay particular attention to enhancing coordination between primary care and secondary care; between hospitals and community providers, and between district nursing and home care.

Asset Testing for Residential Care (Chapter 5)

- Changes to asset testing policy should be considered in the context of improvements to the system of care for older people. Specifically, a time-limited waiver of asset testing in combination with development of community rehabilitation options should be considered.
- The effects of any change in asset testing policy should be carefully evaluated, with particular attention to the rate of admissions and length of stay in residential care post-policy against current benchmark to see the impact.
- Safeguards should be created to ensure that older people make informed decisions about residential care, free from pressure by family members.

Devolution of Age-Related DSS (Chapter 5)

- DHBs need clearer guidance from the Ministry regarding the goals of devolution and expectations of integrated care. Concepts such as "integrated continuum of care" and "ageing in place" should be articulated in greater detail.
- In keeping with a key rationale of devolution (that older people with disability see their doctors for care) Primary Health Organisations (PHOs) should play an important role in a devolved age care system.
- The Ministry should maintain an ongoing interest in facilitating a nationally consistent and comparable assessment process for older people with disability support needs.
- The applicability of the *NZ Disability Strategy* to older people should be clarified to ensure that its focus on maximizing independence is not lost.

Consumer Centeredness and Service Flexibility (Chapter 6)

- Self-direction should be promoted by lifting the moratorium on self-managed contracts.
- Peer counselling and advocacy programs should be developed.
- MOH and MSD could create a collaborative competitive grants program that promotes greater service flexibility for consumers.
- MOH and MSD should collaborate to make residential care subsidies for people of all ages portable to supported living or independent living arrangements.
- MOH and MSD should collaborate to create savings incentives for consumers receiving income support benefits.
- Self direction initiatives should be culturally sensitive to ensure continuing popularity with Mäori and other cultures.
- Work with Housing NZ Corporation to expand the availability of accessible and affordable mainstream housing options for supported living, such as State houses and flats.

Needs Assessment and Service Coordination (Chapter 6)

- Re-deploy NASC resources to focus on people with significant needs. For those with relatively low and straightforward needs (e.g., a few hours of home help), streamline the process to avoid full assessments in favour of quick screening for eligibility.

- Move toward a nationally consistent and comparable assessment process by piloting a standardized, automated assessment tool.
- Reorient assessments toward people's goals for greater community inclusion.
- Pilot multi-agency assessment and coordination mechanisms that consider and address needs comprehensively for people with disabilities.

Information Based Policy Making (Chapter 6)

- DSD should continue to improve its information systems to enable it to collect reliable, person-level data on service utilization, costs, demographic information and assessed level of need.
- ODI should explore the feasibility of linking data files across agencies to facilitate multi-agency collaboration.
- ODI should consider allocating a portion of its annual administrative budget for evaluation of initiatives throughout government agencies.
- ODI, DSD, and other interested agencies should explore the potential for ongoing research partnerships with the University system.
- DSD should explore the potential for undertaking data analysis in partnership with ACC.

REFERENCES

Alzheimer’s New Zealand. Annual Report 2001.

Ashton, Toni. 2000. *New Zealand: Long-Term Care in A Decade of Change*. Health Affairs. v. 19, n. 3: 72-85.

Benjamin, A.E. 2001. *Consumer Directed Services at Home: A New Model for Persons with Disabilities*. Health Affairs, v. 20, n. 6: 80-95.

Cutler, David M. 2001. *Declining Disability Among the Elderly*. Health Affairs, v. 20, n. 6: 11-27.

Daniels and Ors v Attorney-General, 2002. Judgement (1) of Baragwanath J. In the High Court of New Zealand, Auckland Registry. M 1615-SW99.

Department of Labour. 2001. Pathways to Inclusion: *Ngä ara whakauru ki te iwi whänui* Improving Vocational Services for People with Disabilities. Wellington.

Dyson, Ruth, Associate Minister of Social Services and Employment. 2002. “Vocational Services Big Budget Winner.” Media Statement issued 6 May, 2002.

