

Briefing to the Incoming Minister

Making a World of Difference

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Making a World of Difference

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Cover: *Pictured are members of the deaf community on the steps of Parliament after attending the New Zealand Sign Language Bill's first reading. Everyone is applauding in the deaf way by waving their hands.*

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Introduction

One in five New Zealanders is disabled. In 2001, this amounted to a total of 743,800 people. Disabled New Zealanders are a diverse group, representing all sectors of society and a wide range of impairment types.

The experience of disability occurs when people with impairments are excluded from places and activities most New Zealanders take for granted. Many disabled people are seriously disadvantaged by exclusion, and are unable to participate in society on an equal basis with others.

As the Minister for Disability Issues, you are an advocate for disabled people. You make broad policy decisions that lead the direction of government engagement with disability issues. Your position also allows you to evaluate policies presented from other portfolios from a disability perspective and you have a statutory role, under the New Zealand Public Health and Disability Act 2000, to inform your colleagues of progress and trends.

A primary function of the Office for Disability Issues is to support and advise you in this role. In doing so we recognise the views, experience and wisdom of disabled New Zealanders and their families, and we provide a channel for the disability sector to raise issues with government. We have a leadership role across government agencies, and between them and the disability sector.

In this briefing we provide an overview of disability issues, including key concepts of what disability is and the current experience of disabled people. We highlight their aspirations and describe progress government has made in response. We also outline challenges and opportunities for further work.

The messages on the next page are a summary of the priority challenges we believe government faces in improving the life experience of disabled New Zealanders.

We look forward to working with you.

Dr Jan Scown
Director
Office for Disability Issues

Our role is to support you and keep you in touch with the disability sector

Key messages

- Many disabled people are unable to reach their potential or participate fully in the community because of the barriers they face in doing things that most New Zealanders take for granted. The barriers range from the purely physical, to the attitudinal.
- Disabled people are over-represented in lower-paid occupations, and are likely to have fewer financial and family resources than the general population. This economic disadvantage is compounded by the financial cost of disability.
- As a group, disabled people generally have poorer general health status, and poor access to support services and other arrangements that might allow them to move from a marginalised position in society.
- Government can make a key difference in reducing the debilitating experience of disability and the comparative disadvantage suffered by many disabled people.
- Disabled people can enjoy increasing work opportunities, through access to the right education, equipment and environmental accommodations, and promotion of positive employer attitudes.
- The everyday needs of disabled New Zealanders can be met, and their personal potential realised, through the tailoring of support services to meet the diversity of individual circumstances.
- Society's understanding of, and attitudes towards, disability can be transformed through the raising of public awareness and the promotion of disabled people as leaders in business and the community.
- Overall, the quality of disabled people's lives can be improved through sound investment guided by the New Zealand Disability Strategy, and by disabled people and their families having a say in the policy and service developments that affect them.
- As the Minister for Disability Issues your role, in government and established in legislation, is critical to making this difference for disabled people possible.

part one

Overview – the situation today

Part one : Overview – the situation today

Society is disabling

We live in a disabling society ... Our society is built in a way that assumes we can all move quickly from one side of the road to the other; that we can all see signs, read directions, hear announcements, reach buttons, have the strength to open heavy doors and have stable moods and perceptions.¹

The experience of disability occurs when people with impairments are excluded from places and activities most of us take for granted. It happens when our infrastructure and systems do not accommodate the diverse abilities and needs of all citizens.²

Disability is a common yet diverse experience

One in five New Zealanders experience disability

Disability touches most people's lives, either personally or through their family and friends. The rate of disability in New Zealand is one person in five, according to the 1996 and 2001 Census and Post-Census Disability Surveys.³

In 2001, a total of 743,800 New Zealanders reported some level of disability. This included an estimated 626,500 adults (over 15 years old), and 90,000 children living in households, and 27,300 people living in residential facilities.

In 2001, an estimated 432,100 people relied on some form of disability support. Of these:

- about 110,700 people needed daily help with tasks such as preparing meals, shopping, housework, bathing or dressing (including 22,600 people in residential facilities)

- about 321,400 people needed an assistive device or help with heavier or more difficult household tasks (including 4,400 people in residential facilities).

Disability is influenced by the nature of a person's impairment(s). These can be intellectual, psychiatric, physical, neurological or sensory, and be temporary, intermittent or ongoing. Gender, age, ethnicity and culture can also have a profound and sometimes compounding effect on an individual's experience of disability.

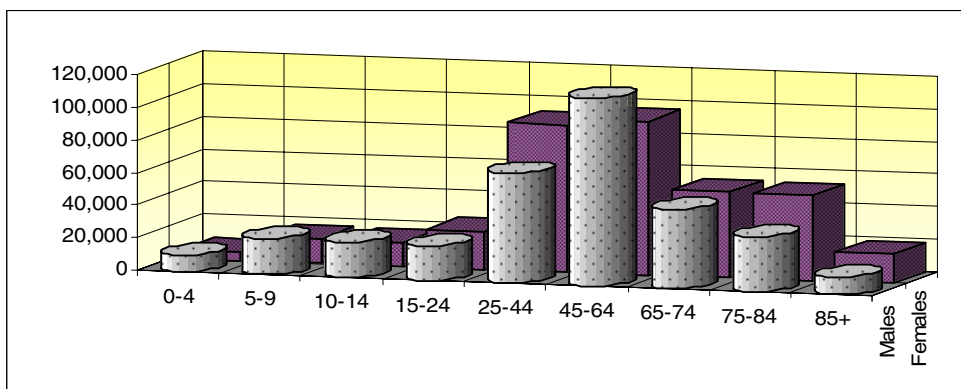
Likelihood of disability increases with age

Older people are substantially more likely than younger people to experience disability. In 2001, 11 percent of children aged 0 to 14 years, 13 percent of adults aged 15 to 44 years and 25 percent of adults aged between 45 and 64 years reported an impairment. This compares with 54 percent of people aged 65 years or over (including 87 percent of people aged 85 and over).

However, as illustrated in figure 1.1, in terms of overall numbers most disabled people are part of the working age population.

Most disabled people are of working age

Figure 1.1 Numbers of disabled New Zealanders according to age and gender

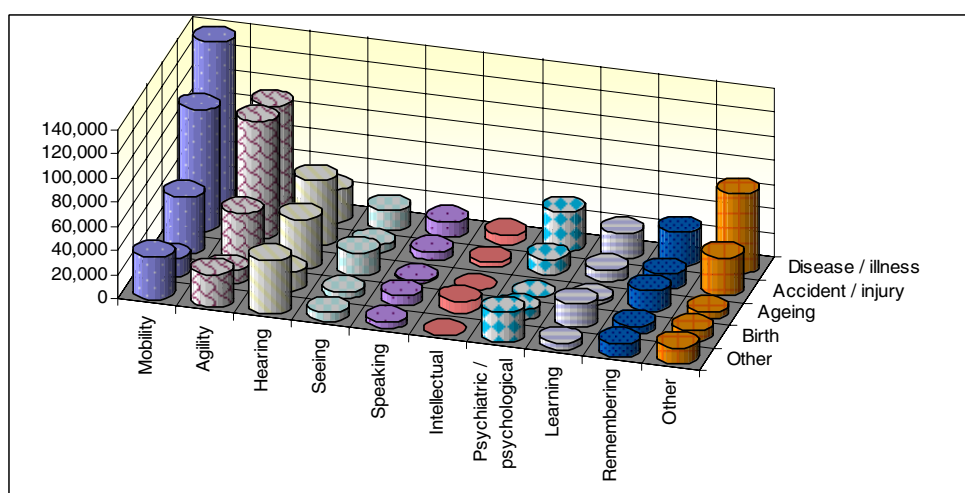


Source: Statistics NZ Disability Survey, 2001

Immobility caused by illness is the most common adult impairment

Loss of mobility and agility are the most common impairments. These most often result from illness, with accidents being the second most common cause. The majority of disabled people (57 percent of disabled adults in 2001) have more than one type of impairment, often with varied causes. The prevalence of multiple impairments increases with age. Figure 1.2 shows the types of impairments and their various causes.

Figure 1.2 Impairment types for disabled adults



Source: Statistics NZ Disability Survey, 2001

Disabled people have the same aspirations as others

Disabled people believe in a fair go for all, just like other New Zealanders

I should be paid for the work I do.

(Focus group participant, National Health Committee, 2003)⁴

Giving everyone a 'fair go' is a core value of New Zealand society. It reflects a long-standing ambition for a society that promotes the equal enjoyment of human rights. This was re-confirmed by wide public consultation in 2004, which found that New Zealanders consistently identified human rights with giving everyone a fair go, and unhesitatingly endorsed human rights as important.⁵

The New Zealand Disability Strategy is our framework for a non-disabling society

Disabled people and their families seek a society in which we can all feel we have that 'fair go', an inclusive and non-disabling society, which is good for all New Zealanders. The New Zealand Disability Strategy, launched in 2001, was agreed between disabled people, their families, providers and government, as a plan for creating this non-disabling society.

Disabled people want a say in policy that affects them

Nothing about us without us.

(International disability catch cry)

An underpinning value of the New Zealand Disability Strategy is that the voices, experiences and wisdom of disabled people and their families should play a much larger role in informing policy decisions. Proper consideration of disability perspectives and issues in the development of government policy will help ensure barriers to participation are not ignored or created, and that opportunities for positive change are recognised.

