











**Enabling participation by disabled New Zealanders** 





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#### **OVERVIEW**

New Zealand's approach to disability issues and disabled people has changed over the last 15 years, like it has in the rest of the developed world. This change presents challenges to what government services are provided, how these services are delivered and, more broadly, to some of society's attitudes towards disabled people.

Driving this change are the raised expectations and aspirations of disabled people themselves. Disabled people expect to participate as full and equal citizens – with the same set of rights, obligations and opportunities that other people have. The New Zealand Disability Strategy and the recently ratified United Nations Convention on the Rights of Persons with Disabilities both reflect this.

To realise their aspirations, disabled people need access to the goods, services and facilities that others can access. Some disabled people may also need disability-specific support services to help them to be as independent as possible at each stage of the life cycle. Regardless of the services needed, disabled people need to retain control over their lives, and the decisions that affect them.

Responding to this change is made more challenging, and also more urgent, by another key driver – demographics. Today around one in six New Zealanders are disabled. With an ageing population, we expect a 60 per cent increase in the number of disabled people over the next 40 years.

As Minister for Disability Issues, you have a statutory role to oversee the New Zealand Disability Strategy, established under the New Zealand Public Health and Disability Act 2000. The New Zealand Disability Strategy requires a whole of government response, and your position will allow you to influence other portfolios from a disability perspective.

The Office for Disability Issues is committed to helping disabled people achieve full inclusion in society by supporting you in your role as Minister for Disability Issues. In doing so we are guided by the views and experience of disabled people and their families and others within the disability sector.<sup>1</sup>

In this briefing we give you an overview of current disability issues and challenges, and identify some opportunities we have to address those challenges and advance the position of disabled New Zealanders.

We look forward to working with you.

Dr Jan Scown Director Office for Disability Issues

#### **EXECUTIVE SUMMARY**

New Zealand has experienced increasing prosperity over the last 15 years. Job growth and active employment policies and services have reduced unemployment. Higher wages and greater financial support from government for low to middle income working families have helped to improve people's standard of living and financial security. This prosperity, however, has not been shared by everyone. On a range of social indicators such as education, employment and income levels, disabled people continue to fare less well than others.

Because disabled people make up a significant proportion of the population that has poorer outcomes, New Zealand cannot make real social and economic progress until disabled people have the same opportunities to gain qualifications, to be employed, and to earn a decent living that other people have.

Current thinking on disability is reflected in two instruments that inform government policy and practice with respect to disability issues: the New Zealand Disability Strategy (the Disability Strategy) and the United Nations Convention on the Rights of Persons with Disability. These instruments recognise that disabled people have the same rights of citizenship as everyone else – including the opportunity to participate in society and to lead lives similar to those of other people ('an ordinary life'<sup>2</sup>).

While disabled people acknowledge the positive achievements made in recent years, they are seeking more rapid progress. Major challenges remain. Disabled people's full participation in society is limited by their lack of access to things that help most people to operate in society, to take advantage of opportunities and to achieve goals. These things include access to information, communications, transport, buildings and the physical environment.

In addition to being able to access things used by the population at large, disabled people need to be able to access modern, appropriate and good quality disability supports and they want to have a choice over who provides these services. Because their aspirations have changed, disabled people now expect to have more control over their lives and to have a say in the decisions that affect them. They expect the support they receive to increase their autonomy, not to diminish it (as could happen in the past).

To meet these challenges, opportunities to act exist across most portfolios, as well as in areas specific to disabled people and their families and whānau. The implementation of the New Zealand Disability Strategy and the findings from three recent important reviews of disability supports provide a platform for action. Disabled

people have a keen interest in the outcomes of these reviews, and how recommendations are progressed.

Because of the cross-sector, cross-government nature of disability issues, we propose that a Disability Sector Forum, comprised of the chief executives of relevant agencies, be established to provide better leadership around such issues. The Forum could work together to enhance progress on shared outcomes.

## **PART**

1

The Current Situation

In spite of recent gains, disabled people continue to be overrepresented among those who lack qualifications, who are not working, and/or who have low incomes. Because the population of disabled people is growing, making real gains in New Zealand's overall wellbeing and prosperity means addressing the challenges faced by disabled people. The expectations as to how those challenges are addressed by government and by society have changed.

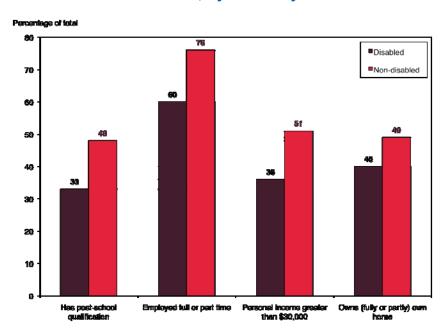
## All New Zealanders aspire to a good life

New Zealand has experienced increasing prosperity over the last 15 years. Job growth and active employment policies and services have reduced unemployment. Higher wages and greater financial support from government for low to middle income working families have helped to improve people's standard of living and financial security.

### Disabled people tend to have poorer outcomes

While there have been improvements for disabled people, they have not shared equally in this prosperity. Figure 1 shows that, on a range of key indicators, disabled New Zealanders are doing considerably less well than other New Zealanders.<sup>3</sup> This, in combination with the extra costs of living with disability, results in many disabled people being unable to accumulate the level of assets needed to be financially secure and independent.

Figure 1. Proportion of people having selected socio-economic characteristics, by disability status



# We cannot make real economic and social gains without addressing disability issues

We are not going to be able to meet broader social objectives like ending child poverty, attaining a decent standard of living for everyone or improving labour productivity if we do not make further progress towards addressing the challenges that face disabled people. Disabled people are disproportionately represented among those who lack qualifications, who do not have work, and who are living on low incomes.

