# Work in Progress

## 2004–2005

Fifth annual report from the Minister for Disability Issues
to the House of Representatives on implementing
the New Zealand Disability Strategy

# Work in Progress

## 2004–2005

Fifth annual report from the Minister for Disability Issues
to the House of Representatives on implementing
the New Zealand Disability Strategy

*Work in Progress: 2004–2005* was published in December 2005
by the Office for Disability Issues, Ministry of Social Development.

Report presented under the New Zealand Public Health and Disability Act 2000
(section 8).

ISSN 1176-5453

This document is available electronically on the following website:
www.odi.govt.nz

It is also available in alternative formats on request from:

Office for Disability Issues
Ministry of Social Development
PO Box 1556
Wellington
phone: (04) 916 3300
fax: (04) 918 0075
email: odi@msd.govt.nz

Cover photo: Alice Leslie at Sea Scouts in Evans Bay Wellington.
Photo by Sally Thorburn.

# Contents

# Minister's foreword

I am very pleased to present this fifth progress report on implementation of the New Zealand Disability Strategy.

The Disabled Persons Assembly said in last year's report that it was "time to raise the bar". I believe this report is doing this, and that it will help build on the momentum of activity aimed at creating a non-disabling society.

For the first time the progress report presents the voices and stories of disabled New Zealanders and their families. These give a much richer picture of the situation for disabled New Zealanders in 2005. I urge you also to look at the complete stories on the Office for Disability Issues website. They are a powerful presentation of the issues and opportunities associated with implementing the Disability Strategy.

Also for the first time, this report presents a set of measurable indicators to help focus information on outcomes as well as describing activity and giving a more general sense of trends.

I am particularly interested in the information about government websites. The internet is becoming increasingly important for accessing all sorts of information and services from government. To make best use of these developments and the opportunities to improve participation for disabled people, it is critical that the websites are accessible to all of us. Government agencies have reported activity to improve accessibility of their websites, and the survey outlined in this report shows how well they are doing and what more they need to do.

The report has a few stories mainly about community-based initiatives around the country that make a real difference in the lives of disabled people. This is not a comprehensive look at nationwide activity, but it gives a sense of what can be done, and it should be an inspiration to people in a position to support such initiatives.

Our government will be continuing its real commitment to "making a world of difference". I believe this report not only describes significant progress towards our goals but also contributes to increasing understanding about disability in New Zealand.

**Hon Ruth Dyson**
Minister for Disability Issues

# Message from the Disabled Persons Assembly

It is satisfying to note that government agencies have made the New Zealand Disability Strategy a regular part of their annual planning and reporting cycle. And it's encouraging to see the growing number of crown entities and territorial authorities willingly taking part in Strategy implementation, even though they are not required to.

But there is still much to be done. All territorial authorities and district health boards should follow the example of their colleagues who have joined with government departments in making the Strategy a guiding force in addressing disability issues. After all, it is these bodies that have an immediate impact on the quality of our lives – and in many instances, our very existence.

Information, the key to power and control, still remains inaccessible in many cases. A recent survey of government websites revealed many inadequacies and gaps in the usability of websites by disabled people. And if the state of government websites is patchy, the websites operated by non-government disability organisations are in even more parlous condition. And at a societal level, not enough has been done to give effect to the Strategy's most critical objective: to educate for a non-disabling society. We still desperately need a well-resourced, well-planned public campaign directed at removing the stigma and discriminatory attitudes associated with disability.

An impressive addition to this year's progress report has been the inclusion of our stories. They are powerful illustrations of the ways in which our lives can either be valued and enhanced, or devalued and excluded.

They also pose a crucial question: how can we know if, and when, the Strategy's objectives are making a difference? When will we see the improvements in educational achievement; the rights of employment and decent income taken as read; access to transport, health and personalised services realised; exercising recreational, cultural and lifestyle choice become a matter of course? This report presents indicators of progress in all these areas, which is a useful addition. However, these need to be translated into milestones for departments to aim at.

We expect that the Strategy will be reviewed soon. Without wishing to anticipate too much about the future, at the very least we will expect our voices to lead, guide and inform that process.

**Mike Gourley**
President DPA New Zealand

# Introduction

## The structure of the report

This report has five chapters consistent with action areas or themes within the New Zealand Disability Strategy. These themes are shown in the diagram below (this information is also on the contents page).

**Inclusive and non-disabling society**

**1 Upholding citizenship**

Encourage and educate for a non-disabling society

Ensure rights for disabled people

Foster leadership by disabled people

**2 Building government capacity**

Foster an aware and responsive public service

Collect and use relevant information about disabled people and disability issues

**3 Improving disability support services**

Create long-term support systems centred on the individual

**4 Promoting participation by disabled people in all areas of life**

Provide the best education for disabled people

Provide opportunities in employment and economic development

Support quality living in the community

Support lifestyle choices, recreation and culture

**5 Addressing diversity of need**

Promote participation of disabled Māori

Promote participation of disabled Pacific peoples

Enable children and youth to lead full and active lives

Promote participation of disabled women in order to improve their quality of life

Value families, whānau and people providing ongoing support

Progress for people with intellectual disabilities

Each of the 15 Strategy objectives is presented in the report with:

- measurable indicators
- latest trends and data
- a description of activity over the 2004–2005 year
- gaps and opportunities for further work.