Eschenbach, Bill. 2002. Unpublished Ministry of Health data analysis linking acute hospital discharge to ATR admissions in Christchurch hospitals.

Evening Post. June 13, 2002, p.2. *Government Breaks Promise, Say Elderly*. By Bernie Steeds and Ruth Berry. Wellington.

Finch, Michael, Rosalie A. Kane, Robert Kane, Jon Christianson, Bryan Dowd, Charlene Harrington and Robert Newcomber. 1991. Design of 2nd Generation S/HMO Demonstration: An Analysis of Multiple Incentives. Minneapolis, Minnesota: Health Policy Center, School of Public Health, University of Minnesota.

Gauld, Robin. 2001. Revolving Doors: New Zealand's Health Reforms. Wellington: Institute of Policy Studies and The Health Services Research Centre, Victoria University of Wellington.

Hay, Iain. 1989. The Caring Commodity: The Provision of Health Care in New Zealand. Auckland: Oxford University Press

Health and Disability Commissioner. 2001. Annual Report of the Health and Disability Commissioner for the Year Ended 30 June 2001. Auckland.

Health Services Research Centre. 2001. National Demonstration Integrated Care Pilot Projects: Overview Report; Final Evaluation Report. Wellington: Victoria University of Wellington.

Human Rights Commission *Komihana Tikanga Tangata*. 2002. Tirohia. Issue 2, 2002.

Human Rights Commission *Komihana Tikanga Tangata*. 2001. Report of the Human Rights Commission *Komihana Tikanga Tangata* for the Year Ended 30 June 2001. Wellington.

Human Rights Commission *Komihana Tikanga Tangata*. 2000. Report of the Human Rights Commission *Komihana Tikanga Tangata* for the Year Ended 30 June 2000. Wellington.

Intersect Waikato. 2002. Focusing on Abilities not Disabilities: The Waikato Whole of Government Approach to an Employment Strategy for People with Disabilities. (Phase One Report: Analysis of Government Agency Stocktake). Hamilton.

King, Annette. 2000. *First reading, NZPHD Bill*. 17 August, 2000.

Kingi, Tania. 2002. Unpublished manuscript courtesy of the author.

Koopman-Boyden P.G. 1975. A Proposal for Future Social Research on the Elderly in New Zealand. Department of Health Occasional Paper no. 3. Wellington.

Mental Health Commission. 1998. Blueprint for Mental Health Services in New Zealand : How Things Need To Be. Wellington.

Merlis, Mark. 2000. *Caring for the Frail Elderly: An International Review*. Health Affairs. v. 19, n. 3, 141-149.

Ministerial Task Force on Social Welfare Services. 1986. Supplementary Paper No. 1: The Development of Social Welfare Services in New Zealand. Wellington.

Ministry of Health. 2002a. Health of Older People Strategy. Wellington.

Ministry of Health. 2002b. Support Needs Assessment and Service Co-ordination Policy, Procedure and Information Reporting Guidelines. 2002 version. Wellington.

Ministry of Health. 2001a. A Brief Summary of the Analysis of Submissions to the New Zealand Disability Strategy Discussion Document. April, 2001. Wellington.

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

Ministry of Health. 2001c. Mäori Disability Action Plan for the Disability Issues Directorate. Discussion Paper, October, 2001. Wellington.

Ministry of Health. 1994. The New Zealand Framework for Service Delivery: Disability Support Services. Wellington.

Ministry of Health and Health Funding Authority. 1998. Disability Support Services Strategic Work Programme: Building on the New Deal. Wellington: Ministry of Health.

Ministry of Social Development. 2002. Ministry of Social Development Report: Opportunities for Sickness Benefit and Invalids Benefit Recipients: Progress with Implementation of Demonstration Projects. 7 February, 2002. Wellington.

Ministry of Social Development. 2001. New Zealand Positive Ageing Strategy. Wellington.

Ministry of Social Development and Ministry of Health. 2002. "Flow-on Effects of Implementing the Vocational Services Strategy for People with Disabilities." Unpublished paper, Ref. No. 20022181. Wellington.