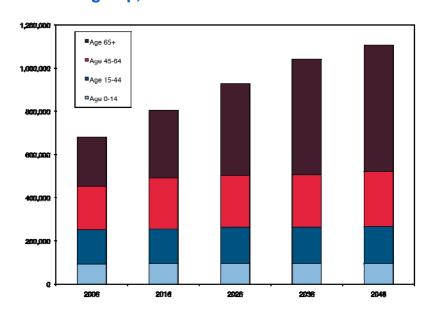
Recent New Zealand research indicates that 28 per cent of families include an adult family member with some degree of disability. Where the disability is moderate to severe (21 per cent of all families), this is associated with lower overall economic living standards and an increasing likelihood of being in severe hardship.<sup>4</sup>

## The disabled population is diverse

Your portfolio, and the Office for Disability Issues, is concerned with all disabled people regardless of the type of impairment, cause, time of onset, or services and supports required. This encompasses anyone with long-term physical, psychological, psychiatric, intellectual, neurological or sensory impairments that, in combination with various external barriers, hinder their full and effective participation in society on an equal basis with others.<sup>5</sup>

One in every six New Zealanders is disabled. We expect the number of disabled people to grow by 60 per cent as our population ages over the next 40 years. <sup>6</sup>

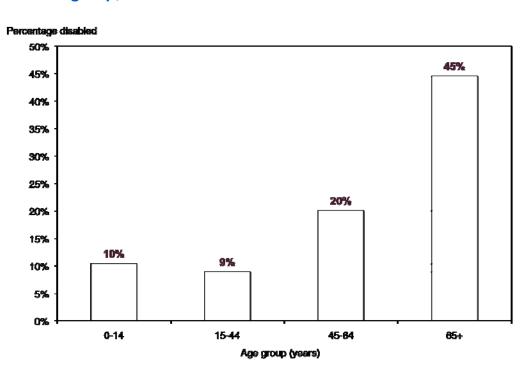
Figure 2. Projected number of disabled New Zealanders, by age group, 2006–2046



660,300 New Zealanders have a disability. This number will grow substantially over the coming decades

The number of disabled New Zealanders will grow substantially over the coming decades This expectation is based on the marked increase in disability prevalence with increasing age.<sup>7</sup>

Figure 3. Disabled people as a proportion of people in each age group, 2006



Disabled people want to be in control of their own lives

#### Disabled people want the same opportunities as everyone else

The aspirations of disabled people and their families and whānau in New Zealand, and across the world, have changed considerably over recent decades. Current thinking on disability recognises that disabled people have the same rights of citizenship as everyone else. This includes the opportunity to participate in society and to lead an ordinary life. Disabled people, however, face barriers that are quite different to those facing non-disabled people. This current thinking is reflected in the New Zealand Disability Strategy, written in partnership with disabled people in 2001.

This approach challenges assumptions that, in the past, meant disabled children were denied education and people with intellectual disabilities and/or other complex support needs lived in residential institutions (rather than in their communities like everyone else).

The shift in thinking can be illustrated in the experiences of today's young disabled adults. These young people have been educated at their local school along with their non-disabled peers, sharing the same sorts of aspirations for their adult lives as their former schoolmates, and expecting the same sorts of opportunities.

Consistent with this shift in thinking are new expectations around the role disability support services play, and how they are delivered. Disabled people, like others, want to be in control of their own lives, to be involved in decisions that affect them, and to live their lives with as much dignity and autonomy as possible. Often, to get access to the support services they need, people have had to go through processes that categorised them as 'invalid', 'unemployable', 'dependant' or 'unsafe' (and so forth). People tell us they want services that are easy to access, reliable and provided in ordinary settings. Support services should enable them to achieve the goals they set for themselves, rather than the goals being determined or limited by the nature of the supports provided.

Disabled people want to be in control of their own lives

For example, we used to assume that people on an Invalids Benefit were not able to work, so benefit eligibility rules limited them to 15 hours paid work a week. Since last year people who want to work more than 15 hours can do so with the right support, which may be continuing to receive some level of Invalids Benefit to top up their income.

More can be done. Some young physically-disabled people, to receive the daily living support they require, have to live in an aged-residential care facility. This is inappropriate for their age and stage of life and does not meet their other needs.

# The New Zealand Disability Strategy and the United Nations Convention on the Rights of Persons with Disabilities

The New Zealand Disability Strategy reflects this modern citizenship-based approach. It recognises we live in a disabling society – one built largely in a way that assumes many things. For example, it assumes we can all move quickly from one side of the road to the other; we can all see signs, read directions, hear announcements, reach buttons; and we all have the strength to open heavy doors. It also assumes we all have stable moods and perceptions. While New Zealand has standards for accessibility, many of our public and private buildings and other spaces remain largely inaccessible. In the main, our schools, workplaces, supermarkets, banks, marae, churches and houses have been designed and built for non-disabled users.

The Disability Strategy is about changing New Zealand from a disabling society to an inclusive one. Government agencies develop annual work plans to implement the Strategy, and the Minister for Disability Issues reports annually to Parliament on progress.

Disabled people have a high degree of ownership of the New Zealand Disability Strategy and of the United Nations Convention on the Rights of Persons with Disabilities. They lobbied strongly for each of them and were integrally involved in their development. They expect, in the

The New Zealand Disability Strategy has wide sector support spirit of both, to have a leading role in their implementation and monitoring.

# United Nations Convention on the Rights of Persons with Disabilities

The purpose of the Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.



The Convention is consistent with the fully inclusive approach of the New Zealand Disability Strategy, and was ratified by New Zealand on 26 September 2008.

New Zealand led the negotiations on the United Nations Convention on the Rights of Persons with Disabilities (from 2002 to 2006) and included disabled people as full participants in our delegation. This meant the Convention modelled and directly incorporated the needs and aspirations of disabled people and is very practically focused. The Disability Strategy provided a framework that could be translated internationally. In recognition of our international leadership and also of our domestic practices New Zealand received the 2007 Franklin Delano Roosevelt International Disability Award. This prestigious award recognises sustained achievements by a country in promoting the participation of disabled people in society.

## Government impacts on people's outcomes in many ways

Government can and does make a difference to people's day-to-day wellbeing, the skills, knowledge and resources with which they build their lives, and the quality of the communities and the environments in which they live and work.

Government does this through a range of policy instruments: legislation, regulatory frameworks, public education, income transfers, the direct provision of services, full and partial funding of services, and community development. As members of the general population, disabled people access government services available to everyone.

In addition, disabled people access disability-related services. Broadly, these disability-related services support people to communicate, move around, look after themselves and their families, and make decisions. As detailed in the Appendix, funding for disability-related support services comes from 11 Votes, together with

New Zealand played a significant role in negotiating the United Nations Convention funding from three Crown agencies. For the 2005/2006 year the total was about \$2.8 billion.

At 35 per cent of total expenditure, the cost of residential care services (such as group homes or rest homes) represents the single largest disability support service expenditure category. The second highest category (19 per cent) is non-residential care services (personal care and home help). We expect these proportions will shift as services are increasingly designed to enable people to continue to live in their own homes and communities.

Income assistance for disabled people is provided separately from their disability supports. Like many other countries, New Zealand has experienced growth in the numbers of people who receive income support on the grounds of disability and/or health conditions. The Appendix provides more detail about the growth in numbers of people who receive income assistance through Invalid's and Sickness Benefits.