Disabled people want ordinary choices, rights and responsibilities

I want to be in my own home with a brown Labrador dog and a cat, and talk on the phone to my friends.

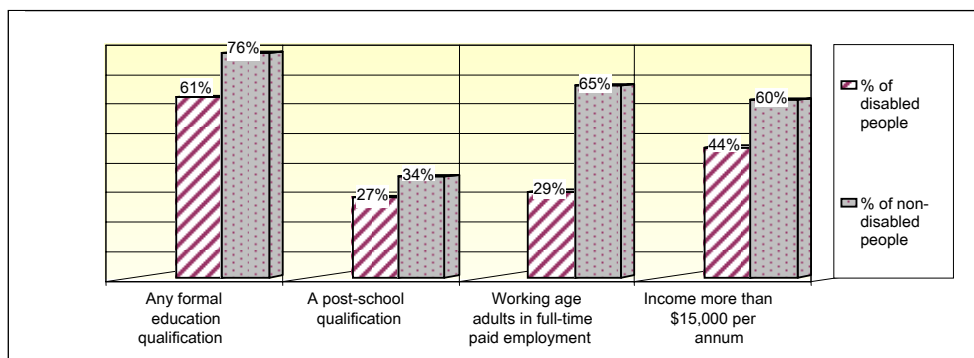
(Focus group participant, National Health Committee, 2003)⁶

The aspirations of disabled people are as ambitious or as simple, and certainly as diverse, as those of the general population. However, the barriers to achieving these aspirations are quite different to those facing non-disabled people.

Many disabled people experience a cycle of deprivation

We design our environments to accommodate the limitations of most people (for example, we put lifts in tall buildings). However, we often ignore the needs of people with less common limitations. These barriers are unfair, and make the lives of disabled people more difficult. This is borne out by statistics.

Figure 1.3 The status of disabled people compared to non-disabled people



Source: Statistics NZ Disability Survey, 2001

Figure 1.3 shows that, on a range of indicators, disabled people experience considerable disadvantage. They are over-represented in lower-paid occupations, and in 2001 almost half of working age disabled adults had incomes less than \$15,000 per year. It is not surprising that disabled adults are also less likely to own or partly own their home.

Research shows poorer general health status among disabled people, and poor access to support services and other arrangements that might allow them to move from a marginalised position in society.

Complaints to the Human Rights Commission about discrimination on the grounds of disability have increased in the last few years, to nearly one quarter of the total number of complaints. This may indicate increased awareness and advocacy rather than increased discrimination. The number of complaints of discrimination on the grounds of disability is second only to the number on grounds of race.

Government can make a real difference

Fortunately, most disability issues are not intractable problems, and government has responded to them.

Moving from a needs to a strengths focus

Government has provided for disabled people through services, legislation and regulation for over a century. Historically, activity was confined to the health and welfare sectors and focused on either fixing the impairment or, failing that, paying a benefit and providing housing.

The transfer of disability support services from 'institutional' to 'community' settings has uncovered opportunities for action in many more sectors and a more positive approach to disability – one that focuses on enhancing disabled peoples' participation within all areas of life. The resulting 'whole of government' approach to disability is now accepted internationally as achieving the best outcomes for all concerned.

However, it still remains a challenge for government to respond to current understandings of disability, while working within structures that are the legacy of historic approaches. A number of key areas need a particularly focused response. These areas present government with both a challenge and an opportunity to create a more inclusive society, where people with impairments can participate.

The next section of this briefing considers these areas.

There are many opportunities for action, but significant challenges too

part two

Current challenges

Part two : Current challenges

The New Zealand Disability Strategy needs to be progressed

The New Zealand Disability Strategy, launched in 2001, was agreed following extensive consultation. It has widespread support, and expectations of its success are high within the disability sector. It is a long-term plan, and therefore requires ongoing commitment, determination, optimism and bi-partisan support by government and the sector.

We are encouraged by the continuing commitment of government agencies to the New Zealand Disability Strategy's implementation. It demonstrates a raised consciousness of the whole of government approach to a whole of society strategy.

(The Disabled Persons Assembly, 2004)⁷

At first glance the Strategy may seem too high level and, at the same time, too 'motherhood and apple pie' to be effective. However, it profoundly challenges most aspects of the way society has historically dealt with disability issues.

The Strategy lays out clear ideas and agreements about what constitutes an inclusive society and what activities are needed across all of government and all of society to achieve it. It also introduces requirements for government agencies and the wider community to transform their understanding of disability, and suggests many practical steps.

There are some clear examples of recent achievements resulting from commitment to the Strategy's goals, including the progress of the New Zealand Sign Language Bill and the establishment of a cross-government review of long-term disability support services.

The Office monitors and reports on the Strategy's implementation. We do this in the following ways:

- monitoring and illuminating – identifying and documenting activity, issues, trends and outcomes for disabled people and their families

The New Zealand Disability Strategy requires ongoing commitment from government and the disability sector

The Office promotes and monitors the Strategy within and outside government

- ensuring compliance – reminding agencies of their obligations in relation to the Strategy, and reporting to Ministers, Parliament and to the public on progress
- promoting, informing and influencing – improving understanding of disability issues and the Strategy in the wider population through, for example, presentations, seminars, our website, www.odi.govt.nz and newsletters.

We support a Disability Advisory Council, established in May 2005, whose primary function is to provide advice to us on progressing the Strategy and on any emerging issues. The Council is made up of disabled people and their families who have been selected by consumer organisations nominated by the Office. It does not include representatives from professional bodies, providers or funders.

Section 8 of the New Zealand Public Health and Disability Act 2000, which sets out your duties and powers as Minister for Disability Issues, requires you to report each year on the Strategy's progress. In addition, Cabinet has committed to a review of the Strategy's progress after a period of five then 10 years (in 2006 and 2011 respectively).

Support services must meet increasing and diverse needs

Currently, New Zealand's systems for delivering disability support services reflect a range of historic and disjointed approaches to disability.

This results in complicated access to services, gaps and overlaps in provision and significant inequities. Moreover, the systems sometimes lack the flexibility necessary to meet diverse needs and can create disincentives to participate and be independent.

Each day I wake up I know I should be thrilled that I can share the breath with my four children and husband. At night I dream that this muddled brain will wake up refreshed, my body pain-free and energy restored.

I knew this life several years ago ... then I took a heavy fall and knocked myself out. From that day onward I am a different person.

I have had a long and difficult process trying to get help. All I ever asked for was some help to cope with changes and challenges I faced coming to terms with the new me. I'm still waiting and wondering how you work with the system and get well.

If I could get a message to the system, I would say, 'Please give me your time, concentrate your efforts, just for a bit and complete the paper work, then put in place the recommendations and supports. Then I'll not have to keep writing, ringing and reminding.'⁸

Given the increasing prevalence of impairment in the population, work to reduce disability must focus on improving support services. As a guiding principle, government needs to consider the choices and responsibilities that a non-disabled person expects to experience in their life, and it needs to provide disability support systems that allow disabled people the same opportunities.

We have been leading an interdepartmental review of long-term disability support services, which is advising on how they can be improved. Findings to date include the observation that the current arrangements for providing supports are not working as well as they should for disabled people and their families. Improvements to entitlements, funding structures and administrative arrangements for disability support are likely to help disabled people to better govern their own lives.

Work to reduce disability must make support services more flexible, accessible and equitable

Disabled people want to work

Contrary to the views of some, disabled people want to work. Consultation has repeatedly found that access to employment is high on their agenda.⁹ For this to be possible disabled people need the right education, equipment, environmental accommodations such as flexible hours, and positive employer attitudes. They also need effective income support in or out of work, to better manage the costs of disability that can be a real barrier to employment.

I was just a teenager when I started having mood swings and hearing voices that other people didn't understand. I lived in a small town, and the gossip spread like wildfire. After a while I didn't even want to go to the corner dairy because of the way people looked at me and I lost what little confidence I had left. I also ended up losing a lot of years out of my life.

What made a difference for me was being able to work. I moved out of the town where I grew up and got a part-time job. It wasn't really challenging but I couldn't seem to get the sort of job I wanted. I ended up going and getting some training and then I got the idea for the business I still run today. My parents helped me out with a loan to get started because the banks didn't want to know me.

I don't think its easy for anyone to get a business going. The failure rates are high. But if you've got a sound idea, what you really need is the opportunity.¹⁰

The current demand for labour, coupled with the number of disabled people wanting to work, provides an ideal opportunity for government to promote employment for disabled people. The Ministry of Social Development, the Department of Labour, and the Ministry of Health are all focused on improving vocational services to invalids and sickness beneficiaries and other disabled people. This focus needs to be maintained.

Community knowledge and attitudes need to be built

The consultation undertaken to develop the New Zealand Disability Strategy identified 'attitudes' as the major barrier to the full participation of disabled people in all parts of daily life. To implement the Strategy we need to improve public knowledge and behaviour towards disabled people.

The 'Like Minds, Like Mine' Campaign funded by the Ministry of Health aims to counter the stigma and discrimination experienced by people with mental illness. It has received many accolades nationally and internationally, and has led to measurable changes in community attitudes.¹¹ There is a lot that can be learned from this campaign and applied in the wider disability sector,¹² including successful use of a mass media campaign and fostering leadership of people with experience of mental illness.

We have begun to work together towards common goals with the 'Like Minds, Like Mine' Campaign, the Mental Health Commission and the Human Rights Commission. However, further work is required to address discrimination and to promote greater knowledge of disability issues.