National Health Committee. 2000. Report of the National Health Committee on Health Care for Older People. Wellington.

New Zealand Disability Strategy Reference Group. 2000. Correspondence to Hon Lianne Dalziel, Minister for Disability Issues. 18 December, 2000.

OECD. 2001. OECD Health Data 2001: A Comparative Analysis of 30 Countries. www.oecd.org/els/health/

Ratima, MM, MH Durie, GR Allan, PS Morrison, A Gillies and JA Waldon. 1995. He Anga Whakamana. A Framework for the Delivery of Disability Support Services for Mäori. Wellington: National Advisory Committee on Core Health and Disability Support Services.

Rawls, John. 1972. A Theory of Justice. Oxford: Clarendon Press.

Richmond, David, Jonathan Baskett, Ruth Bonita and Pam Melding. 1995. Care for Older People in New Zealand: A Report to The National Advisory Committee on Core Health and Disability Suupport Services. Wellington: New Zealand Ministry of Health.

Royal Commission of Inquiry. 1972. (Royal Commission on Social Security in New Zealand). Social Security in New Zealand: Report of the Royal Commission of Inquiry. Wellington.

Royal Commission on Social Policy (v. IV). 1988. The April Report, Volume IV: Social Perspectives. Wellington.

Shipley, Jenny and Simon Upton (a). 1992 (March). Support for Independence: A Discussion Paper on the Funding and Delivery of Disability Support Services. Wellington: Minister of Social Welfare and Minister of Health.

Shipley, Jenny and Simon Upton (b). 1992 (August). Support for Independence for People with Disabilities: A Government Statement on the Funding and Delivery of Health and Disability Services. Wellington: Minister of Social Welfare and Minister of Health.

Statistics New Zealand. 2002. 2001 New Zealand Disability Survey. www.stats.govt.nz

Stone, Robyn., ed. 2000. *Consumer Direction in Long-Term Care*. Special issue of Generations, v. 24, n. 3.

Tinetti, Mary, Dorothy Baker, William T. Gallo, Aman Nanda, Peter Charpentier and John O'Leary. 2002. *Evaluation of Restorative Care vs Usual Care for Older Adults Receiving an Acute Episode of Home Care*. JAMA v.287, n. 16, 2098-2105.

WAVE Advisory Board to the Director-General of Health. 2001. From Strategy to Reality : the WAVE Project. *Kia hopu te ngaru*. Wellington.

APPENDIX A: PERSONS WHO PROVIDED INTERVIEWS OR OTHER ASSISTANCE

Max Abbott, Dean and Professor of Psychology and Public Health, Auckland University of Technology, and Deputy Chair, Waitemata DHB, Auckland

George Akast, NZ Disability Strategy Co-ordinator, Disability Services Directorate, Ministry of Health, Auckland

Jocelyn Armstrong, Associate Professor, University of Illinois at Urbana-Champaign

Katherine Baxter, Manager, Community Policy, Ministry of Social Development, Wellington

Jeff Bennett, Regional Contracts Manager, Work and Income NZ, Hamilton

Sue Bidrose, Senior Policy Analyst, Ministry of Social Development, Wellington

Adri Booth, Executive Officer, Life Unlimited, Hamilton

Anne Bray, Director, The Donald Beasley Institute, Dunedin

Mark Brown, Senior Locality Manager, Disability Services Directorate, Ministry of Health, Hamilton

Libby Carr, Policy Manager, Disability Services Directorate, Ministry of Health, Wellington

Pete Carter, General Manager, DSS & Mental Health Funding, Northland DHB, Whangarei

Jane Cartwright, Planning Manager, Planning & Funding, Canterbury DHB, Christchurch

Tess Casey, Executive Officer, NZ Federation of Vocational and Support Services, Wellington

Roy Chan, Commercial Analyst, Disability Services Directorate, Ministry of Health, Hamilton

Jenny Chong, Community Health Services Manager, Nurse Maude Association, Christchurch