## **PART**

2

**Current Challenges** 

To participate in society as full and equal citizens, disabled people need access to the things that other people take for granted, such as information and transport. They also need easy access to disability-specific supports that help them to participate in society. Disabled people want to lead ordinary lives, similar to those lived by other New Zealanders.

### We need to make more progress on disability issues

New Zealand has made real progress towards increasing the participation of its disabled citizens over the last 15 years. For example, it is no longer generally accepted that disabled people should be housed, educated or employed separately from other people. Disabled people are more likely to live in the community and to support themselves through employment than was the case in the past.

Despite these achievements, a review of progress after six years of implementing the New Zealand Disability Strategy (2001–2007)<sup>8</sup> found that disabled people feel that progress is not rapid enough and fundamental barriers to their participation still exist. While the disability survey conducted by Statistics New Zealand after the 2006 Census shows some improvement in important outcome areas, disabled people still continue to do significantly less well than the general population.

The key challenges to be addressed if we are to improve outcomes for disabled people are:

- ongoing discrimination
- a range of issues around improving access
- the changing expectations of disabled people and their families and whānau around the nature of disability support services
- supporting people's growing aspirations for themselves
- ensuring the needs of future generations of disabled people are planned for.

#### **Participation requires access**

At all life stages, disabled people face particular challenges in achieving commonly-shared goals. Everyone wants to be successful in education, finding and retaining employment, having an adequate income, staying healthy, supporting oneself and leading an independent life. To do this, everyone needs access to information, communication, transportation, buildings and environments and, for

Some good things have happened already...

...but people want to see faster progress

> Everyone needs access to information, transport and buildings

disabled people, appropriate disability supports. Disabled people, however, still face barriers accessing these basic necessities.

Improving outcomes for disabled people is not just about getting specialised disability supports right – it is also about effecting change at much broader levels (like town planning) and ensuring government initiatives that affect the general population cater for the access needs of disabled people from the outset. As Minister for Disability Issues, you have the opportunity to influence your colleagues in this regard.

## Good transitions to employment are vital for disabled people

One of the biggest issues facing disabled young people and their parents is the need for planned transitions from school to work, tertiary education or training and other meaningful day-time activities. With the right assistance, disabled young people can make better transitions from school to adult life. To be successful, transition planning needs to start around the age of 14 years. Young people and their parents can experience uncertainty as they move out of compulsory education where their son or daughter has an entitlement to the support they receive into an adult world where there is no such entitlement (employment services are discretionary).

The challenges around employment include discrimination in the labour market and workplace and low expectations and assumptions about what disabled people can and cannot do. For example, employers often say the workplace is not a safe environment for disabled people. This means people with valuable skills and strong motivation can struggle to participate as fully as they are able to.

#### Successful employment can be achieved with a flexible approach

Ben was born with cerebral palsy and required a wheelchair to get around. He found no employers were willing to give him a go because of his disability, despite having excellent qualifications and previous work experience. Ben finally found employment within an electronics company who were willing to make the required workplace adjustments – installing a ramp at the entrance to the workshop – and he now works five to six days a week designing and testing electronics equipment. The electronics company found Ben was also an excellent trainer, and he now imparts his extensive skills to others.

Sarah had worked as an editor on a newspaper for over 10 years when she was diagnosed with depression. Sarah took leave from work when her symptoms were most severe and with professional treatment, including medication, Sarah became confident she could once again do her job. After disclosing her disability to her manager, she was able to come to an agreement about her work schedule that

We need to challenge assumptions about what disabled people can and cannot do suited both her and the employer. This included being able to work from home when necessary, and the flexibility to attend professional treatment sessions during work hours. The business benefited by retaining a hardworking and dedicated employee with 10 years of knowledge and experience.<sup>9</sup>

Many people find their first job (and subsequent jobs) because of family, whānau or other social connections. This can be harder for people when their social networks are small, as is often the case for disabled people. Once people are working, they can face challenges in understanding the culture of the workplace and in 'fitting in'. Retaining work can be as problematic for these reasons as finding it in the first place.

Some disabled people need equipment and workplace modifications for them to be effective and to work to their full capacity, or to retain a job following an accident. Accessible transport to and from work and accessible workplaces are also critical factors in ensuring people can work.

Where disabled people are unable to work full-time, finding meaningful voluntary or leisure activities is another challenge for them and their families and whānau. Finding quality work that pays a decent wage can also be difficult.

Details of government's current provision of services supporting people to move from school to work and other options, and other employment services, are provided in the Appendix.

#### Transport needs to be accessible

Living an ordinary life means being able to get from place to place, whether it's from home to school or work, to friends' places, to social and community events – in your neighbourhood or beyond.

Despite the considerable progress made in improving the accessibility of the public transport system, there are various barriers that prevent many disabled people getting from place to place so they can fully participate in society. At the same time, there is a growing appreciation that the benefits of improving the accessibility of public transport are not limited to disabled people – people with temporary injuries or illness, parents with children and buggies, people carrying groceries, people who are getting frailer, all benefit from improved accessibility.

An approach to urban design that is comprehensive and takes into account how transport and the built environment connect and work together would address some of these accessibility issues.

Everyone benefits from improved accessibility

## Buildings and the physical environment need to be accessible

Disabled people want to be able to live and move about independently. This means carrying out ordinary domestic tasks in their own homes as well as undertaking ordinary social, economic and civic activities in their communities.

Currently, New Zealand's housing stock is not meeting disabled people's housing needs. There is a considerable unmet need for accessible, safe, warm, comfortable housing that works well for young and old people with impaired mobility. This unmet need is likely to increase as disability and impaired mobility increases in the ageing population.

Disabled people and the government spend considerable amounts on housing modifications. Much of this expenditure is on basic home alterations such as widening doorways and installing wet area showers – modifications that would be easier and more cost-effective if they were routinely integrated into newly built and renovated housing.

An accessible, well-performing housing stock that meets the needs of people as these needs change would be 'future-proofed'.

The New Zealand Housing Strategy<sup>10</sup> includes mechanisms to encourage the use of universal design principles in state and private housing to make housing more usable for everyone.

The countries most successful in engaging the private sector in providing accessible housing for the general population (that is, Japan, Norway and the United States of America) either offer financial incentives and/or have strong legislative or regulatory frameworks.<sup>11</sup>

## Lifetime Design

Lifetime Design is a way of designing products and places that deliver the greatest ease of use for most people and allow adaptations in the future as needs change.

A Lifetime Design Foundation was established in New Zealand by CCS Disability Action to promote the Lifetime Design concept. It has received a positive response and a strong demonstration of support from a wide cross-section of business, government and the community. MSD is a member of the Foundation Council and has provided some initial start-up funding for the project.