Policy making needs to integrate a disability perspective

Making a world of difference is by no means all about expensive or complicated initiatives. It is about ensuring policy makers appreciate that past practice in the disability arena is not usually a good guide to future decisions. All sectors of government need to understand the inherent policy tensions in disability issues in order to get the balance right. In particular, the tensions between:

- safety versus the freedom of choice experienced in an ordinary life
- universal design or provision versus targeted individual support
- state versus individual and family responsibility to provide support
- national consistency or standards versus local and flexible provision
- community or provider autonomy versus individual autonomy.

All points on each spectrum are appropriate in different circumstances. However, historically the balance has often been skewed towards the end of the spectrum that minimises individual participation and independence.

Better knowledge and understanding can change attitudes

Policy must balance opposing tensions and avoid inadvertently creating barriers

We recognise that disabled people have the same aspirations as others

Policy decisions have tended to favour safety over freedom and targeted support rather than more general provision.

Sometimes unrelated policy drivers have led to decisions that have not considered the effect on disabled people, but have had fundamental impacts on their lives. For example, the introduction of national standards, along with an increased emphasis on family responsibility and provider autonomy, can inadvertently decrease individual autonomy and choice for the disabled person and present barriers to participation.

The New Zealand Disability Strategy provides an opportunity to address these issues, as relevant policy areas come under consideration. Examples include reviews of regulations, legislation or policies, such as the Building Act 2004, the Residential Tenancies Act 1986 and the Fire Service Act 1975.

Although these policy projects do not have disability at the top of their agenda, the Minister for Disability Issues and the Office for Disability Issues can advocate for improvements from a disability perspective. An example would be ensuring that workplace safety regulations do not make employment of disabled people a liability.

It is possible to move too far in the opposite direction, to forget, for example, that safety considerations and personal freedom are both important. Targeted support, as opposed to universal design or provision, is sometimes more consistent with economic and human rights concerns. For example, special education curricula are necessary for some young people.

Recognition of human rights is important

The core problem in the field of disability is the relative invisibility of persons with disabilities, both in society and under the existing international human rights instruments.

(Report to the UN, 2002)¹³

A wider public understanding of rights in relation to disability issues will help to ensure both the motivation and capacity within society to honour those rights. This includes the capacity of those who make and those who administer the law.

Promoting understanding will be most effective alongside an improved legislative rights framework that better acknowledges disability issues and provides for proper remedies. New Zealand is taking steps towards achieving this in both the national and international arenas.

The United Nations is currently developing a binding international convention to protect the rights of disabled people. It aims to address the serious neglect of disabled people's rights by making disability issues more visible, helping to shape human rights norms to meet the particular circumstances of disabled people, and by making states' obligations clearer.

Active engagement in this process provides an impetus to scrutinise New Zealand's disability policy and practices systematically, within the context of international practice. New Zealand is also taking a lead role in the negotiation process, and has won strong international praise for its disability policy over the last few years.

Interest has been shown in the New Zealand Sign Language Bill, the establishment of an Office for Disability Issues and the New Zealand Disability Strategy as models for positive change. Together these initiatives highlight New Zealand's disability initiatives.

Recognition of New Zealand's leadership in addressing disability issues is reflected in our appointment as Chair of the United Nations committee for developing the convention. Our continued leadership should help the ratification of an effective convention. This will boost the enjoyment of rights by the 600 million disabled people around the globe and strengthen New Zealand's own human rights legislative framework.

Legal expertise needs to be developed

Under national human rights law, not all distinctions are considered discriminatory. Discriminatory distinctions are those that impose burdens, obligations or disadvantages on individuals who are members of groups protected by the prohibited grounds of discrimination (which include disability).

Where people require different treatment to achieve equality, the failure to provide it can impose burdens, obligations and disadvantages, and is

Our recent disability initiatives have won international praise

New Zealand chairs the UN committee developing an international convention on the rights of disabled people

There is ongoing debate about what is considered “reasonable”

therefore considered to be discriminatory. This central principle, that treating people equally does not necessarily mean treating them the same, is particularly relevant to disabled people.

Most non-discrimination provisions are about what not to do, rather than requiring positive action. However, non-discrimination in relation to disability sometimes requires some positive provision. This is acknowledged in the Human Rights Act 1993, through a stipulation that any affirmative or proactive measures needed to ensure equal participation for disabled people, or to eliminate systemic discrimination, must be reasonable.¹⁴

However, interpretation of what is considered ‘reasonable’ is not always agreed, and the law in this area is evolving both here and overseas. Achieving full human rights for disabled people will require a clearer understanding of what provisions or accommodations it is reasonable to expect.

This work is occurring through the development of the UN convention, as well as evolving jurisprudence. The challenge for government is to use these developments to provide a framework for changing expectations across society.

We need to strengthen engagement with disabled people

Engagement with disabled people by government presents some challenges. There can be tensions between groups associated with different interests, and competition for resources.

Resources, representation, and identification are tensions within the disability sector

There can also be issues with perceived legitimacy of representation. Some groups, though usually identified by others as part of the disability sector, may not primarily associate themselves with it. For example, deaf people may regard themselves as part of a distinct cultural minority group, with its own language and customs, rather than as a group that experiences disability. Many mental health organisations and service users identify as part of the health sector.

There are also older people’s organisations with a major interest in many disability issues (such as support), because a high proportion of members

experience some disability. However, they do not necessarily identify with the disability sector.

Negative connotations around historic concepts of disability have led many, if not most, groups to reject the 'disability' label at some point. They have argued that 'there is nothing wrong with us, we are just different, with different support needs'.

It will be important for government to continue to manage these tensions sensitively.

Advice and information need support

A number of 'not-for-profit' disability organisations provide information, advice, awareness promotion, peer support and advocacy. These services are critical to the lives of disabled people and their families, and play a central role in effective implementation of the New Zealand Disability Strategy. However, many organisations lack the skills, knowledge and capacity to play a full and effective role in implementing the Strategy.

The Ministry of Social Development and the Office for the Community and Voluntary Sector are working together to address capacity issues across community organisations. The Office for Disability Issues is assisting in this work, to help with capacity building within the disability sector. It will, however, take time to address all of the issues.

There is also a need for improved direct government support and appropriate compensation for organisations and individuals that provide their knowledge and advice to government. Treasury guidelines¹⁵ for contracting with non-government organisations provide some useful guidance to agencies. They acknowledge that a purely competitive or price reduction approach to contracting can set organisations up to fail.

Developing the support workforce requires cross-agency commitment

An undervalued and casualised support workforce threatens the successful implementation of the New Zealand Disability Strategy. Turning this situation around requires more than simply increasing funding for 'more of

We are addressing capacity issues within the sector – but it will take time

The support workforce is undervalued and casualised

the same'. The workforce needs to be skilled and empowered to do a different and better job that is more consistent with the Strategy.

Community-based support involves a wide range of activities delivered in a number of settings. A range of sectors have a stake in the development of the support workforce, and an intersectoral approach to workforce development is needed.

Separate sectors do have projects underway to address their particular interests, such as the Quality and Safety Project of the Ministry of Health. However, workforce issues would be better addressed as a larger, cross-government exercise, as it would then be possible to consider training and provide more attractive career pathways across a wider field. The Health Workforce Advisory Committee is currently considering how best to progress this work.

Developing the workforce will require significant resources and commitment from stakeholders. This includes disabled people and family groups, unions, professional associations, providers (non-government and government), Standards New Zealand, funders (the Ministry of Health, DHBs, the Ministry of Education, ACC and the Ministry of Social Development), NZQA, Industry Training Organisations, and the Tertiary Education Commission. It will also require close engagement by the Office.

Personal advocacy needs to be more effective and accessible

A range of advocacy services that vary in type, philosophy and values exists in New Zealand. However, there are some significant gaps in advocacy services for some impairment types and for some areas of life.

The Health and Disability Commissioner provides an advocacy role and complaints mechanism for issues related to disability support or health services. The Human Rights Commission provides mediation for breaches of human rights.

Both these services are bound by a legislative framework and a complaints system that tends to provide longer-term dispute resolution processes, rather than immediate support with an issue. There are also a number of

general complaints and information services attached to, for example, health services, housing (the Tenancy Tribunal) and income support.

General advocacy services, such as community law centres, can be used by anyone. However, these services do not have particular expertise in or understanding of disability issues, and they are usually provided by people who do not have a good understanding of disability. This results in general advocacy services being both inaccessible and ineffective for disabled people.

Work is needed to describe current advocacy services in New Zealand and to develop options for improving them, including capacity-building initiatives for people currently working in advocacy roles.

Disabled people have an interest in bio-ethics

[I]t has become increasingly clear that advances in genetics are producing serious threats, both pragmatic and attitudinal, to the very existence, uniqueness and diversity of disabled people. ... [T]hese threats are hidden by a virtuous mask of the objectives of cure, enhancement and alleviation of suffering.¹⁶

Bio-ethical issues are a growing concern for disabled people. There is by no means any consensus on how to progress these issues. However, as a starting point, there is consensus that disabled people must have a voice in all discussions that explore our society's collective values and the concepts that underpin these issues.