This information is complemented by excerpts from stories of disabled people and families and case studies of good practice.

## Improving things for disabled people

> In 10 years from now I would like to be part of a society that is empathetic but not sympathetic and inclusive but not patronising to disabled people. I would like to see disabled people participating fully in society in their own way and people accepting that there are many ways to contribute, many ways to live life.
>
> Kent, *Life is for Living*, to be published at www.odi.govt.nz

The Disability Strategy was launched in 2001 following extensive consultation, and continues to be embraced by government and the disability sector. The Strategy has a clear set of ideas and agreements about what an inclusive society for disabled people and their families would look like and what actions will help make this happen.

Government agencies are required to develop annual disability strategy implementation plans. Thirty-six departments and five Crown entities developed plans for the 2005–2006 year and these are published on the Office for Disability Issues website. Forty-one agencies also reported on their activities for the 2004–2005 year to contribute to this annual report to parliament required under the New Zealand Public Health and Disability Act 2000.

Writing reports about how things are going with the Strategy is more than a compliance exercise. The reports record and build our knowledge and understanding of disability issues and of the strategies to address these issues. This fifth annual report shines a spotlight on disability in New Zealand and promotes activity to implement the Disability Strategy.

## Illuminating disability issues and progress on addressing them

The relative importance of different kinds of information and knowledge has been hotly debated. However, there is consensus that the best results are found using a mixture of information types and sources. This report uses subjective and objective information and quantitative and qualitative research to provide measurable, as well as more descriptive and anecdotal, indicators of progress. The result is a snapshot or overview of what we know about the issues, activities and outcomes facing disabled New Zealanders and their families during 2004–2005 and any trends of change.

## Using real life stories

> Make our realities heard in our voices.
>
> *Life is for Living*, to be published at www.odi.govt.nz

For the first time the "voices" and "faces" of disabled people and their families are woven throughout the report. True-life stories bring a human dimension to the official statistics and remind us of the significance of work done to address disability issues. These stories along with other information sources build on previous reports to give us a clearer picture of the situation of disabled people.

Many of the voices and faces in this report are excerpts from stories to be published by the Office for Disability Issues. They are based on a series of interviews, undertaken mainly in July 2005, and will be available at www.odi.govt.nz.

## Using measurable indicators

…I've seen some changes for the better in the last two to three years in access issues.

Three years ago I couldn't catch buses from my place to town because they all had stairs. Now all buses that go from my place to town have ramps. I think a lot of places are becoming more accessible for disabled people. People are looking for ways to get people with disabilities out into the community, to shops or movies or whatever.

We have a piece of documentation now [the Disability Strategy] that says "this is what we want" and it has encouraged owners of places to be more aware of the needs of people with disabilities.

It would be really cool if people had more "big picture" awareness of our needs – not just an awareness of a need to provide ramps.

Red, *Life is for Living*, to be published at www.odi.govt.nz

The Disability Strategy employs a pan-disability and cross-government approach to disability issues, which inherently involves generalised and high level objectives. However, to measure progress towards outcomes it is useful to focus on how some more specific things would look if we achieved or were moving towards the objectives of the Strategy. To do this the report presents indicators under each objective. The full set of 21 indicators is outlined at the end of the document. While most indicators relate to long-term outcomes some are shorter-term milestones or conditions that contribute to the achievement of longer-term outcomes.

To be precise and measurable the indicators are less comprehensive than the Strategy objectives. They "indicate" progress rather than prove it; we need to draw on other information for the full picture. Moreover, choosing indicators is limited by what information is or can be made available. There will be opportunities to refine and add to the indicators in the future.

The indicators and related data in this report tend to show the situation at a particular point in time. They provide a baseline from which to measure future change. For example, many of the indicators draw on the post-census 2001 Disability Survey, which describes the situation at the time the Strategy was launched. We will have better trend data after the 2006 census.

## What has been happening to create a non-disabling society – a summary

The report includes examples of good practice by government, local authorities and non-government agencies. The picture is not complete but covers the range of activities under way to address disability issues.