David Chrisp, Service Development Manager, Disability Services Directorate, Ministry of Health, Wellington

Lesley Clarke, Executive Director, New Zealand Private Hospitals Association, Wellington

Grant Cleland, Creative Solutions, Christchurch

Kylie Clode, Senior Policy Analyst, Disability Services Directorate, Ministry of Health, Wellington

Gill Coe, Project Manager, Planning and Funding, Canterbury DHB, Christchurch

Cherie Cook, Respite Co-ordinator, Community Assessment & Rehabilitation Services, Northland Health, Whangarei

Karen Coutts, Policy Analyst, Disability Services Directorate, Ministry of Health, Wellington

Maureen Craven, Parent & Family Resource Centre, Auckland

Jackie Cumming, Director, Health Services Research Centre, Victoria University of Wellington

Fleur D'Souza, Business Support Manager, Disability Services Directorate, Ministry of Health, Wellington

Gordon Davies, Deputy Director-General, DHB Funding and Performance Directorate, Ministry of Health, Wellington

Trish Davis, Locality Manager, Disability Services Directorate, Ministry of Health, Hamilton

Barry de Geest, Ripple Trust, Auckland

Vaughan Dodd, NZ Disability Strategy Co-ordinator, Disability Services Directorate, Ministry of Health, Auckland

Trisha Donovan, Executive Assistant, Disability Services Directorate, Ministry of Health, Wellington

Jan Dowland, Executive Director, IHC New Zealand, Wellington

Hon Ruth Dyson, Minister for Disability Issues, Wellington

Raymond Eberhard, Manager Social Services, Hohepa Homes, Christchurch

Wendy Edgar, Senior Analyst/Project Manager, Health of Older People, Sector Policy Directorate, Ministry of Health

Chris Ellis, Awareness Consultant, Project Management & Staff Training, Auckland

Juliet Elworthy, Senior Policy Analyst, Ministry of Social Development, Wellington

Richard Faull, Board Member, Ian Axford (New Zealand) Fellowship, Auckland

Paulette Finlay, Senior Analyst, Health of Older People, Sector Policy Directorate, Ministry of Health, Wellington

Pam Fletcher, Senior Analyst, Health of Older People, Sector Policy Directorate, Ministry of Health, Wellington

Anne Foley, Quality Coordonator, Disability Services Directorate, Ministry of Health, Wellington

Glenda Foster, Manager, Rehabilitation and Assessment Services, ACC, Wellington

Moira Geerkens, Services Manager, New Zealand CCS, Whangarei

Judy Glackin, Manager, Health of Older People and Sector Regulation, Sector Policy Directorate, Ministry of Health, Wellington

Kathy Glass, Coordinator, Taranaki APEPSI Trust, New Plymouth

Jean Green, Community Services Manager, IHC New Zealand, Auckland

Cindy Haika, Chief Executive, Care Plus, Whangarei

Ruth Harrison, Chief Executive, Workbridge Wellington

Erica Heeley, Business Support Manager, Disability Services Directorate, Ministry of Health, Wellington

Benedict Hefford, Project Manager, Disability Services Directorate, Ministry of Health, Wellington

Donna Hegarty, Managing Director, Rescare Homes Trust, Auckland

David Henderson, Consultant/Advisor to Rehabilitation International, Wellington

Huhana Hickey, Hamilton

Sandy Hohepa, Manaarki Waurua, Whakamarama Marae

Nigel Hubbard, Chief Analyst, ACC, Wellington

Katrina Ings, Regional Commissioner, Work and Income NZ, Hamilton

Georgina (Puhi) Iopata, Manager, Te Puna Ora O Mataatua Charitable Trust, Whakatane

Stephen Jacobs, Project Manager, Disability Services Directorate, Ministry of Health, Wellington

Dale Johnson, Consumer Advisor, Disability Services Directorate, Ministry of Health, Hamilton

Judith M. Johnson, Managing Director, Heretaunga Home & Village, Upper Hutt, and Executive Committee Member, Residential Care New Zealand