New Zealand needs to engage in international debate

Rising numbers of sickness and invalids beneficiaries is an international trend, partly related to the ageing population. New Zealand will benefit from considering the effectiveness of other countries' responses to this common issue. Moreover, the general approach to disability adopted by the New Zealand Disability Strategy is reflected in many other countries' disability policies.¹⁷

We need to improve general advocacy services for disabled people

Bio-ethical issues are a concern for disabled people

Sharing our experiences and exchanging ideas will contribute to the growing body of international knowledge about how to improve opportunities and outcomes for disabled people.

part three

Opportunities for action

Part three : Opportunities for action

We have made good progress in understanding and addressing disability issues through the framework outlined in the New Zealand Disability Strategy, and this work continues. Current action is orientated around five themes:

- Promoting citizenship, by fostering society's ability to include disabled people. This requires initiatives to improve public awareness of disability, to raise the visibility and promote the leadership of disabled people, and to ensure disabled people's rights are upheld (more about this on page 30).
- Building government capacity, by ensuring agencies have the necessary knowledge, skills and systems to address disability issues. This requires improved information collection and understanding of what will help to eliminate barriers to participation (more about this on page 32).
- Improving disability support services, by ensuring the way they are provided enables disabled people to have ordinary choices and responsibilities (more about this on page 33).
- Promoting participation by disabled people in all areas of life, by identifying and maximising opportunities in all sectors of the community. This requires government agencies to take disability issues into account when making decisions in a wide range of sectors; for example, addressing longstanding barriers in transport, sports and recreation, relationship services or companies regulations (more about this on page 36).
- Addressing diversity of need, by acknowledging that, in addition to common issues, there is huge diversity among disabled people. It is also important to address the specific needs of disabled people's families (more about this on page 42).

Citizenship, capacity, services, participation, and diversity are the key themes of the New Zealand Disability Strategy

The NZSL Bill seeks official recognition of NZSL and deaf people's right to use their language

Promoting citizenship

Passing the New Zealand Sign Language Bill

For many deaf people, New Zealand Sign Language (NZSL) is an essential and natural language.¹⁸ The historic lack of acknowledgement of this has resulted in injustices. For example, deaf people report being denied interpreters in court proceedings, facing disorderly conduct charges where their use of NZSL was misinterpreted as aggressive behaviour, and receiving medical misdiagnoses.

In the past, sign languages were actively prohibited due to misconceptions. Research has since found that sign languages are real languages, and that lip reading involves a lot of guesswork and does not provide effective communication.

Deaf people often have low English literacy levels and low educational achievement, largely resulting from a lack of NZSL resources that could provide access to the education curriculum.

We have been responsible for developing a New Zealand Sign Language Bill. The first reading of the Bill took place in Parliament on 22 June 2004, and was supported by all political parties. The Bill at its first reading provided for:

- the official recognition of deaf people's language, NZSL, as a unique New Zealand language with equal status to that of spoken languages
- the right for users of NZSL to use their language in legal proceedings
- principles to guide government departments in achieving the objectives of the Bill when providing information and other services to the deaf community
- regular reporting by the Minister for Disability Issues on the progress being made in implementing these principles for government departments.

The Justice and Electoral Select Committee reported back on the NZSL Bill in July 2005. Once passed, the Bill will be a major step in addressing the needs of many deaf New Zealanders, and will send a strong message of inclusiveness to both deaf people and the wider disabled community.

The Bill will send a strong message of fairness and inclusiveness

We need to progress this work, by:

- developing the capacity of the NZSL interpreter workforce, including how we can ensure consistent standards among interpreters
- reviewing funding mechanisms for NZSL interpreters
- improving NZSL access in education, health, employment, the justice sector and public broadcasting, using the New Zealand Disability Strategy work plans and reporting processes
- developing mechanisms to promote NZSL.

Fostering leadership

An important component of any campaign for an inclusive society is increased visibility of successful disabled people. This provides positive role models for the disabled and non-disabled population and helps to raise community expectations. Government also has a commitment to ensuring balanced representation on Crown bodies to reflect wider New Zealand society, and to strengthen connections with stakeholders.

To assist appropriate representation of disabled people at governance levels, Budget 2005 allocated funds to establish a nominations service within the Office, to promote the appointment of disabled people to Crown boards and committees. We need to establish and promote this service. We also need to create capacity-building initiatives to ensure that sufficient numbers of disabled people skilled in governance are available for such appointments.

Developing personal advocacy and communications services

The National Health Committee's seminal report on the lives of adults with an intellectual disability¹⁹ noted a gap in advocacy services for a group that often finds communication difficult. We need to continue exploring options for personal advocacy and communication services for people with an intellectual disability, in the context of wider work on advocacy for disabled people.

A new nominations service will promote the appointment of disabled people to Crown boards and committees

We are exploring options for advocacy services for adults with intellectual disabilities

Our contribution towards a UN convention on the rights of disabled people sends a strong and positive message

Supporting United Nations negotiations on a disability convention

In 2001, the UN established an ad hoc committee to consider an international binding convention to promote and protect the rights of disabled people. In May 2003, Cabinet agreed that New Zealand should take an active role in these negotiations and that we would co-ordinate the engagement in close association with the Ministry of Foreign Affairs and Trade, and in partnership with representatives of disabled people.²⁰

We have been active in proposing context and texts aimed at strengthening the convention. We have also promoted partnerships between government and non-government organisations in national and international negotiations related to disability issues, and facilitated agreement between countries on a convention text.

As noted, New Zealand has played a co-ordinating role at ad hoc committee meetings, and has now been appointed Chair of the committee. This is an honour and achievement for New Zealand, and a considerable commitment for future delegations. It is anticipated that the convention may be ratified by the end of 2008, although there are no guarantees on this timeframe.

New Zealand's support for the UN convention is sending a strong message to disabled people in this country, that government is committed to fostering action towards disability issues. This has been recognised by, among others, the Disabled Persons Assembly.²¹ We need to continue New Zealand's commitment to this important work.

Building government capacity

Developing and promoting a disability perspective tool

We have developed a disability perspective tool for government agencies, to help them consider and address the impacts of any legislation, policy, programme or decision on disabled people. The tool includes supporting instruments and has been provided to agencies in draft form.

We need to progress this work by publishing the disability perspective tool online (we are aiming for publication by the end of 2005), regularly updating

Our disability perspective tool will be published online by the end of 2005

the resource, and promoting its use through, for example, giving seminars and providing awareness raising material.

Improving information research and statistics

Several government agencies that deliver disability support services have developed disability-related research programmes. Of particular note is a project to examine the cost of disability in New Zealand, co-funded by the Health Research Council and the Ministry of Social Development. We are a member of the project steering committee.

Many agencies collect data related to disability for administrative purposes. However, major variances in definitions, eligibility criteria for services and general approaches to disability limit the capacity of government to use this data to develop evidence-based advice on cross-agency issues.

Along with Statistics New Zealand, we are undertaking a stocktake of these data sources. The stocktake will include the systematic identification, documentation, and evaluation of the statistical potential of administrative and other data sources.

This work will help ensure the development of sound, evidence-based disability-related policy advice across government.

Improving disability support services

Disability supports include a wide range of service types

The current approach to disability has led to a concept of 'disability supports' as a particular set of services with common goals of participation and independence. They include:

- home-based support, including personal care and home care
- long-term residential facilities
- transport support, such as vehicle modifications or taxi services
- housing support, such as housing modifications and alarm systems
- equipment support, such as wheelchairs, hearing aids and Braille machines

Our stocktake of disability data will provide a good basis for policy development

The funding and delivery of disability supports is varied, and often conflicting, across agencies

- communication support, such as NZSL interpreters
- carer support, such as respite care
- (re)habilitation training for social, educational and vocational settings
- financial support, such as the Disability Allowance, aimed at meeting the specific costs of disability (note that this does not include general income support).

Funding for support services comes from 10 different Votes and the ACC account, as well as charity, gambling proceeds and volunteer services. In 2003/2004, government expenditure on these services amounted to approximately \$2,689m. The bulk of provision is through:

- Ministry of Health (approximately \$1,660m in the 2003/2004 year)
- Ministry of Social Development (approximately \$393m in the 2003/2004 year)
- Ministry of Education (approximately \$362m in the 2003/2004 year)
- ACC (approximately \$274m in the 2003/2004 year).

Other agencies that fund some support services include the Ministry of Transport, Housing New Zealand Corporation, Child, Youth and Family, the Ministry of Economic Development, the State Services Commission and the Department of Internal Affairs – Lottery Grants Board.

Each of these funding agencies has its own goals, priorities, funding mechanisms and logic for providing support services. Some agencies provide services on a demand-driven basis according to an entitlement (ACC) and/or an income test (Social Development). Other services are provided out of a capped budget rationed on the basis of clinical, educational and/or vocational need.

There are serious problems with current systems for providing supports

Not surprisingly, historical differences in the systems for providing support services result in a lack of consistent or co-ordinated criteria for support across agencies and regions, and a wide range of eligibility mechanisms. This has profound and far-reaching implications for disabled people and their families, including difficulties accessing services, gaps in provision, a general lack of coherence across services, and inequities.

For disabled people, the current system leads to problems with access and provision

One of the most striking inequities is the disparity between aspects of ACC and Ministry of Health provision. This directly impacts on what type and how much assistance a disabled person and their family receive throughout their lives, solely based on whether an impairment is the result of illness, age or a congenital condition, or as a result of injury.

Consultation around the New Zealand Disability Strategy in 2001 raised many issues with the way supports are provided. In addition to the incoherence of the systems, the lack of flexibility and inability to accommodate diverse needs for all areas of life was criticised.