CCS Disability Action is also establishing Lifemark, a quality standard certification of the inclusion of Lifetime Design concepts. It is working to establish a niche commercial market in housing and housing products.

Accessibility
enhancements are
more cost-effective
when built in at the
start

Lifetime Design has been a successful concept around the world. Related initiatives (under many names such as Universal Design, Housing for Life, Adaptable Homes, Visit-ability, Ageing in Place) share the goal of creating a world that works better for everyone regardless of age or ability. 12

## People want modern, appropriate disability supports

For some disabled people and their families and whānau, support alone is not enough. Getting access to the supports they need, where and when they need them, and in the right 'amounts' and quality is one of the longest-standing battles disabled people face. We have to make sure we have a workforce trained and equipped to deliver high-quality rehabilitation and habilitation services.

As noted earlier, the expectations and aspirations of disabled people and their families have been changing. Institutional models and forms of care are no longer acceptable to them. People want to have more say over what support they receive and who provides it.

Carers, (like disabled people) want to be involved in the decisions that affect them. A Carers' Strategy and five-year action plan has been developed to address these issues. <sup>13</sup>

Demand for disability supports will continue to increase as the population ages, and medical advances mean people with significant disabilities are living longer. Technological innovations also mean there is a greater range of ways to improve disabled people's lives – bringing with them additional costs. A third driver of costs in the sector is the demand by disability support workers (who are historically among the lowest paid workers in this country) for better pay and conditions. This factor has implications for service quality.

Managing the increases in demand for disability supports is one of the biggest challenges facing government in the disability sector. Achieving sustainable funding is an outcome currently exercising different funding agencies, in particular the Ministries of Health, Education and Social Development and the Accident Compensation Corporation (ACC).

Part of the challenge of leading an ordinary life involves making sure services for the general population are accessible to everyone, including disabled people (as well as other people who might have particular needs, for example parents with young children, and older New Zealanders).

Getting access to Disability supports is a key challenge for some disabled people

# Some argue that people in comparable situations should be treated similarly

That people in comparable situations receive different services, supports and levels of financial assistance has been a contentious issue in the disability sector for some time. Government provision in two different situations has recently been challenged in Court. The first case related to differential provision based on the cause of disability (ACC versus other government provision). The Court found in this case that, while the differential provision of supports was clearly discriminatory, it was legal under current New Zealand law.

The second Court case relates to families who care for a disabled family member. The families involved are seeking to receive a carers' payment equivalent to that received by people providing those services on behalf of the state. A decision has yet to be made in this case. Irrespective of the Court findings, the issue is likely to remain contentious and a source of grievance into the future.

### We need to plan for the future

Future-proofing for coming generations is a major challenge. This will involve focusing more on early intervention so needs can be met and managed before they become acute or secondary disabilities arise. Early intervention is particularly important in providing support to children with disabilities and their families, and for people who experience mental illness. Future-proofing also involves influencing designers, town planners, architects, engineers and others to make sure we do not miss opportunities to modify our built environment and technologies at the right (initial) stage. That way we avoid the need to do expensive 'retro-fits' later to meet the needs of an ageing population. Everyone benefits from this sort of future proofing – not just disabled people.

**PART** 

3

Opportunities for Action

The challenges noted in this briefing are not new. It will take many years of concerted effort before we have a fully inclusive New Zealand where disabled people are benefiting equally alongside other New Zealanders. However, there are opportunities to accelerate progress on two fronts – improving our system of providing disability-specific supports, and improving the accessibility of the wider environment within which disabled people live.

### We will need to respond to recent reviews

Three significant reviews looking at aspects of disability issues have reported in the last 15 months. These examined:

- long-term disability supports (led by the Office for Disability Issues)<sup>14</sup>
- the implementation of the New Zealand Disability Strategy (reviewed by an independent agency)
- quality of care and service provision for disabled people (conducted by the Social Services Select Committee).

The disability sector is keenly interested in the findings of these reviews, and the extent to which their recommendations will be implemented. While positive results have already been achieved, progress to date has not been as fast as disabled people want.

### Review of long-term disability supports

The Office for Disability Issues completed a review of long-term disability supports in August 2007. The review looked at how to enhance the provision of disability support services so they improve the outcomes for disabled people and their families. A particular focus was on how to make such services simple to access, seamless and more equitable.

Consultation around the development of the Disability Strategy, and since, has raised many issues about the way disability supports are provided. From government's point of view there are overlaps, gaps and areas for improving administrative efficiency. From the perspective of disabled people and their families disability supports are complicated to access, inflexible and inequitable (across age groups, geographical areas, cause of impairment, type of impairment, and funders). We can make good gains by improving access to services, by simplifying assessment processes, and by replacing rigid service categories (for example, 'gardening' or 'home help') with services determined by whatever the person wants support with.

The review noted the issues described above stem from incremental service and policy development and from differences in the

Disability supports are often experienced as complicated to access and inflexible

Significant work is already underway to address identified issues

fundamental purposes and philosophy of the various sector agencies. Responding coherently and consistently to the large and changing demand for support has also been hampered by disjointed planning activity.

There is already significant work underway across government to implement the recommendations from the review to improve the focus on outcomes, to enhance consumer choice and service flexibility, to build capability, and to improve co-ordination and contracting practices. This work includes:

- expanding supported independent living
- increasing access to individualised funding
- moving to outcomes-focused funding
- simplifying and better aligning assessment processes
- costing of a single, highly visible and accessible entry point to all government disability support information
- a greater focus on preparing and supporting disabled people entering paid employment or leaving school
- ensuring services for all children and young people include a focus on disabled children and young people
- longer-term planning for priority areas including disability supports, making targets and achievements more transparent.

Funding injections, mainly through the Ministries of Health and Social Development, have allowed for higher contract rates to service providers and improved terms of employment for the lowest paid support workers, and enhanced the provision of some disability supports such as equipment and housing modifications.

Making progress in these areas will improve access to disability supports and will address many of the sector's concerns. There are opportunities for agencies to improve services within current funding. Other areas for action, however, will advance more quickly if additional funding is secured.

#### New Zealand Disability Strategy implementation review 2001–2007

In August 2008 the first review of the implementation of the New Zealand Disability Strategy was released. The review was done independently of the Office for Disability Issues. While there are annual ministerial reports against the Strategy presented to Parliament, this review provided an opportunity to stand back and assess overall progress.

The vision and objectives of the Disability Strategy continue to be relevant The review found that, overall, central government agencies have undertaken a significant level of activity to implement the Disability Strategy, and that life experiences are improving for disabled people. Progress, however, has not been as fast as disabled people and their families want. All participants in the review were positive about the Disability Strategy and noted that its vision and objectives are still relevant.