The structure of the report does not reflect a hierarchy of priority, nor are the themes mutually exclusive. Progress towards the vision of the Disability Strategy requires simultaneous progress; work towards one objective may contribute to several or all themes. Collectively the objectives of the Disability Strategy aim to:

1. **uphold citizenship,** by fostering society's ability to include disabled people. Chapter one highlights include the Like Minds project and its evaluations, negotiations on the United Nations Convention on the Rights of Disabled People, initial work to improve advocacy services, development of a nominations service for the appointment of disabled people to Crown boards and committees, the establishment of a national disability advisory council and local authority disability reference groups, and improved access to voting. To build on the momentum created, there should be more opportunities for co-ordination and idea sharing. In particular, we need to learn more about what mix of activities will work best to ensure individuals and systems in society do not exclude disabled people. It is clear this will include initiatives that raise the visibility and promote the leadership of disabled people.
2. **build government capacity,** by ensuring agencies have the necessary knowledge, skills and systems to address disability issues and to be responsive to disabled people. Chapter two provides information for the first time on how accessible government websites are and how to improve them. A highlight here is the increase in the collection and use of disability information by government.
3. **improve disability support services,** ensuring disabled people are able to make ordinary choices and have ordinary responsibilities in their lives. Chapter three summarises some of the ongoing issues around providing support services, and current interagency policy development under way to address these issues.

4 **promote participation by disabled people in all areas of life,** by identifying and maximising opportunities in all sectors of the community. Chapter four shows evidence of work being done to improve access to, and choice in, education, employment, housing, the built environment, transport, communication, health services, sports and recreation, arts and culture and relationships. However, there is also plenty of room for improvement.

Most of the information about the outcomes for disabled people in this chapter is based on 2001 data. We will not have a good picture of what has changed until the next post-census Disability Survey in 2006.

5 **address diversity of need,** by acknowledging that in addition to common issues, there is huge diversity amongst disabled people. Chapter five outlines activity and issues specifically related to disabled Māori, Pacific people, children and young people and disabled people's families.

Chapter five also updates progress made towards better addressing the needs of New Zealanders with an intellectual disability, in response to the National Advisory Committee on Health and Disability report *To have an Ordinary Life*. Since 2001 when the Disability Strategy was released, there have been other government directives and reports on disability issues. To streamline planning and reporting activity, co-ordinate work across government and ensure progress on disability issues, it is useful to integrate the planning and reporting arrangements.

THOMAS

# Chapter one: Upholding citizenship

A society in which we all have the chance to reach our potential is good for all New Zealanders. Disabled people and their families aspire to have the sorts of ordinary choices, rights and responsibilities that others expect and experience in their lives.

A fair go
for all

## Objective 1: Encourage and educate for a non-disabling society

Indicator 1: Level of public understanding and knowledge about disabled people and disability issues.

Disabled people have often identified negative public attitudes and behaviour as a major barrier to their enjoyment of full citizenship. Key components of the Disability Strategy's tactics for addressing these barriers include public education, promotion of rights and fostering leadership of disabled people. Together these activities should help to improve attitudes and behaviour towards disabled people. Progress towards this goal will be evident when an increasing percentage of the population demonstrates knowledge and understanding of how the infrastructure, systems, attitudes and behaviour within the community can disable people.

> …these days I have a lot more self-esteem and confidence, but the biggest thing that impacts on my self-esteem is other people's ignorant attitude towards me. When I am out there, getting on with my life to the best of my ability, I come into contact with people who say and do stupid things to me, about me, and in front of me... It really makes it difficult, but it is also why I make the effort to get out there and try to do normal things, to show these ignorant people that I'm not actually that different.
>
> My friends, family and boyfriend all treat me like a "normal" human being and, to be fair, there are a reasonably large number of people in society who treat disabled people as they should be treated, with respect and no discrimination.
>
> But there are some people who have no idea how to relate to impaired people, and that is quite sad… It would be great to think that, in the future, society will change and the ignorance surrounding the way people with impairments are treated will disappear and there will be a whole lot more respect for everyone in society.
>
> Anna, *Life is for Living*, to be published at www.odi.govt.nz

### *Latest trends and data*

Currently there is no baseline information on the general knowledge the public has about disability across all impairment types. However, there is a raft of reports and evaluations assessing the understanding and attitudes in New Zealand towards mental illness and, more specifically, assessing discrimination against people with experience of mental illness. The latest of these include:

- Comprehensive evaluation of the Ministry of Health Like Minds project, including major attitude-tracking surveys, which show significant progress has been made over the last eight years. Evaluation findings can be seen at www.likeminds.govt.nz.

> Commenting on some of these [Like Minds project] evaluation findings, Auckland University Director of Clinical Psychology, Dr John Read, said the change in attitudes was … "brilliant news"… "Stigma is such a powerful inhibitor of people's recovery." The campaign had succeeded "because they have genuinely involved users of mental health services right from the beginning in planning and delivering it". This applied to the ads and to the regional work, such as visiting schools and community groups. Dr Read said "contact with those with mental health difficulties breaks down the stereotypes – once you've met someone; that tends to change your attitude".
>
> Johnston, M. 2005

- *Discriminating Times? A re-survey of New Zealand print media reporting on mental health* published by the Mental Health Commission in 2005. This survey repeated a systematic survey of print media in 1997 and 1998 and found a significant improvement in the way people with experience of mental illness were represented by the print media.