There is a consensus among disabled people that, despite incremental advances in some areas, the current framework for providing disability support services is still generally unable to support the whole-of-life outcomes to which disabled people aspire.

This is an ongoing area of tension for disabled people and, as far as they are concerned, the Strategy is meaningless if it does not correlate with high quality support service provision.

We have undertaken lengthy scoping work for policy development to address these issues. This work has exposed issues in gaining traction across agencies, in part due to the diverse mix of policy drivers and general lack of co-ordination between policy makers, purchasers and providers around disability support as a whole. These problems are not new – there has been a long history of attempts to improve co-ordination.²²

The establishment of a review of long-term disability support services

In July 2004, the Government directed us to lead an interdepartmental review of disability support services. The purpose of the review is to advise government on how to improve systems for providing disability support services, so that they:

- are consistent with the New Zealand Disability Strategy
- are simpler and easier to access, more co-ordinated, fairly distributed, and more flexible
- improve outcomes for disabled people and their families.

Services lack flexibility, equity and coherence

The problems are not new, but they are critical

This advice will propose structures and processes that allow people with similar impairments and associated needs to have improved and more equitable access to long-term support services, taking into account individual circumstances.

The scope of the review does not extend to considering changes:

- to the underlying principles of the ACC Scheme
- to the funding arrangements for health treatment or clinical services
- to the way shorter-term supports are provided (those needed for six months or less)
- to levels of income support
- to general taxation and levies.

Progress on the review

The Office has been talking with both the government and disability sectors to build on information previously gathered concerning current support services. This includes information concerning issues with existing supports, and the disability sector's vision for the future.

This information is assisting us to consider how to best answer the questions being addressed by the review, and to advise on options for improving disability supports so that they are sensible, fair, and effective, and consistent with the vision of the New Zealand Disability Strategy.

Promoting participation in all areas of life

We encourage all government agencies to consider and address barriers to participation for disabled people, in their areas of influence. We do this through monitoring the New Zealand Disability Strategy implementation plans that every agency develops.

We also give second-opinion advice on policy development across agencies. This involves a substantial commitment of our time in participating in working groups, and also involves consultation over Cabinet papers.

Our work focuses on promoting participation by disabled people in all areas of life, by identifying and maximising opportunities in all sectors of the community (as illustrated in figure 3.1).

We promote participation by disabled people in all areas of life

Figure 3.1 Areas of Life



Figure adapted from a model developed by the National Health Committee, 2003

Supporting quality housing in the community

While most disabled people do not live in institutional settings, a legacy of segregation persists in some public policies and regulations around housing. This can limit the sorts of choices disabled people have about where and how they live. For example, sometimes access to supports is contractually connected to accommodation provision. This can result in disabled children being required to live in residential facilities designed for older people rather than receiving support at home, with their family.

There are also problems in the interpretation of building regulations. These result in houses in which disabled people live having to meet more stringent fire safety requirements than similar houses accommodating non-disabled people.

We advise on how housing policy can support quality living in the community

We need to continue to ensure that housing policy supports quality living in the community for disabled people, through giving advice on:

- access to support services and accommodation services
- the Building Act 2004 and review of the Building Code
- the implementation of the New Zealand Housing Strategy
- the review of the Residential Tenancies Act 1986
- developments in Housing New Zealand Corporation services, and more specialised home support and home modification services that allow disabled people to live well in the community.

Promoting quality health care

International literature reviews conducted by the National Health Committee and the Mental Health Commission have found that disabled people have higher mortality and morbidity than non-disabled people. The same reviews show a lack of health promotion and illness prevention information available in accessible formats. There is also evidence of poor prescribing practice, and unnecessarily high levels of medication among adults with intellectual disability.

The Primary Health Care Strategy provides an opportunity to address these issues, through innovations in health care provision. However, we need to work with the Ministry of Health to build the skills and awareness of health care providers to capitalise on this opportunity.

Supporting access to transport

Many disabled people rely on public transport. In April 2004, the Human Rights Commission initiated a national inquiry into the accessibility of public land transport, as a result of high numbers of complaints by disabled people. The consultation report shows that at each point of a journey, from finding information about timetables and accessible services, to arriving at their destination, many disabled people face considerable problems.

These include difficulties boarding and getting off trains, buses or aeroplanes, and inadequate seating. Also, because most disabled people

are on low incomes, the cost of more accessible transport such as taxis is a barrier.

Local authorities operate a Total Mobility Scheme, which is jointly funded by the Ministry of Transport and local authorities. The scheme provides a subsidised transport service to people with serious mobility constraints. It provides disabled people with taxi vouchers, which usually cover 50 percent of the taxi fare, as well as providing funding assistance to taxi operators for the purchase and installation of wheelchair hoists in taxi vans.

However, the scheme is not currently available in many regions, and is often not promoted. Where it is offered, a growing demand means that the regional budgets are often capped. Furthermore, many disabled people cannot afford the subsidised taxi fares.

The Transport Strategy 2002 includes a commitment to improve the consistency and quality of the Total Mobility Scheme across New Zealand, and the development of a framework to measure improvements in mobility. We need to continue with our participation in this work.

Providing employment opportunities

Access to jobs is very high on the agenda for disabled people. It is seen as the key to breaking the vicious cycle of deprivation, and creating the inclusive society they aspire to. A great deal of activity has occurred in this area since the launch of the New Zealand Disability Strategy.

Work by the Department of Labour is aiming to improve the employment environment through promoting the value of a diverse workforce. It includes support for policies enabling work-life balance, including flexible working hours, to improve employment opportunities for disabled people and their families.

The Pathways to Inclusion Strategy was developed following extensive consultation with the disability sector in 2001. It is a plan for moving the emphasis in vocational services away from sheltered work to supporting disabled people into real jobs and meaningful participation in their community. The implementation of this Strategy includes repealing the Disabled Persons Employment Promotion Act 1960, and tightening

provisions that allow disabled people to be paid less than the minimum wage.

The current structures for the Sickness and Invalids Benefits can provide disincentives for finding work. To help address this, the Ministry of Social Development is developing a new service delivery model, implementation of which began in mid-2005.

This model extends employment assistance to sickness and invalid beneficiaries and enhances case management. It is based on outcomes that disabled people and their families can achieve, whether it be full-time, part-time or intermittent employment and/or improved social outcomes.

It includes initiatives for facilitating continuation of or re-engagement with employment, including retraining, following the onset of disability due to accident or illness. Importantly, the model does not presume that disabled people, or those experiencing ill health, cannot work.

The Ministry of Social Development is also developing transition services, which focus on supporting disabled people in the move from school to work and/or community participation. A separate pilot is working on transition to retirement for disabled people.

The State Services Commission runs the Mainstream Supported Employment Programme, which assists disabled people to gain work in the state sector.

We need to continue to monitor and feed into all of these work programmes, which are making major inroads into improving employment opportunities for disabled people.

Providing the best education

The Disabled Persons Assembly's Annual Report 2003 outlined concerns that education funding generally does not follow a person through their education, with the result that parents of and disabled people themselves have to fight for disability support services at each level of education. Concerns have also been expressed about the special education funding framework not being flexible enough, and not always being consistently applied around New Zealand.

The Ministry of Education's Group Special Education currently provides a complex range of funding to schools and individuals. Historically, it has adopted an approach of making step by step improvements to these services, rather than conducting an overall review.

The Ministry of Education intends to put in place an action plan to improve aspects of its current services, and an outcomes framework that can be monitored to inform future developments. This should assist in building a body of knowledge about what practices are effective in special education. We need to continue working closely with the Ministry, to ensure progress in this work is consistent with the New Zealand Disability Strategy.

Ensuring disabled people can pay for what they need

Many disabled people who are not in paid work, or who are in low paid work, rely on income assistance (usually from ACC, Work and Income benefits or superannuation), while others are supported by partners. Often additional disability-related expenses consume what income they have and erode their general standard of living. Adequacy of income support provision to meet the extra costs of disability is a major issue for disabled people.

The Ministry of Social Development is currently undertaking work to modernise the benefit system including addressing the costs of disability. We need to continue to keep a close watch on this work and participate in the policy development, to ensure opportunities are maximised and that barriers are not inadvertently created.

Supporting citizenship

Inadequate access to public spaces and environments can limit the ability of disabled people to enjoy public places as other New Zealanders do. The Building Act 2004 requires that newly-built public spaces meet access standards. However, there are issues with compliance and knowledge among local authorities who administer the Act and related Building Code. We envisage improvements in this area following a review of the Code.

We need to continue to maintain a watch on legislative amendments in this and a number of other areas, such as criminal justice, family and property rights law, for example, to ensure disabled people's interests are not inadvertently affected.

We support the Ministry of Education's work to improve special education services

We monitor legislation to ensure disabled people are not adversely affected

Addressing diversity of need

Meeting the needs of disabled children and youth

In 2003, the United Nations Committee on the Rights of the Child recommended that New Zealand better integrate disabled children into mainstream education and other aspects of society. In recent years, the Human Rights Commission has received a number of complaints from parents about access to the services and support needed for disabled children.

The Department of Child, Youth and Family Services provides care and family support services for disabled children and young people, where there are substantiated care and protection concerns. These services may include respite care, therapeutic and behavioural support, assistance with material needs, and school and recreational activities.

They can also include 'out-of-family' placement where a family can no longer provide full-time care in their own home. In these circumstances the lead agency is a Needs Assessment and Service Co-ordination Agency, with the Department of Child, Youth and Family Services arranging for review through a Family Group Conference.