Government activity has concentrated on gaining a greater understanding of the issues for disabled people and their families and whānau. The review makes recommendations about:

- greater prioritisation of activities that will make a real difference to disabled people
- better engagement with disabled people
- enhanced monitoring to improve the effectiveness of future implementation activity
- extending implementation beyond the government sector into wider agencies and society.

Work is progressing on these recommendations. In particular, the Office for Disability Issues is working to develop a framework for longer-term planning and reporting. This will make targets and achievements more transparent and will encourage multi-agency and multi-year reporting in key areas.

#### **Social Services Select Committee Report**

In September 2008 the Social Services Select Committee concluded its inquiry into the quality of care and service provision for disabled people.

The inquiry was prompted by concerns raised in the media about two major residential service providers and by more generally expressed dissatisfaction with current service provision. The issues raised with the Committee were not new.

The Committee has made a number of recommendations that can be grouped under the following themes:

- · enhancing leadership and accountability structures
- improving advocacy and complaints processes
- improving the monitoring of services
- improving the way people access information and supports
- ensuring services fill identified gaps, are age-appropriate, and enhance consumer choice

Disabled people will be keenly interested in the Government's response to the Select Committee report developing a disability sector workforce strategy.

The Committee recommended a lead agency be appointed to provide leadership and accountability.

Another idea canvassed by the Select Committee was Local Area Coordination, which operates in Western Australia. This model is based on principles relating to self-sufficiency, self-determination, and relationships with family, whānau, friends and the community. Once a person's requirements for a 'good life' are established, they are helped to access services to help them live that life, rather than determining and providing specified services for disabled people. This approach is demonstrably capable of achieving significant benefits for a large number of people, while having relatively low infrastructure and operational costs. Its application could be explored further.

Government has yet to respond to the Select Committee report. A response will be required early in the life of the new Parliament. This represents an opportunity for the government to send a message to the sector about its priorities and its plans for addressing disability issues.

## We can enhance Sector Leadership

To achieve greater traction, disability issues require stronger leadership from, and a higher profile among, the agencies accountable for general policy development and service, and those responsible for disability supports. This leadership could be achieved through the establishment of a "Disability Sector Forum" made up of the chief executives of agencies that make (or could make) a critical difference in the lives of disabled people. These could be agencies with responsibilities for transport, building and housing, health, education, social and employment services, accident compensation and rehabilitation, among others.

We envisage such a forum would be headed by the Chief Executive of a designated lead agency, and its members would be held accountable through formal arrangements for the achievement of shared outcomes for the disability sector. The establishment of such a group at the most senior executive level will lift the profile of disability issues within those agencies, will enable better traction to be made on actions and will improve the coherency of approaches across the agencies best placed to effect positive change for disabled people.

Similar forums have been set up in recent years in the social, economic and environmental sectors and have been successful. They are a useful mechanism within the public management system, enhancing progress towards joint outcomes without requiring structural change.

Making more progress requires joined up action

Successful cross-government precedents for this way of working also exist within the social sector, for example, in dealing with issues of family violence and youth gangs.

### A good start in life provides a foundation for life

Social Sector Chief Executives (Health, Education, Justice and Social Development) have been working on what will make the greatest difference in addressing future social issues for New Zealand. One of the resounding findings from research here and overseas is that the foundation for positive results across a wide range of social areas is getting a good start in life.

Good access to neo-natal services and an investment in parenting make a huge difference in child development, with a payoff throughout life. The chances of success at school, in further education, in employment and in other aspects of life are all improved if children get a good start. This can be reinforced through participation in early childhood education and in school itself.

We need to make sure the needs of disabled children, and of children whose parents are disabled, are factored into the development of services and strategies to give all children a strong start. This will be critical in ensuring future generations of disabled people are as well placed as they can be to live ordinary and successful lives.

Part of this approach will be to enhance early intervention services known to make a difference, and to support families from the start to use their personal and local community networks to develop practical solutions to meet their goals and needs.

#### Making good transitions from school is a priority

In the same way the requirements of disabled people should be factored into early childhood development, they need to be a part of the current thinking on how best to ensure all young people make a successful transition into adulthood. Young disabled people have particular needs, but they also have many of the same aspirations as other young people as they move forward.

The review of long-term disability supports identified issues for disabled young people in transitioning successfully from school. Improving early transition planning to ensure continuity and making mainstream services available where appropriate to young disabled people will reduce the chances of these young people missing out at a critical stage of their life.

#### Disabled people want meaningful work and participation

Recent developments in employment policy and services will help to reduce barriers to employment for disabled people. These

The needs of disabled children need to be factored into development of services and strategies to give all children a strong start

Disabled people need support to make the transition from school to working life, just like other young people developments include removing the blanket provisions that enabled specified employers to pay disabled people less than the minimum wage, and Work and Income's focus on providing employment assistance to a wider range of working age people. We need to continue to work to remove barriers, including changing the remaining misconceptions held by many in the labour market and workplace.

Our income support system was based on the assumption disabled people cannot work. Now we recognise many disabled people want to work, and can with the right support. Work and Income's practice and policy has changed to allow disabled people the same access as others to education, training and employment programmes and supports. However, vestiges of the old 'can't do' thinking linger, either formally in different pieces of legislation or policies, or informally in practice and in the attitudes of people providing services, employers and even families. We need to remove these barriers.

As employment rates of disabled people increase, the focus will need to shift to secure and well paid jobs with opportunities for training and career advancement.

### An Employers' Disability Network

An exciting opportunity in this area is the establishment of an Employers' Disability Network to support employers' understanding of disabled people, both as employees and as customers. There is a lot of interest in this concept from private business, Chambers of Commerce, and public sector employers in New Zealand. The Network, based on a successful model in the UK and Australia, will promote inclusion for disabled people, develop practical solutions to barriers, and help businesses gain skilled workers. The likely benefits include smarter recruitment, lower staff turnover, improved productivity, more customer-focused service and a positive social impact. We anticipate holding the first meeting of the Network before the end of the year.

#### **Vocational services**

The focus in recent years on clarifying the role and purpose of vocational services, as well as increased funding levels in the sector, has led to improvements in service consistency, coverage and capacity. We have an opportunity now to focus on improving the quality of the vocational services provided, including improving their flexibility and responsiveness to individuals' aspirations and ensuring they remain relevant and up to date.

Government has recently decided to transfer the responsibility and funding for day services for disabled people under 65 years of age from the Ministry of Health to the Ministry of Social Development. This

An Employer's Disability Network is being established places them alongside vocational and employment services, including the Mainstream programme, and provides opportunities for better service co-ordination.