Lisa Johnson, Analyst, Social Policy Branch, The Treasury, Wellington

Lynn Jones, Te Whänau Continuing Care Hospital & Elderly Care Centre, Levin

Diane Jorgensen, Chief Executive Officer, Wellington Masonic Villages Trust, Lower Hutt

Jools Joslin, Project Manager, Disability Services Directorate, Ministry of Health, Wellington

Margaret Kearney, Service Manager, IHC New Zealand Residential Services, North/West Auckland

Betty-Ann Kelly, Policy Analyst, Ministry of Social Development, Wellington

Rachel Kingi, Home Care Co-ordinator, Te Puna Ora O Mataatua Charitable Trust, Whakatane

Tania Kingi, Service Manager, Disability Services Directorate, Ministry of Health, Auckland

Robyn Klos, CEO, Gracelands Te Awamutu Gracelands Trust, Te Awamutu

Peter Leatham, Senior Locality Manager, Disability Services Directorate, Ministry of Health, Christchurch

Bernerd Leuthart, Registrar, Waiwhetu Medical Centre, Waiwhetu

Mark Leggett, Southern Regional Manager, Healthcare NZ Limited, Christchurch

Warren Lindberg, Commissioner, Human Rights Commission, Auckland

Marianne Linton, Research Analyst, Disability Services Directorate, Ministry of Health, Wellington

John Litton, Village Manager, Wellington Masonic Villages Trust, Levin

Judith Lunny, Consultant, Auckland Providers Network, Auckland

Kate Lynch, Senior Analyst, Labour Market Policy Group, Department of Labour, Wellington

Sanjeev Malhorta, Commercial Analyst, Disability Services Directorate, Ministry of Health, Wellington

Natalia Mander, Kiwiable Leisure Care Co-ordinator, Christchurch City Council, Christchurch

Victoria Manning, Project Co-ordinator, Disability Support Services, Victoria University of Wellington

Neil Martin, Senior Manager, Equity and Population Policy, Ministry of Social Development, Wellington

Nicholas Mays, Adviser, Health, Social Policy Branch, The Treasury, Wellington

Sally McAdam, Executive Team Leader, Employ, Gracelands Te Awamutu Gracelands Trust, Te Awamutu

Norine McBride, Senior Policy Analyst, Disability Services Directorate, Ministry of Health, Wellington

Sue Merrilees, Policy Analyst, Disability Services Directorate, Ministry of Health, Wellington

Heather Michaels, Clinical Manager, Care Plus, Whangarei

Nigel Millar, Clinical Director & Geriatrician, Older Persons Health, Canterbury DHB, Christchurch

Loraine Milne, Project Manager, Disability Services Directorate, Ministry of Health, Wellington

Jennifer Moor, Locality Manager, Disability Services Directorate, Ministry of Health, Auckland

Alison Morgan, Project Manager, Waitemata DHB, Auckland

Lester Mundell, Chief Advisor, Disability Services Directorate, Ministry of Health, Wellington

Anne Murphy, Managing Director, Focus 2000, Auckland

Bronwen L. Newdick, General Manager, Disabilities Resource Centre Trust, Whakatane

Dave Nicholl, Quality Manager, Disability Services Directorate, Ministry of Health, Wellington

Pip Nicholls, Manager, Accessability, New Plymouth

Patsy Nikora, Women’s Health Co-ordinator, Te Puna Ora O Mataatua Charitable Trust, Whakatane

Lesley Nilsson, Nurse Manager, Hunt Healthcare Group Limited, Wellington

Catherine O'Donnell, Manager, Lansdowne Hospital and Retirement Home, Auckland

Ron Paterson, Health and Disability Commissioner, Auckland

Christine Petch, Business Support Manager, Disability Services Directorate, Ministry of Health, Hamilton

Maree Pierce, Locality Manager, Disability Services Directorate, Ministry of Health, Hamilton