Some people are concerned that families who wish to access support first need to reach a crisis point. A Budget 2005 initiative aims to support families before care and protection issues arise.

The Youth Development Strategy Aotearoa 2002 includes the objective of "enabling disabled children and youth to lead full and active lives". It identifies key issues for young disabled people, including providing opportunities for connections with peers, in particular with young non-disabled people, and opportunities for meaningful work and ongoing education.

We need to closely engage with these areas of work.

Meeting the needs of disabled women

In consultation for the development of the New Zealand Disability Strategy, disabled women reported that they received less home help assistance than

Support is available for disabled children and young people with care and protection needs

A Budget 2005 initiative aims to provide support before care and protection needs arise

men. This is because of an assumption they will be able to find ways of managing a role that has traditionally belonged to women. Similarly, they reported a lack of assistance with their parenting responsibilities, such as affordable childcare.

After having my baby and returning to the ward, people reacted to me really differently. Some people were very supportive. Others assumed that I was just a visitor from another ward or were amazed that I had actually been able to have my own baby. Some mothers I talked to even overheard comments like, 'I think it's disgusting, letting them have babies'.

Once I got home with my baby people would gaze into the pram and show surprise that my baby was 'normal'. I was inundated with the standard 'Oh, however do you manage?'. I got used to it and replied 'Just like any mother ... except I wheel instead of walk between chores'.²³

The United Nations committee for the Convention on the Elimination of all Forms of Discrimination against Women (CEDAW), in its response to New Zealand's 2002 progress report, included comments on issues for disabled women. It noted:

- a concern that the management of the sexual behaviour and reproductive health of women with intellectual impairment has been over-medicalised and over-managed, thereby compromising the rights of the women concerned
- that action should be taken to make sure disabled women do not suffer discrimination in the areas of employment and access to health care and loans
- that New Zealand should pay attention to ensuring married disabled women are able to be economically independent.

The Action Plan for New Zealand Women, launched in March 2004, includes a focus on disabled women. It states that the Ministry of Women's Affairs will work with us to help promote the inclusion of issues for disabled

We are helping to tackle the issues for disabled Māori

women in the New Zealand Disability Strategy implementation plans. We are engaging with the Ministry to make progress in this area.

Meeting the needs of disabled Māori

Disability support services have tended to reflect a lack of awareness and understanding of Māori culture and preferences, and difficulties in communicating with Māori clients. Māori often report discomfort in using services, or avoid using them altogether.

Historically, there has been a lack of attention to the causes of disability for Māori.

Poverty, poor housing and unemployment adversely affect health and wellbeing. Lack of educational achievement and disease/illness are reported as the most common causes of disability for Māori. Research has shown that Māori are also significantly over-represented in psychiatric disability figures ... The growing inequality in survival chances between Māori and non-Māori, and the differing chronic disease mortality rate in middle and old age must be considered, as these mortality trends coincide with the major social and economic differences between Māori and non-Māori.²⁴

These compounding and often overlooked causes of disability for Māori have resulted in a relative disadvantage compared with other disabled people. This is exacerbated by lack of culturally appropriate disability support services, coupled with a low uptake in service use.

We need to do further work across government to address these issues, including promotion of appropriate disability support services for Māori.

Meeting the needs of disabled Pacific peoples

Mainstream support services for disabled people tend not to be appropriate for Pacific peoples. There is a lack of Pacific providers, access to relevant information and transport to services.

Pacific peoples, like Māori, experience a relative disadvantage compared with other disabled people.

We are also addressing the issues for disabled Pacific peoples

This is particularly in the areas of socioeconomic status, service use, access to amenities (such as private transport and non-rental homes) and knowledge of the resources available to them... Pacific peoples are also more likely to have relatively severe levels of disability, to need or receive more disability-related assistance, and to have more severe disability at younger ages.²⁵

We need to improve information and communication, tackle discrimination and improve socioeconomic opportunities for Pacific people who are disabled.

Meeting the needs of disabled people's families

In New Zealand, as in other countries, there has been an implicit social contract under which caring is viewed as a natural part of family life, so that people are obliged to care for family members as a familial duty rather than for payment.

At the same time, there has been general acknowledgement that families caring for disabled people have responsibilities over and above those faced by other families, resulting in greater costs to the family.

While a range of provision is available to assist family caregivers of disabled people, there is growing awareness that more support is needed. Problems for family caregivers include a lack of information about available government services, exclusion of low-cost items from funding support, and general difficulties in accessing services.

Hardship for middle-income families subject to income testing for the Disability Allowance, and the lack of co-ordination between services, are key issues.

**Families caring
for disabled
people need
greater support**

One April morning, after eight months of assessment, observations and countless appointments we were told that our physically perfect, attractive four-year-old daughter was 'handicapped'. She was diagnosed as having autism and intellectual disability. The grief was almost all-consuming and our lives changed forever.

Our daughter's inability to understand people and language caused her constant stress. She coped by organising her life into structured routines that only she knew. She is now nineteen and a valued member of our family. With a lot of energy from us and professional behaviour support, our daughter now has an acceptable communication method – we all write everything.

We still feel tremendous grief, but now it is for our daughter, not ourselves. Just coping is difficult for our family and for her. This has been compounded by the difficulties of the 'system' and an unaccepting community. With each milestone it feels as if we are the first ones to have got there.

After years of trying ... we are faced with the task of supporting our daughter into adulthood. All we hope for is that our daughter be an accepted, valued member of our community who has the opportunity to contribute and participate.²⁶

Issues include financial hardship, lack of information, service co-ordination and lack of support for young carers

Sometimes children and young people are providing care for disabled family members. Other countries provide formal recognition of the carer's needs in these circumstances. In the United Kingdom, for example, young carers receive their own needs assessment when services for their family are being organised. At present in New Zealand, there is no support specifically for young carers.

A number of interest groups for family caregivers and other informal caregivers have emerged in recent years. These are likely to play an increasingly important role in advocating changes to policy and provision relating to family caregiving.

Current provisions generally do not allow family members to be formally employed as caregivers. ACC provisions do allow disabled people to

engage immediate family members, but other government agencies' provisions do not.

This prohibition on family caregivers receiving government-funded wages or entitlements was challenged in 2001 by the Human Rights Review Tribunal, in *IHC v Hill*.²⁷ The Tribunal ordered that IHC had to consider an application from the Hills to be the contracted caregivers for their adult son, on the same basis as applications from non-family members.

In response to these events the Government asked us to lead a review of payments to, and support of, family caregivers of disabled people.

Initial consultation and scoping work found that the Tribunal's decision raised difficult and complex ethical and practical issues:

- independence – could disabled people become locked into dependence on their families, and would family members feel pressured to take on a caregiver role?
- choice – would disabled people feel obliged to accept a family member as their contracted caregiver, and would service provider organisations promote this option solely because it appears less expensive than others?
- quality – are family members always the best caregivers, and how could care provided by families be formally monitored to make sure that it meets basic standards?

In March 2004, Government approved statements of objectives for family caregiving of disabled people, and of responsibilities in meeting related costs. These statements were publicly released at the Caring for the Carers Summit in March 2005.²⁸

We need to progress the review through two lines of work. First, analysing the current policy which makes family members ineligible for paid employment as caregivers. Second, developing a range of options for assisting family caregivers. We would then use these options as a basis for consultation with the disability sector.

**We are leading
a review of
payments to
and support for
family
caregivers**

Effective services, respite care, and advocacy are at least as important as payment

This second line of work would go beyond the issue of whether or not family members should be employed as caregivers. This recognises that, overall, payment to caregivers is seen by many as less important than other measures, such as assessment of family caregivers' needs, advocacy and information brokerage services, increased opportunities for family caregivers to enter employment, improved respite care, and help with specific costs.

part four

How the Office for Disability Issues works

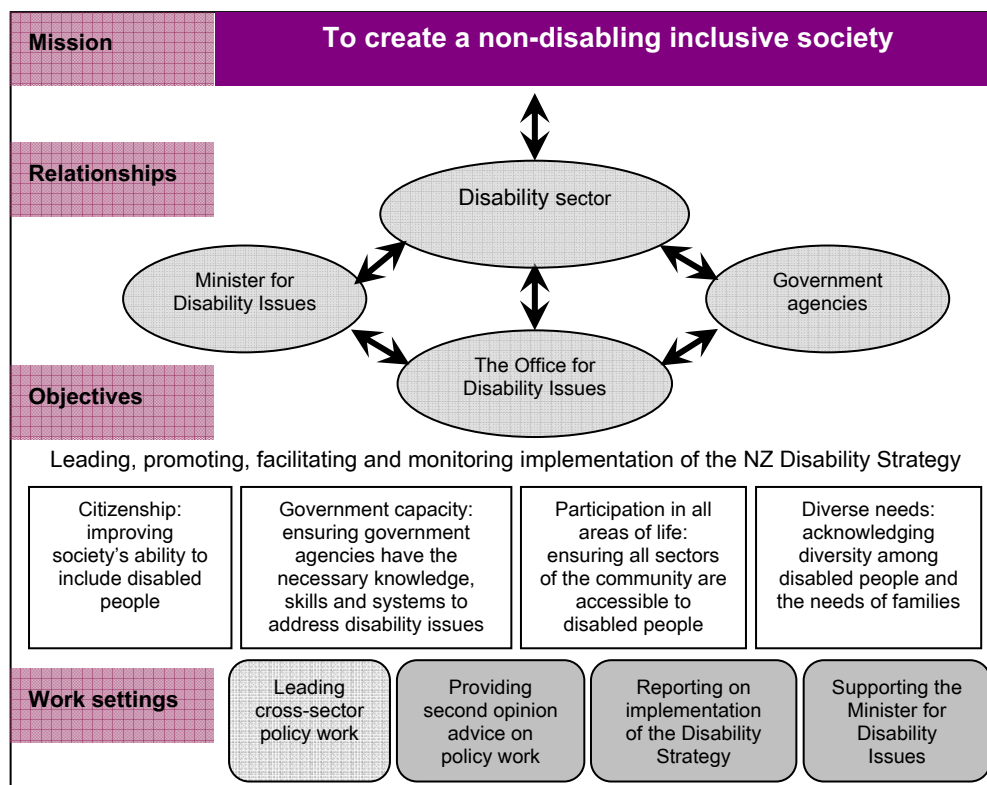
Part four : How the Office for Disability Issues works

Our role

The Office for Disability Issues was established in 2002 as a focal point for disability issues, working across government agencies as well as between government and the disability sector. We work to create a non-disabling, inclusive society (as illustrated in figure 4.1).