### Simplifying access will help disabled people

For disabled people and their families and whānau to remain in control of their lives, services need to support them without getting in their way. Typically, accessing supports requires significant time and energy on the part of the person and/or their family and whānau.

The emphasis needs to be on more streamlined needs assessment and coordination, to ensure that the person receives just the right level of help at the right time.

### Service developments for older people

MSD is currently developing a new approach for delivering services to older people. The aim of the development is to better support those older people who need more help. Most New Zealand superannuitants can manage very well, with little need for extra help. However, they are more likely to require support services as they become 'older olds'. Those who enter old age with a disability or who become disabled as they age, are likely to be among this group.

The intensity of the MSD's interaction with each older person will be based on the complexity of their need. For the majority of older people there will be a low level of engagement. For a significant group who have moderate service needs, the MSD will help with information and service brokerage. For the small group who have intensive support needs, the MSD plans to work with other agencies to ensure the appropriate services are wrapped around the client and their family and whānau.

Improving access to services for older people will help many disabled people

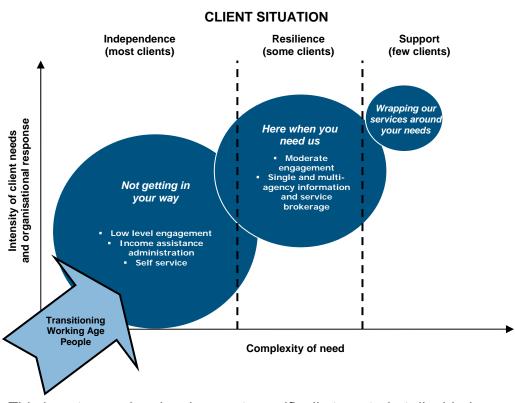


Figure 4. Ministry of Social Development Service to Seniors model

This is not a service development specifically targeted at disabled people. However, given the ageing of the population and the anticipated growth in the number of older New Zealanders living with disability, it provides a significant opportunity to improve outcomes for a sizeable proportion of disabled people.

### Universal design principles will affect a wide range of areas

'Universal design' means products, environments, programmes and services are designed so they can be used by all people without the need for adaptation or specialised design. There is scope for promoting universal design principles and practice particularly in the areas of housing and building design, town planning, transport and communications.

If usability is designed in from the start, not only will a particular service or amenity be usable for more people, but it will tend to have a longer useful life. For example, as their occupants become older and less agile or less mobile, houses designed using universal design principles will not need to be modified, or the modifications will be relatively easy and less costly than for other homes.

The Building Act 2004 requires new and refitted buildings to which the public have access be accessible for disabled people, but this does

not apply to housing. However, the Department of Building and Housing has been reviewing the Building Code and considering how universal design principles could be incorporated into the Code – which would affect the building of houses.

When access and use is considered early in the building design and planning stages, the cost of making buildings accessible is negligible compared to the total cost. By contrast, the cost of modifying an inaccessible building can be considerable.

Agencies such as the Ministries of Health and Social Development, Housing New Zealand Corporation, ACC and others have a considerable stake in housing quality and its impact on heath and other social and economic outcomes. Already, some of these agencies are working in partnership with disability and private sector agencies to develop non-regulatory mechanisms to provide market incentives for the use of universal, or 'lifetime', design solutions.

### Vienna - an accessible city

For a number of generations Vienna has had a relatively older population compared to other cities of its size in Europe. As a consequence, Vienna has incorporated into its transport systems many accessibility features to help people who may be frailer, slower, or less agile to get around. Catering for the needs of its older population has meant that it is also easier for younger disabled people, people with temporary injuries or illness, families and others to get around.

**PART** 

4

The Office for Disability Issues

The Office for Disability Issues supports and advises the Minister for Disability Issues, and provides a focal point for government's consideration of disability issues and its relationship with the disability sector. The work of the Office is underpinned by the New Zealand Disability Strategy and the United Nations Convention on the Rights of Disabled Persons. The Office will work with you to develop a work programme that reflects your priorities.

#### Our role

The Office for Disability Issues was established in 2002 as a focal point for disability issues. The Office has the following key roles:

- supporting the Minister for Disability Issues
- providing policy advice on disability issues, including leading strategic policy development on disability issues across government
- maintaining an overview of, and contributing a disability perspective to, policy development by other agencies
- meeting formal international obligations in relation to disability issues
- promoting, monitoring and reporting on the progress of the New Zealand Disability Strategy within government and the wider community
- ensuring the disability sector has a voice within government by building strong government - disability sector relationships to enhance understanding of sector perspectives, issues and concerns (including around emerging issues).

The New Zealand Disability Strategy underpins our work. However, we are not responsible for implementing the Strategy. Our role is to promote, guide, lead, inform and advise wherever appropriate. The recently ratified United Nations Convention on the Rights of Persons with Disabilities provides the detail that will help to inform the implementation of both our Strategy and the Convention itself.

We do not deliver disability support services, or hold funding.

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.

### Our responsibilities

One of our primary functions is to support and advise you as the Minister responsible for Disability Issues. Section 8 of the New Zealand Public Health and Disability Act 2000 sets out your duties and powers as Minister for Disability Issues. These include:

- 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 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 will help you to ensure all government departments meet their responsibilities towards disabled people. This includes requiring all government departments and ACC to provide annual plans and report on their progress in implementing the Strategy, that the Office is consulted on relevant Cabinet papers, and that these provide a disability perspective (where appropriate).

We will ensure you are well informed about current disability issues, developments and trends for disabled people and the disability sector, and we will provide you with advice on opportunities for leadership on disability issues. This will include advising you through fortnightly updates and regular briefings.

The effective management of ministerial correspondence is critical to maintaining credibility with the sector and the public. We draft replies to ministerial correspondence, parliamentary questions, notes for speeches and requests made under the Official Information Act 1982.

## **Building strong relationships**

Other Ministries, Departments and Crown agencies have specific roles with regard to disability policy and services. These include the Ministries of Education, Health and Social Development, the Departments of Building and Housing and Labour, the Accident Compensation Corporation, the Mental Health Commission, the Human Rights Commission and the Office of the Health and Disability Commissioner. We maintain close relationships with the relevant officials in each of these agencies. We also have regular contact with all government agencies with a role in implementing the New Zealand Disability Strategy.