Amanda Pitceathly, Manager, Ignite, New Plymouth

Tu'uta Pome'e, Manager, PIASS Trust, Auckland

Karen Poutasi, Director-General of Health, Ministry of Health, Wellington

Barb Purdie, Trustee, Taranaki APEPSI Trust, New Plymouth

Wendy Rhodes, Project Manager, Disability Services Directorate, Ministry of Health, Wellington

Hëmi Ririnui-Horne, Manager, Mäori Service Development, Disability Services Directorate, Ministry of Health, Wellington

Simon Robb, Project Manager, DHB Funding and Performance Directorate, Ministry of Health, Wellington

Barbara Rocco, National President, IHC New Zealand, Picton

Ramona Rongonui, Advocate for Disability Services for Mäori of Taranaki, He Whakaru Ruhau Trust, New Plymouth

Catherine Roughan, Chief Executive Officer, St John of God Health and Disability Services, Christchurch

Jeanette Rowden, Manager, Community Homes, St John of God Health and Disability Services, Christchurch

Raymond Ruka, Board Member, New Zealand CCS, Taheke

Susanne Scanlen, Manager, Northland Disabilities Resource Centre, Whangarei

Jan Scown, Chief Executive, Community Living Trust, Hamilton

Katie Scott, Personal Assistant to DDG, Disability Services Directorate, Ministry of Health, Wellington

Carol Searle, Deputy Director-General, Disability Services Directorate, Ministry of Health, Wellington

Susan Sherrard, Ripple Trust, Auckland

Anne Simpson, General Manager, Life Links, Christchurch

Jane Smart, General Manager, Hunt Group, Wellington

Valerie Smith, Advisor, Disability Services Directorate, Ministry of Health, Wellington

Victoria Smith, CEO, Te Roopu Waiora, Auckland

Bob Stephens, Senior Lecturer, Victoria University of Wellington

Gil Stokes, Head of School, School of Nursing and Midwifery, Auckland University of Technology

Lorna Sullivan, Chief Executive, Access Ability Limited, Papatoetoe

Tania Thomas, Director of Advocacy, Health and Disability Consumer Advocacy Service, Auckland

Denise Udy, National Rehabilitation Manager, ACC, Wellington

Trisha Ventom, Kiwiable Co-ordinator, Christchurch City Council, Christchurch

Russell Vickery, Regional Representative, Tai Tokerau and Tamaki Makaura, New Zealand CCS, Auckland

Kim Von Lanthen, Chief Analyst, Health, The Treasury, Wellington

Carol Voyce, Registered Nurse, Community Health Service, Age Concern Canterbury, Christchurch

Sandie Waddell, Senior Locality Manager, Disability Services Directorate, Ministry of Health, Wellington

Rodd Watts, Senior Locality Manager, Disability Services Directorate, Ministry of Health Auckland

Olive Webb, Psychologist, Richmond Fellowship, and Chair, Disability Support Advisory Committee, Canterbury DHB, Christchurch

Therese Weir, Locality Manager, Disability Services Directorate, Ministry of Health, Auckland

Jean Wheldale, Vocational Services Co-ordinator,Day Services, IHC New Zealand, Auckland

Janice V. White, Manager, Disability Support Link, Hamilton

Matthew Whiting, Community Support Worker, New Zealand CCS, Christchurch

Wendi Wicks, Policy Researcher, DPA (New Zealand) Inc, Wellington

Jonathan Wilkinson, Team Leader/Regional Systems Administrator, New Zealand CCS, Whangarei

Gary Williams, Chief Executive Officer, DPA (New Zealand) Inc, Wellington

Sue Williams, Project Manager, Pegasus Health, Christchurch

Denise Wilson, Education Adviser, Health and Disability Commissioner, Auckland

Janice Wilson, Deputy Director-General, Mental Health, Ministry of Health, Wellington

Catherine Winfrey, Ministry of Social Development, Wellington

Chris Wright, Waiwhetu Medical Centre, Waiwhetu

Valerie Wright-St Clair, Head of School, School of Occupational Therapy, Auckland University of Technology

William W. Wrightson, Member, Building Industry Authority, Wellington

Maree Yong, Wellington