The Office for Disability Issues was established in 2002 as a focal point for disability issues within government

Figure 4.1 Strategic focus of the Office for Disability Issues



Within this broader context, the Office has the following key roles:

- supporting the Minister for Disability Issues
- providing policy advice on disability issues, including
 - leading strategic policy development across government

The New Zealand Disability Strategy underpins all our work

- maintaining an overview of, and contributing a disability perspective to, policy development by other agencies
- meeting formal international obligations
- promoting, monitoring and reporting on progress of the New Zealand Disability Strategy within government and the wider community
- building strong relationships with the disability sector.

The New Zealand Disability Strategy underpins all of our work. However, we cannot implement the Strategy on our own, as the scope of change required is wide reaching and the policies and programmes of other government agencies have major impacts on the lives of disabled people. Rather, we promote, guide, lead, inform and advise wherever appropriate.

We do not hold funding or deliver services directly to individuals. We do, however, fund some capacity-building initiatives, and we place particular value on effective partnership with the disability sector.

Our responsibilities

Supporting you, the Minister for Disability Issues

A primary function of the Office for Disability Issues is to support and advise you. We will ensure that you are well informed about key issues and trends for disabled people and the disability sector, and provide advice regarding opportunities for leadership.

As portfolio Minister, you are responsible for the priorities and work programme of the Office. There is a direct working relationship between the Office's Director and you.

The activities of the Office are funded from Vote: Social Development. The Minister for Social Development and Employment is responsible for the administrative infrastructure that supports the work of the Disability Issues portfolio.

The Chief Executive of the Ministry of Social Development is accountable to the Minister for Social Development and Employment for the outputs and performance of the Office. This occurs through the formal accountability

You have a direct working relationship with the Office's Director

systems of the Ministry's Statement of Intent, the Vote: Social Development Output Plan, and the Annual Report.

Section 8 of the New Zealand Public Health and Disability Act 2000 sets out your duties and powers as Minister for Disability Issues, including:

- preparing, amending or replacing a New Zealand Disability Strategy as a framework for the Government's overall direction for the disability sector, and for improving disability support services
- consulting with organisations and individuals that you consider appropriate, before determining the Strategy
- reporting each year on progress in implementing the Strategy
- making publicly available, and presenting to the House of Representatives, a copy of the Strategy or any amendment of it or replacement to it, and reporting as soon as practicable after its determination or completion.

Cabinet assists you to ensure all government departments meet their responsibilities towards disabled people. This is formalised by a direction that:

- all government departments provide annual plans and reports on progress in implementing the Strategy
- where appropriate, Cabinet papers include a disability perspective
- ministers direct departmental Chief Executives to ensure that their staff are familiar with the vision and objectives in the Strategy
- officials consult us at the earliest possible stage on papers being submitted to Cabinet committees.

The effective management of ministerial correspondence is critical to maintaining credibility with the sector and the public. For this reason we prioritise our support, including drafting replies to ministerial correspondence, parliamentary questions, notes for speeches and requests made under the Official Information Act 1982.

Fortnightly updates and briefings on request ensure you are well informed about current disability issues, particularly those that might arise in Cabinet discussions.

You have key duties and powers concerning the New Zealand Disability Strategy

All government departments report once a year on how they implement the Strategy

We have strong relationships with central and local government, disability groups and disabled people

Building strong relationships

A number of other ministers, their associated departments and other Crown agencies have specific roles with regard to disability policy and services. These include the Ministry of Health, ACC, the Department of Labour, the Ministry of Education, the Mental Health Commission, the Human Rights Commission and the Office of the Health and Disability Commissioner.

We maintain a close relationship with key members of these government organisations. We also have regular contact with all government agencies with a role in implementing the New Zealand Disability Strategy.

The disability sector has a high level of expectation about our role. Priority has been given to building strong relationships with the sector, and also to developing partnerships between disabled people, central and local government, communities and support agencies.

To help achieve this we:

- support and are advised by a Disability Advisory Council
- have regular meetings with the Chief Executives of large service providers and the Disabled Persons Assembly
- meet and exchange information with all parts of the disability sector on an ad hoc basis
- maintain disability sector contact databases, available to government agencies, to encourage consultation
- support disabled people's participation in the New Zealand delegation to the United Nations for the negotiations on developing a convention on the rights of disabled people
- support some disabled people and their families to attend conferences.

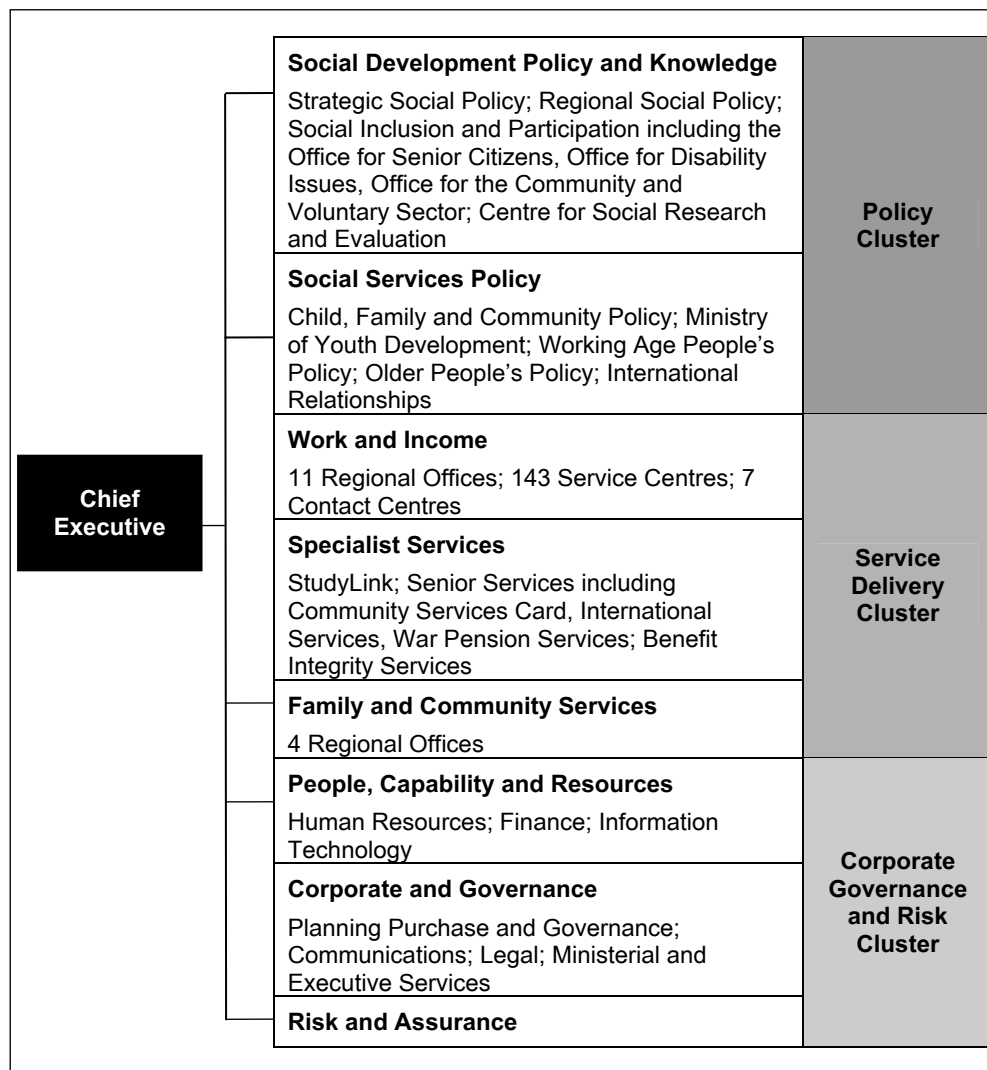
Office Structure

The Office Director is supported by a team of three senior analysts, five analysts and one administrator. We currently also have two additional staff for the duration of a key project.

Relationship to the Ministry of Social Development

The Office is located within the Social Development Policy and Knowledge group of the Ministry of Social Development, along with several units with a whole of government perspective (as illustrated in figure 4.2).