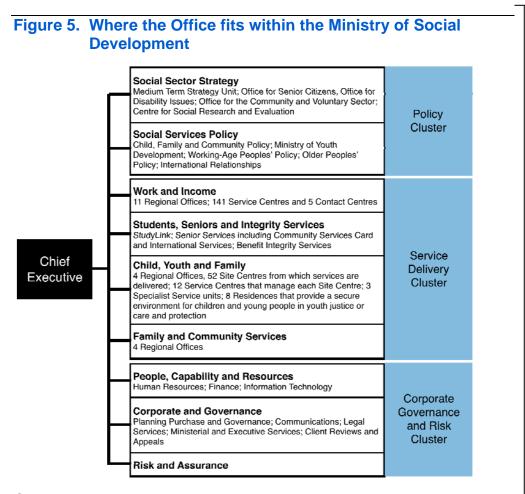
The disability sector has a high level of expectation of us in our role. We give priority to building strong relationships with the sector, and to developing partnerships between disabled people, central and local government, communities and support agencies. To help achieve this we:

- support and are advised by a Disability Advisory Council
- meet regularly with the chief executives of large service providers and DPA Inc (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, to encourage consultation with the sector by government agencies
- supported disabled people's participation in the negotiations to develop the United Nations Convention.

#### Office structure and location

The Office Director is supported by a team of nine – a policy manager and five analysts, a senior advisor and nominations service convenor, and one administrator.

The Office is located within the Social Sector Strategy Group of the Ministry of Social Development.



Our location within the Ministry enables us to access corporate support from the Ministry. Our administration and overhead costs are minimised through the economies of scale available to us as part of a bigger Ministry.

Our inclusion within the Social Sector Strategy Group means we can ensure the issues and interests of disabled people are considered during the Ministry's strategic policy development.

The Office's activities are funded from Vote: Social Development. Our annual work programme is agreed with the Minister for Disability Issues.

## **WORKING WITH YOU**

The Office of Disability Issues works across portfolios and with government agencies to support progress on disability issues. We have a wide network of relationships with the disability sector, and can assist you to make contact and build relationships with key individuals and organisations.

We will work with you to develop a work programme that delivers on your priorities as Minister.

We can provide further briefings 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.

#### **APPENDIX**

### Sources of public funding for disability support services

Funding for disability-related support services comes from a large number of points across government. The review of long-term disability supports completed by the Office for Disability Issues in 2007 identified that 11 Votes, together with funding from the Accident Compensation Corporation account, the Land Transport Fund and the Lottery Grant Scheme, were involved. Table 1 shows disability support service funding from each of the main sources.

Table 1. Public expenditure on disability supports for people with long-term impairments only, by agency, 2005/2006<sup>16</sup>

Ministry/Crown Agency	Expenditure (\$million)	%
Accident Compensation Corporation	256	9
District Health Boards (mainly older people and mental health services, excluding treatment)	905	33
Ministry of Health (mainly physical, sensory and intellectual disability, under 65 years)	699	25
Ministry of Social Development (including Work and Income and Child, Youth and Family funding, but excluding benefit payments)	479	17
Ministry of Education (early childhood, schools and tertiary funding)	402	15
Other	22	1
Total	2,763	100

The cost of residential care services (such as group homes or rest homes) is the single largest disability support service expenditure category (and which excludes the cost of income support payments), accounting for some 35 per cent of expenditure (see Table 2). The cost of non-residential care (personal care services and home help) is just over half that cost, at 19 per cent. Training and therapy costs and the reimbursement of support costs are also significant. Non-residential care costs affect the largest number of disabled people (over 220,000, as opposed to some 43,000 in residential care).

Table 2. Expenditure on disability support services, by service category, 2005/2006<sup>17</sup>

Service category	Expenditure (\$million)	<b>%</b>
Residential care	986	36
Carers (non-residential care)	514	19
Training and therapy	460	17
Individual reimbursement of disability costs	417	15
Employment programmes and subsidies	128	5
Equipment	73	3
Assessment	55	2
Modification	24	1
Human aides	13	0
Information and advice	11	0
Miscellaneous	81	3
Total	2,763	100

# **Growth in the number of disabled people receiving income support**

Table 2 does not show the cost of income support payments to disabled people. That cost falls under Vote: Social Development, for Invalids Benefit, Sickness Benefit and New Zealand Superannuation; and to the ACC scheme, for people disabled by accident. The cost of War Disability Pensions falls under Vote War Pensions.

In recent years, the numbers of New Zealanders receiving Invalids and Sickness Benefits have grown. As at September 2008 we had 83,618 people of working age receiving Invalids Benefit and 48,204 receiving Sickness Benefit, compared to 48,957 and 34,217 respectively at September 1998. Much of this growth is accounted for by population ageing, and because people who once would have moved off these benefits when they qualified for New Zealand Superannuation at age 60 years now remain on them until the age of 65 years.

The comparable ACC numbers are 120,583 in 2007/2008 and 104,011 in 1998/1999. 18

The number of children and young people receiving Special Education Services has grown over the same period from 15,954 in 1998 to 23,783 in 2008. 19

# Government provision of employment services, and services to help young people move from school to work

The Ministry of Social Development funds 65 organisations throughout the country to offer a transition service to students who are in their last year at school and who receive funding through the Ministry of Education's Ongoing Reviewable Resourcing Scheme (ORRS). This gives a broad geographical spread of these services. In some instances it gives disabled students and their families a choice of transition service providers and enables students to experience different post-school options.

Through the Ministry of Social Development the government provides individualised funding of about \$17,600 per person per year for vocational services for students with very high support needs as identified by the Ministry of Education, once they leave school and are aged 16 years or over. (This measure of support indicates the individual requires help with daily tasks such as showering and preparing meals.) As at 1 January 2008, 459 people were receiving services through this programme. The exit rate from the programme is low (approximately 5 per cent a year) as the majority of those accessing the funding require assistance in the long term.

The Ministry of Social Development spends about \$85 million a year on funding vocational services for people with generally lower levels of support needs than those described in the paragraph above, but who still require specialist assistance. These services are operated under the Pathways to Inclusion policy. They are spread around the country and are used by approximately 20,000 people a year, primarily by people who have intellectual disability, who experience mental illness or who have multiple and complex needs. Services provided include supporting people to find and keep jobs and to participate more broadly in their communities.

Vocational services also include Business Enterprises (formerly called 'sheltered workshops') that employ disabled people directly (but not necessarily exclusively so).

## **ENDNOTES**

<sup>1</sup> The term 'disability sector' is used in this Briefing to refer to disabled people and disabled people's organisations, their family members and family organisations, disability advocates, and disability service providers (including their umbrella organisations). The aged care and mental health sectors are included within this definition.