> There is some welcome evidence in this survey that attitudes among journalists are changing. Many reporters are beginning to recognise that hostile or unconsidered reporting on mental health issues is as damaging and unbalanced as, say, openly racist or sexist reporting…
>
> Perhaps the most important new influence discussed in this survey is the growing confidence of the users and providers of mental health services. Previously hidden, these mental health advocates are finding their voices – becoming visible and available participants in the public discourse around mental health issues…
>
> (Pattrick Smellie – excerpt from the foreword of *Discriminating Times*, June 2005)

- *Journeys Towards Equality: Taking Stock of New Zealand's Efforts to Reduce Discrimination Against People with Experience of Mental Illness,* launched by the Mental Health Commission in 2004. This report found that anti-discrimination work has grown enormously in the last decade, to the extent that it now makes sense to talk of a mental health anti-discrimination sector. Ten years ago there was no Mental Health Commission, Like Minds project or Office for Disability Issues, but now New Zealand has organisations to enable progress. The report can be viewed at www.mhc.govt.nz.
- *Respect Costs Nothing,* published by the Mental Health Foundation in 2004, reports the findings from a survey of 785 people with experience of a mental illness. This survey reveals that people who have experienced mental illness have often also experienced discrimination in all aspects of their lives – from employment and housing to discrimination by friends, family and the community. The survey also found that fear of discrimination (often based on past experience) is as crippling as discrimination itself. Fear prevents people from undertaking many activities in their lives. Survey findings can be viewed at www.mentalhealth.org.nz.

> I have seen a little bit of change in attitudes over the last couple of years, but it will take more than the Disability Strategy to wake up everybody's minds. There needs to be more information out there, whether it is through media or anywhere else, to help shift people's ideas and attitudes and to allow disabled people to do their own thing as who they are - not as "so and so with an impairment".
>
> Matthew, *Life is for Living,* to be published at www.odi.govt.nz

## Public education and anti-discrimination programmes

The most substantial disability-related, anti-discrimination programme in New Zealand is the Like Minds project to counter stigma and discrimination associated with mental illness. This project was initiated by the Ministry of Health in response to the findings of the 1996 "Mason Report".

> It is fundamentally wrong that a vulnerable group in our society should be continually subjected to the comments and actions of those who possess an outcast mentality… We are optimistic enough to believe that a well-informed New Zealand public will realise that [people with a mental illness] are people whom we should nurture and value.
>
> Judge Ken Mason, *Inquiry into Mental Health Services,* New Zealand 1996

It was clear from the outset that the Like Minds project was breaking new ground and needed to take a long-term view. The initial budget was $12.6 million over five years beginning in 1997, for both nationwide and community-based programmes. The project has since become a core component of public health services and includes mass media advertising as well as a diverse range of advocacy and awareness-raising initiatives.

There is more work to be done to uphold the rights of people with experience of mental illness, and a need to better co-ordinate with the wider disability and human rights sectors. The Mental Health Commission, the Human Rights Commission, the Office for Disability Issues and the Like Minds project have developed a multi-agency plan, available at www.mhc.govt.nz, which identifies complementary and joint activities. This work will not only enhance efforts to address barriers for people with experience of mental illness but will also strengthen and initiate work for the wider disability sector.

Beyond the Like Minds project, some general disability public education is under way, but, it is neither co-ordinated nor comprehensive. During the 2004–2005 year:

- The Department of Labour and Ministry of Social Development worked to improve employers' attitudes towards disabled people. This work and other government activity to educate particular sectors are described in chapter four of this report.
- The Ministry of Health funded a package of work to promote the Disability Strategy. This included a contract with the Ripple Trust to promote the Strategy in the Auckland and Northland corporate sector.
- The Auckland Disability Providers Network developed and launched a Disability Strategy toolkit, "Kia Rangatu Moving Forward", to an audience of Auckland dignitaries and business people. The kit is aimed at disability providers and organisations such as councils, or businesses that wish to give their staff a working understanding of the Disability Strategy and help with its implementation.
- Air New Zealand produced a video to train their frontline staff in disability awareness. The video aims to improve staff understanding of the needs of customers with vision or mobility impairments, as well as those of people with learning disabilities or epilepsy.

This list of public awareness initiatives is by no means comprehensive but rather illustrates the range of activities. Most non-government organisations with a focus on disability, such as CCS, DPA, the Royal New Zealand Foundation of the Blind, the Deaf Association and IHC undertake some awareness-raising activities and information-sharing services in relation to the population groups they work with.

### The Nelson Hearing Association Inc

The President of the Nelson Hearing Association says that in addition to providing a range of services for people with hearing impairments "the Association focuses on educating the hearing community and facilitating good communication between the hearing and the hearing impaired.

I offer a one-hour training programme for customer service staff on how to communicate with hearing impaired customers/clients and have trained staff in local stores, in banks, and government departments. Staff at Nelson City Council and the Tasman District Library staff have received the training. We are now looking at condensing this training into a small booklet which smaller organisations can use to provide individual training for new staff."