Figure 4.2 Where the Office fits within the Ministry of Social Development



As the chart above shows, these other units are Strategic Social Policy, Regional Social Policy, the Centre for Social Research and Evaluation, and the Offices for Senior Citizens and the Community and Voluntary Sector.

Location within the Ministry of Social Development enables us to access the corporate support provided by the Ministry, including expertise in financial and human resource management, evaluation and research, and communications. Our administration and overhead costs are minimised through the economies of scale available to us as part of the larger Ministry.

Our inclusion within the Social Development Policy and Knowledge Group enables us to contribute to strategic policy development, and ensures that the issues and interests of disabled people are considered in the context of our Ministry's social development policies.

Within the Ministry we also work with the Health and Disability team in the Working Age People's Policy Group and with the Work and Income and Family and Community Services service lines.

Working together

This briefing has provided you with an overview of the disability sector and its issues and challenges. It has outlined our role, and opportunities to make a difference for disabled people in the period ahead. We can provide further briefings, upon request, as a basis for decisions you may wish to take on the issues and actions we have raised.

We look forward to working with you.

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Endnotes

¹ New Zealand Disability Strategy 2001, p3.

² Various models and definitions of disability have been debated by national and international advocacy groups and academics over the last two decades. The general aim has been to reframe our understanding of disability, to promote consideration of strategies that address disability issues beyond the welfare/charity and medical/health policy contexts.

The New Zealand Disability Strategy adopts the 'social model' of disability. This draws on a human rights discourse, defining disabled people as an excluded or oppressed social group. It distinguishes between the impairments that people have, and the barriers to social participation that they experience. It shifts the problem of disability from a focus on a person's impairment.

The disadvantage or restriction of activity is caused by contemporary social organisation which takes no or little account of people who have ... impairments and thus excludes them from the mainstream of social activities. (Oliver, 1990)

However, it is acknowledged by most disabled people that:

Impairment and disability are not dichotomous ... Disability is a complex dialectic of biological, psychological, cultural and socio-political factors, which cannot be extricated except with imprecision. (Shakespeare, 2004)

Reflecting the common use of language, many people with impairments may refer to themselves as having a disability.

The New Zealand Disability Strategy, the Human Rights Act 1993 (see endnote 14) and Statistics New Zealand have all adopted inclusive approaches to disability, which span a wide range of impairment types. This contrasts with some historic notions of disability and some current eligibility mechanisms for support services.

³ All estimates are based on data gathered in the Post-Census Disability Survey conducted by Statistics New Zealand in 2001. Findings are published in 'Disability Counts' on www.statistics.govt.nz They are analysed in more depth by the Ministry of Health and published in 'Living with Disability', available online at www.moh.govt.nz

Statistics New Zealand defines disability as any self-perceived limitation in activity, resulting from a condition or health problem that will continue for more than six months, and will result in a reduction of independent function to the extent that ongoing support is required. The list of types of limitations or impairments includes

hearing, seeing, speaking, agility, mobility, intellectual, psychiatric/psychological, learning, remembering and other.

⁴ Over more than two years the National Health Committee undertook seminal research into the lives of adults with intellectual disabilities. This was published in September 2003 as *To Have an Ordinary Life: Community Membership for Adults with an Intellectual Disability*.

⁵ New Zealand Human Rights Commission, 2004, p8.

⁶ See endnote 4.

⁷ This statement was made by the Disabled Persons Assembly in their foreword to the 2003/2004 Disability Strategy Progress Report, presented to Parliament in October 2004.

⁸ *Making a World of Difference: Whakanui Oranga*, Ministry of Health, September 2000 – a discussion document that invited people who experience disability, along with other interested individuals and groups, to contribute to development of the New Zealand Disability Strategy.

⁹ Consultation around the development of both the New Zealand Disability Strategy and the Pathways to Inclusion Strategy, during the year 2000, found that a priority issue for disabled people was better access to employment. Smaller-scale consultation undertaken by the Office for Disability Issues since 2002 has seen this priority re-confirmed many times.

¹⁰ See endnote 8.

¹¹ The 'Like Minds, Like Mine' Campaign has been underway for more than six years. It involves mass media advertising as well as a diverse range of capacity-building, advocacy and awareness-raising initiatives. Much of the process has been evaluated, providing useful information about how to improve the campaign. Significant findings have supported the use of mass media, careful and inclusive strategic planning, increased targeting, increased participation of people with an experience of mental illness and increased advocacy using a human rights model.

Attitude-tracking surveys have found that public attitudes towards people with mental illness have improved as a result of the campaign's mass media advertising. Also, an in-depth survey of people with mental illness found that over half of the participants reported reduced levels of stigma and discrimination from family, mental health services and the public (see www.likeminds.co.nz).

¹² The term 'disability sector' is often used in discussion of policies for disabled people. The Office for Disability Issues uses the term to include three distinct groups: disabled people, their families/whānau and organisations representing them, and other organisations providing services to disabled people (often referred to as 'providers').

¹³ Quinn and Degener, 2000.

¹⁴ Section 29 of the Human Rights Act 1993. Section 21(1)(h) defines disability as including the following impairments:

- physical disability or impairment
- physical illness
- psychiatric illness
- intellectual or psychological disability or impairment
- any other loss or abnormality of psychological, physiological, or anatomical structure or function
- reliance on a guide dog, wheelchair or other remedial means
- the presence in the body of organisms capable of causing illness.

The Human Rights Act 1993 protects disabled people from discrimination in employment, education, accommodation and the provision of goods, facilities and services. Any affirmative or proactive measures need to be consistent with the Human Rights Act 1993, and the New Zealand Bill of Rights Act 1990.

¹⁵ The Treasury's *Guidelines for Contracting with Non-Government Organisations for Services Sought by the Crown* is a useful resource that signals Government's expectations of agencies and their relationships with non-government organisations. It signals a need to avoid disempowering practices. Ideally, mechanisms used to involve the disability sector in the work of government should help facilitate co-operation, add value, and complement and support the work of individuals and their organisations in the disability sector. The guidelines are available at www.treasury.govt.nz/publicsector/ngo/download.asp

¹⁶ Hurst, 2000.

¹⁷ The rights-based approach that sits behind the New Zealand Disability Strategy is being mirrored in various ways. For example, the European Union adopted a Disability Rights Directive for all member states in 2002. The United States passed the Americans with Disabilities Act 1990. The United Kingdom set up a Disability Rights Commission and has also developed a Disability Strategy with some similarities to New Zealand's. There are also relevant developments in Canada, Australia, and many other countries.

¹⁸ The 2001 Census found almost 28,000 people use NZSL, including both deaf and hearing people. Estimates of how many of these people are deaf range from at least 2,500 to possibly 7,000.

¹⁹ See endnote 4.

²⁰ New Zealand delegations to the UN ad hoc committee in New York have included effective partnerships between officials from the Ministry of Foreign Affairs and

Trade and the Office for Disability Issues, and disabled New Zealanders representing the Human Rights Commission, the Mental Health Commission and the Disabled Persons Assembly. New Zealand's contributions have also been informed by more general consultation with disabled people.

²¹ *Bites*, the December 2004 newsletter of the Disabled Persons Assembly:

The strong support for a UN Convention is an enormously important tangible expression of the real values of the New Zealand Government and its commitment to fostering an approach to disability which is about action rather than mere words.

²² The systems for delivering supports to disabled New Zealanders have gone through evolutionary and at times more radical structural change over the last few decades. In 1994, the 'New Deal' reform transferred funding from the Department of Social Welfare and the Ministry of Health to regional health authorities. The new purchasers were required to incorporate a number of attributes into their purchasing plans, including the ability to co-ordinate disability supports with other services, such as income support and personal health services. They were also required to incorporate an innovative and flexible approach to supports.

A review published in 1998, entitled *Building On The New Deal*, reiterated the need for improvements in flexibility, consistency, intersectoral collaboration and appropriate services for specific groups.

²³ See endnote 8.

²⁴ *Living with Disability in New Zealand*, Ministry of Health 2004.

²⁵ See endnote 24.

²⁶ See endnote 8.

²⁷ IHC was funded by the Health Funding Authority to provide care in the community for intellectually disabled people. IHC entered into caregiver contracts under which intellectually-disabled people were cared for in the homes of caregivers. Mr and Mrs Hill had contended that IHC had breached the Human Rights Act 1993 on the grounds of family status, by disallowing their application to be paid caregivers of their son.

²⁸ In general terms, families have primary responsibility for the wellbeing of their members. As the wellbeing of individuals is related to the wellbeing of their families, government is committed to protecting families from hardship, helping them to be part of their communities, helping them to achieve economic security and independence, and supporting them in meeting the needs of family members.

Government recognises that family caregivers of disabled people face costs exceeding those that families can ordinarily be expected to face. In order to mitigate the negative impact of these costs, government is committed to:

- ensuring that families caring for disabled people are protected from financial hardship and are able to be part of their communities
- working across sectors to ensure that families caring for disabled people have access to a wide range of provision that meets their specific needs
- minimising barriers to families' access to provision that will assist them in providing care for disabled people
- encouraging holistic approaches to supporting families caring for disabled people, so that due attention is given to the wellbeing of the disabled person, the family, and the family caregiver
- ensuring that provision for family caregivers of disabled people recognises cultural preferences
- helping families caring for disabled people build their capacity for providing care, to complement that provided by professional support workers
- assisting families to explore all options to promote the maximum independence and participation of disabled family members, including options for care outside the family.