<sup>2</sup> The 'ordinary life' concept is elaborated in "To Have an 'Ordinary' Life - Kia Whai Oranga 'Noa'. A report to the New Zealand Minister of Health and the Minister for Disability Issues on community membership for adults with an intellectual disability". This 2003 report from the National Health Committee examines the barriers New Zealand adults with an intellectual disability face in trying to participate in society. It provides evidence for change and outlines practical steps to implement the New Zealand Disability Strategy.

Refer <a href="http://www.nhc.health.govt.nz/moh.nsf/indexcm/nhc-ordinary-life?Open">http://www.nhc.health.govt.nz/moh.nsf/indexcm/nhc-ordinary-life?Open</a>

Post-school qualifications: people aged 25–44 years. Disabled = people currently disabled and who had been disabled during formal education. Source: Education and Training. Unpublished report on 2006 New Zealand Disability Survey data.

Employed full or part time: people aged 15–64 years. Source: Disability in the Labour Market in New Zealand in 2006. Statistics New Zealand, October 2008. Derived from Tables 1 and 2.

## http://www.stats.govt.nz/people/health/dlm-oct08.htm

Personal income greater than \$30,000: people aged 15–64 years (proportion of people specifying income). Source: Disability in the Labour Market in New Zealand in 2006. Statistics New Zealand, October 2008. Derived from Table 5.

#### http://www.stats.govt.nz/people/health/dlm-oct08.htm

Owns (fully or partly) own home: people aged 25–44 years. Source: 2001 New Zealand Disability Survey. Living with Disability in New Zealand. Ministry of Health 2004. Appendix Table 6.7.

<sup>4</sup> The Economic Living Standards of Working Age New Zealanders with Disabilities. Luke Smith, John Jensen, and Steven Johnston. Centre for Social Research and Evaluation. Ministry of Social Development, June 2007 (unpublished).

<sup>&</sup>lt;sup>3</sup> Definitions and sources for Figure 1.

http://www.stats.govt.nz/products-and-services/hot-off-the-press/social-conditions/2006-disability-survey-hotp.htm?page=para002Master

http://www.odi.govt.nz/nzds/progress-review/index.html

Work-related stories sourced from the Australian Employers' Network on Disability.

http://www.employersnetworkondisability.com.au/index.php?option=com.content&task=view&id=23&Itemid=16

Names have been changed.

<sup>10</sup> The New Zealand Housing Strategy sets out a vision and strategic direction for housing up to 2015. It takes a collaborative approach to strengthening the housing sector's ability to provide affordable, quality housing for all New Zealanders. The Strategy was launched in May 2005 following extensive consultation. Many people are involved in implementing the Strategy, including government agencies, the private sector, voluntary and community groups and local councils. Housing New Zealand is leading the implementation of the Strategy's programme of action.

http://www.hnzc.co.nz/hnzc/web/research-&-policy/policy-&-strategy/new-zealand-housing-strategy/new-zea

<sup>&</sup>lt;sup>5</sup> Some people who clearly fit this definition do not identify themselves as being disabled. They prefer to describe themselves in other ways – for example, as older people, people with experience of mental illness, or Deaf.

<sup>&</sup>lt;sup>6</sup> Projections based on age group specific disability prevalence rates from the 2006 New Zealand Disability Survey, and Statistics New Zealand age group specific population projections, base 2006, series 5 (medium birth, death and migration assumptions).

<sup>&</sup>lt;sup>7</sup> Source of data for Figure 3: 2006 New Zealand Disability Survey. Statistics New Zealand. Hot Off The Press, 10 October 2007.

<sup>&</sup>lt;sup>8</sup> New Zealand Disability Strategy Implementation Review 2001–2007.

<sup>&</sup>lt;sup>11</sup> Refer Housing and Disability. Future Proofing New Zealand's Housing Stock for an Inclusive Society. Final Report. Prepared for Centre for Housing Research Aotearoa New Zealand. Centre for Research Evaluation and Social Assessment (CRESA). March 2007.

<sup>12</sup> Refer <a href="http://www.lifetimedesign.org.nz/">http://www.lifetimedesign.org.nz/</a>

<sup>13</sup> The New Zealand Carers' Strategy was published on 28 April 2008. The Carers' Strategy is supported by a Five-year Action Plan to begin addressing some of the issues that impact on the thousands of New Zealanders who assist friends and family members that need help with everyday living because of ill health, disability or old age.

The Carers' Strategy was developed in a partnership between government agencies and the New Zealand Carers Alliance, a network of over 40 non-governmental organisations. The Carers' Strategy envisions New Zealand Aotearoa as a society that values individuals, families, whanau or aiga who support others who need help with their everyday living.

Refer <a href="http://www.msd.govt.nz/about-msd-and-our-work/work-programmes/policy-development/carers-strategy/">http://www.msd.govt.nz/about-msd-and-our-work/work-programmes/policy-development/carers-strategy/</a>

<sup>14</sup> Improving Long-term Disability Supports: Maintaining Momentum. March 2008 Cabinet paper.

http://www.odi.govt.nz/what-we-do/review-dss/index.html

<sup>15</sup> Inquiry into the quality of care and service provision for disabled people. Report of the Social Services Select Committee. September 2008.

http://www.parliament.nz/NR/rdonlyres/06259D2F-780B-40A0-9170-005C8C046E72/93089/DBSCH\_SCR\_4194\_6219.pdf

<sup>16</sup> Source: A Picture of Government Funded Disability Support Provision in New Zealand. Structure, Expenditure and Populations in the financial year 2005/2006. Hinrich Kozik, unpublished, Ministry of Social Development, June 2007. pp 22–23.

Given expenditure does not include all national office overheads for all agencies as some accounting practices incorporate these expenses with general overheads and it is difficult to identify them. Also excluded are Income Support payments, clinical services, and services for people with short-term illness. Figures are GST exclusive.

<sup>17</sup> Source: A Picture of Government Funded Disability Support Provision in New Zealand. Structure, Expenditure and Populations in the financial year 2005/2006. Hinrich Kozik, unpublished, Ministry of Social Development, June 2007. p 24.

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Also excluded are Income Support payments, clinical services, and services for people with short-term illness. Figures are GST exclusive.

- <sup>20</sup> Pathways to Inclusion, the government's policy on vocational services for disabled people, was launched in 2001. It has two main goals:
- to increase the participation of disabled people in employment
- to increase the participation of disabled people in their communities.

Pathways to Inclusion provides a policy framework for the overall development of vocational services for disabled people and fits within the overarching policy of the New Zealand Disability Strategy.

<sup>&</sup>lt;sup>18</sup> New entitlement claims (covering all accounts: work, motor vehicle, earners, non-earners and treatment injury). Data provided by the Department of Labour.

<sup>&</sup>lt;sup>19</sup> Source: Ministry of Education.