The Association has also been active in schools. More than five years ago an anonymous benefactor donated $32,000, which allowed the Nelson Association to develop a kit called "Hear More or Less" to be printed and distributed to schools in the Nelson and Tasman areas and other Hearing Associations in New Zealand.

In 2005 a teacher at a Nelson school commented: "I used the Hear More or Less kit at the beginning of this year. I have a hearing impaired student in my class and although some of the students have been in his class for a while I wanted us all to find good ways to work together.

"We used the equipment and the students experienced for themselves what it was like to lose hearing. Our hearing impaired student related to the situations in the kit and shared his own story with the class. We tested out the sound level of noises in our environment. Our hearing impaired student is always included in the class but now the students make sure that he is looking when they speak to him, and speak clearly, no turning away as they are talking. They are more understanding if he misunderstands them or has to ask a question to be sure he has understood something. It has helped our class understanding – the kids are better equipped to include him, and he knows the kids understand his hearing issues a lot better."

JOCELYN BURKE, THE NELSON HEARING ASSOCIATION OFFICE MANAGER AND CHALKIE WHITE, A CLIENT

### *Gaps and opportunities in awareness raising activity*

Most of the activity reported in this section focuses on people with mental illness. This reveals a deficit for the wider disability sector, which arguably has an equal need. There need to be opportunities for sharing knowledge and building on what works.

> When I think about how society relates to disabled people the word naivety comes into my mind… I don't think people are hostile, just ignorant or uneducated. When I see those "know me before you judge me" TV advertisements about mental illness I wish there were a few ads like that about cerebral palsy, muscular dystrophy or spina bifida. I think "disability awareness" is such a cliché – it is more than just making sure places have ramps. It's about educating and informing people about different types of disability and what they can do to not make people with disabilities feel so alienated.
>
> Red, *Life is for Living*, to be published at www.odi.govt.nz

We can use the experience of the mental health sector to inform activity in the wider disability sector. Evaluations of the Like Minds project give a good indication of what works best and needs to be further developed. In particular, we need to increase the visibility of disabled people across society and ensure they lead processes for educating the public. We also need to gather better information on the attitudes and behaviour of the public towards disabled people and disabled people's experience of discrimination.

## Objective 2: Ensure rights for disabled people

**Indicator 2: Level of knowledge and understanding of the rights of disabled people amongst key decision makers, legal practitioners, advocacy agencies and disabled people and their families.**

Good public understanding of rights in relation to disabled people and disability issues helps to ensure the motivation and capacity within society to honour those rights.

Improvements in this indicator would reflect movement towards an intermediate outcome of better public recognition of the human rights of disabled people. This contributes to the long-term goals of an inclusive and non-disabling society.

### *Latest trends and data*

There is no data as yet that indicates the level of public knowledge of disabled people's rights in New Zealand. However, we now have, for the first time, an assessment of the status of human rights in New Zealand for disabled people. The Human Rights Commission published *Human Rights in New Zealand Today: Nga Tika Tangata o te Motu* in September 2004 after an extensive process of consultation.

The report concludes that disabled people are among the most disadvantaged citizens in the country. It identifies pervasive barriers to the full enjoyment by disabled people of their rights, and notes that disability is largely invisible at societal and national levels, partly as a result of the status of disability in human rights frameworks.

However, the Human Rights Commission report, along with other recent activity in national and international arenas, is increasing the visibility of the issues and rights of disabled people.

## Championing disability rights within the international community

Detailed research and analysis by the international disability community highlighted the need for a disability-specific international convention to ensure that disabled people are able to effectively access the human rights to which they are entitled. In 2001 the United Nations agreed to establish an ad hoc committee to consider proposals for a binding convention to promote and protect the rights of disabled people. New Zealand is playing a lead role in the negotiation of this convention, which began in earnest in 2004.

The national processes involved in preparing for the negotiations generate benefits by increasing the visibility of disability issues and human rights commitments across government agencies. The international negotiating process helps to clarify human rights norms and builds domestic and international legal expertise on disability rights. Once adopted and in force the convention should, as far as New Zealand is concerned, reinforce existing domestic strategies and legislation. It is likely the Convention will establish an international mechanism to oversee implementation of and compliance with it.

The New Zealand Government's strong support for these negotiations has been recognised by national and international disability organisations. In April 2005 New Zealand's (then) permanent representative to the UN in New York, Don MacKay – who had been acting as co-ordinator of the negotiations since 2003 – was appointed Chair of the ad hoc committee. This is a significant honour and achievement for New Zealand.

"This major human rights convention represents a shift in the way governments interact with persons with disabilities… Many have said that the rights of persons with disabilities are already guaranteed in existing human rights treaties, but the reality is that persons with disabilities have been deprived of those rights."

…Don MacKay, Chairman of the ad hoc committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities, highlighted the importance of the draft instrument not only for some 600 million people with disabilities around the globe, but also for the United Nations, which had an opportunity to demonstrate, once again, that it could come up with a convention that would directly impact people's lives.

*continued over...*

*continued from previous page...*

A large number of States were participating in the negotiations, he continued. The convention enjoyed support from civil society groups. Some 400 civil society representatives had registered for the meeting – the biggest number ever. Their active participation in the drafting process had given "a very unusual flavour" to the negotiations. The participants had been very focused on the issues, and there had been genuine interaction on the text and proposals. It had not been a United Nations meeting where "people are sitting there reading prepared statements at each other".

Excerpts from United Nations press release and press conference in February and August 2005 www.un.org/News/briefings/docs/2005/

The Office for Disability Issues, in association with the Ministry of Foreign Affairs and Trade and in partnership with representatives of disabled people, co-ordinates New Zealand's involvement in the negotiations.

Consultation with government agencies and disability NGOs was undertaken during July and December 2004 and June to August 2005. This informed the development of instructions for delegations to three separate two-week negotiations at the United Nations.

Over the last year, New Zealand has made numerous and influential interventions. These are recorded in summaries of the proceedings posted on www.un.org/esa/socdev/enable. In particular, New Zealand's interventions have addressed a non-institutional approach to disability services, the legal capacity of all disabled people, minimisation of forced treatment, recognition of sign languages and the separation of the concept of equal access to health services from ideas around rehabilitation and participation of disabled people in all activity that affects them.

New Zealand delegations to the United Nations have continued to model partnership between government officials and disabled New Zealanders, and have included representatives from the Human Rights Commission, the Mental Health Commission and the Disabled Persons Assembly. The Human Rights Commission has also participated in the Asia-Pacific Forum of National Human Rights Institutions, which continues to contribute to the development of the convention.

Negotiations on the first draft of the convention are now complete. The ad hoc committee is ready to move to a second stage of negotiations on an updated draft prepared by the New Zealand Chair. This phase will be focussed on achieving agreement on a final text for adoption.

## Promoting the rights of disabled people within New Zealand

*Mana ki te Tangata: The New Zealand Action Plan for Human Rights* was launched by the Human Rights Commission in March 2005. It has a dedicated section on "Getting it right for disabled people", while the overall plan has more than 40 proposed actions directly related to disabled people. It is a significant milestone in terms of raising the profile of disability rights and knowledge of their neglect.

The government has welcomed the plan and is in the process of developing a detailed response. Many of the proposed actions relating to disability are already under way.

The Office for Disability Issues has asked government agencies to include information related to the action plan in their annual Disability Strategy plans and progress reports. This will help streamline future national or international reporting on the human rights of disabled New Zealanders.

The Human Rights Commission has also piloted resources for people with experience of mental illness to provide rights education. The resources include a facilitators' manual and participants' handbook. Three networks of trainers, known collectively as Korowai Whaimana, have been recruited and trained. Ways to support and develop trainers are now being investigated and trialled.

### *Gaps and opportunities to improve legal expertise about disability rights*

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. Avoiding discrimination against disabled people will not only involve treating them equally but taking steps to ensure they have equal access to a service. Employers can make changes to ensure a disabled person can do a job, or providers can provide ramps to ensure disabled people can access a service. Making such changes to accommodate a disabled person is known as "reasonable accommodation". There are exceptions from human rights law if it is not reasonable to expect employers or providers to provide an accommodation.

However, interpretation of what is considered "reasonable" is not always agreed and law in this area is evolving here and overseas. Better realisation of human rights for disabled people will require further articulation of what provisions or accommodations are reasonable to expect. This work will occur through the UN convention as well as through evolving jurisprudence. The challenge for government is to use these developments to provide a framework to change expectations across society.

## Improving access to personal advocacy services

Over the 2004–2005 year the Accident Compensation Corporation (ACC) worked to improve their advocacy service. Telephone advocacy services are now available through an 0800 line, and an advocacy liaison co-ordinator has been employed to enhance working relationships with community advocacy groups.

The Office of the Health and Disability Commissioner also reports a number of initiatives to improve access to their advocacy services. These include:

- an audio version of key information, available on CD from public libraries
- an accessibility checklist for staff to use when organising off-site events

- disability awareness training for staff
- three think tanks with the disability sector to identify initiatives for raising disabled people's awareness of rights
- the development of a co-presenter/co-facilitator package for presentations to disabled persons. A group of disabled people, including Māori and Pasifika persons, were identified to deliver it.

The Office for Disability Issues has initiated work to develop options for the provision of personal advocacy and communication services for people with an intellectual disability in the context of wider work on advocacy for disabled people. Initial work has included a literature review and consultation.

> I used to be very good at advocating for others, and for myself, but I am realising that when you are fatigued and not well it is a real struggle to get access to service providers and have them listen and deliver services.
>
> Max, *Life is for Living*, to be published at www.odi.govt.nz

### *Gaps and opportunities to improve advocacy services*

A range of advocacy services is available to disabled people in New Zealand:

- the Health and Disability Commissioner and the Human Rights Commission provide advocacy services bound by a legislative framework for longer-term dispute resolution (rather than immediate support with an issue)
- complaints processes attached to particular services or sectors, such as the Tenancy Tribunal, district health boards and work and income services
- community law centres.

However, these services are sometimes provided by people who do not have particular expertise in, or understanding of, disability issues. Moreover there are significant gaps for some advocacy needs and some impairment types. Work is needed to improve advocacy services, including capacity building initiatives for people currently working in advocacy roles.

## Objective 5: Foster leadership by disabled people

Two indicators for this objective focus on leadership in the public service and government boards and bodies. The government has a commitment to ensuring balanced representation on Crown bodies and in the public sector to reflect wider New Zealand society, and to strengthen connections with stakeholders.

It is also important to recognise successful disabled people in all parts of society. The increased visibility of successful disabled people provides positive role models for the disabled and non-disabled population and helps to raise community expectations.

> My vision for our society 10 years from now is that people will realise that yes, we are all different; not just in our hair colour, country of origin and values, but that some of us have an impairment and can be different too. However we all have skills and can make a contribution to our communities in our own way. Hopefully we will see more people with impairments out and about in the community, taking leadership roles and taking part in everyday activities, going to work and being able to make choices about their lives.
>
> Gail, *Life is for Living*,
> to be published at www.odi.govt.nz

## Promoting disabled leaders in government and state sector governance bodies

### Indicator 3: Number of disabled people appointed to government boards or bodies.

To assist appropriate representation of disabled people at governance levels, the government allocated in its 2005 Budget $568,000 over the next four years for the Office for Disability Issues to establish and maintain a nominations service to promote the appointment of disabled people to Crown boards and committees. The funding will also provide appropriate training to develop the skills and experience of potential nominees.

Once this project is up and running there should be data available to measure trends.

### Indicator 4: Number of disabled people in governance or management roles in the public sector.

The government should be a role model for other employers and ensure disabled people are represented in the public service at a similar rate to their numbers in the population. Moreover, they should be represented at management and governance levels. The government is in a good position to lead the way in making better use of the often untapped potential of disabled employees.

### *The latest trends and data*

In 2002, the State Services Commission published a report on the *Career Progression and Development Survey, 2000.*

The survey found that within the public service:

- disabled people had similar jobs and similar earnings to other staff
- disabled public servants tended to be older than other public servants
- 18% of disabled staff (compared to 11% of others) cited a lack of support from their manager as having deterred them from applying for a promotion
- 38% of disabled people (compared to 26% of others) rated their access to high-profile work as "poor"
- 34% of disabled people (compared to 19% of others) reported having experienced unfair treatment on the basis of a personal characteristic.

The report also provided information on the public service workforce. As at June 2000, based on the Human Resource Capability Survey data, this showed that:

- 10% of public servants reported having a disability
- 9% of public sector managers reported having a disability.

The State Services Commission is repeating the Career Progression and Development Survey in 2005 and findings will be reported by the end of the year. The 2002 report and findings from the new survey will be available on www.ssc.govt.nz.

Some government agencies reported on the number of their staff who identified as disabled for the 2004-2005 year. This information is not reliable, however, as it is based on self-reporting and there are disincentives to identifying as disabled. Also, the data are not often updated after someone has joined a department.

The State Services Commission is concerned about the usefulness of the disability data collected via the Human Resource Capability Survey. Concerns initially arose because this data showed a steady decline in the representation of disabled staff, from 11% in the public sector in 1998 to 7% in 2002. This was well below the 15% that Statistics NZ reported which is likely to be due to differences in definitions between Statistics NZ post census Disability Surveys and the State Services Commission surveys.

In July 2005, the State Services Commission completed a review of disability data collection across the public sector with recommendations to improve the situation.

### *Activity to support the recruitment and promotion of disabled public servants*

A number of departments reported activity during the 2004–2005 year designed to develop and support their disabled staff. For example:

- the State Services Commission continued to promote the "Mainstream" supported employment programme to 147 eligible state sector organisations. The programme supported over 200 placements. The Commission also held a seminar for all state sector human resource managers to promote good practices for disabled staff

- the New Zealand Police, National Library, Ministry of Education and the Department of Internal Affairs have established and supported networks for their disabled staff
- the Police actively promoted their disability network and developed articles for their disability intranet on the benefits of employing disabled people
- the Ministry of Health updated their database on the recruitment of disabled people, access to equipment and workplace support strategies and services
- several agencies reported that appropriate ergonomic equipment and software is available for disabled staff.

### *Gaps and opportunities to support participation and leadership by disabled people in the public sector*

While there has been increased activity aimed at building the capacity of disabled employees in the public service, there is a lot more to be done. In particular, a proposal to develop a disabled staff network across all agencies may be a useful initiative.

## Promoting leadership in the disability sector by disabled people

An underpinning principle of the Disability Strategy is that the voices, experiences and wisdom of disabled people and their families should play a larger role in informing policy decisions. This will help ensure barriers to participation are not ignored or created, and that opportunities for positive change are recognised.

> If implementing the Disability Strategy means making service providers accessible and accountable, and it means disabled people are given more opportunities to advocate for themselves, and the solutions they propose are adopted, then there will be a constructive way forward for disabled people. I've spent a good part of my life advocating for services, but I never raise an issue without offering a workable solution. I'm sure most consultation with disabled people is like that, focused on practical, workable solutions to real problems.
>
> Max, *Life is for Living*, to be published at www.odi.govt.nz

Government agencies reported an array of initiatives seeking to better engage with disabled people and families for the 2004 -2005 year:

- The Office for Disability Issues established the Disability Advisory Council in May 2005. Its primary function is to provide advice to the Office on progress in implementing the Disability Strategy and any emerging issues. The Council is made up of disabled people and their families selected by consumer organisations nominated by the Office. It does not include representatives from professional bodies, providers or funders.

THE DISABILITY ADVISORY COUNCIL

- A Consumer Outlook Group meets every two months with ACC senior managers to promote an understanding of ACC claimants, help ACC gather information on matters related to effective delivery of services and give ACC the chance to share relevant information with key organisations that represent consumers.
- ACC appointed one of their disabled employees to the Social Commission of Rehabilitation as Chair and consulted with disability groups in the development of a health purchasing strategy for 2005-2006.
- The Health and Disability Commissioner developed a database of disabled individuals and disability networks available for consultation.
- Statistics New Zealand established a reference group, including representatives of disabled people and families, to inform the development of the next post-census Disability Survey.
- The Ministry of Health held nine forums with disabled people as the first stage of implementing their Consumer Participation Project, which aims to increase the involvement of disabled people and whānau in Disability Services Directorate activities.

It is very pleasing to see a number of local authorities have set up disability reference groups. In particular, Whangarei, Auckland, Hamilton, Wellington and Christchurch councils provide welcome role models for other councils to follow.

Reference groups ensure that issues affecting disabled people are heard by the council, that workable solutions are developed and future planning considers them. Some councils have also appointed disability liaison officers who work with the reference groups to progress initiatives.

## Key elements of creating Absolutely Positively Accessible Wellington

- The council holds an Accessible Wellington Forum attended by all senior council managers. It is an opportunity for the community to discuss disability issues in the city.
- In 1996 a Disability Reference Group was established as an avenue for community issues and information to be brought to the council and as an expert advisory group. Kaeti Rigarlsford has been on the Group for five years and has served a term as rotating chairperson. She says: "WCC has taken on board a commitment to an accessible Wellington. The value of our disabled community inputting into city planning is recognised. The fact that the Disability Reference Group is paid a meeting fee values and respects the views of disabled people. It acknowledges that we are visible, skilled, accountable and knowledgeable in our field. It puts the responsibility on us to be out in the community listening to people's needs and issues, and working with council to reflect solutions to these issues in policies and actions. We have the responsibility to present council's proposed initiatives to the disability community and the council welcomes consultation feedback. WCC is contracting members of the disabled community to carry out research, provide advice etc. People are being paid at contract rates and their expertise is recognised and valued.
- In 2001 a part-time disability liaison officer was appointed. The position soon became full time to support the reference group, raise awareness of disability issues within council and support the council in implementing the Disability Strategy. The position allows council officers to take regular opportunities for formal and informal consulting.
- A key to ensuring that disability issues are considered when all council decisions are made is for the disability liaison officer and reference group to work with an informed and committed councillor who is pro-active in placing awareness of disability issues before other councillors.
- There is commitment from the CEO to addressing disability issues.

See page 61 for information about results of the WCC approach to disability.

KAETI RIGARLSFORD AND ROSS LIVINGSTON FROM THE DISABILITY REFERENCE GROUP WITH COUNCILLOR STEPHANIE COOK AND DISABILITY LIAISON OFFICER JENNY RAINS.

## Building the leadership and capacity of disabled people and family organisations

Over the past four years the Ministry of Health contracted for Disability Empowerment Advocacy and Support (DEAS) services in the Auckland and northern region. Various providers and initiatives evolved from these contracts to deliver services for disabled people by disabled people. For example, the Ripple Trust, a not-for-profit organisation governed by disabled people, has held a number of disabled person forums in the last year. Other organisations have focused on the specific needs of disabled Māori, disabled Pacific people, families and different parts of the region. The Ministry of Health no longer funds DEAS services. However, four organisations that evolved from the DEAS contracts are now contracted to provide an information and advisory service.

### Walking the talk

Te Tai Tokerau DEAS Trust was formed in 2003 to implement the disability empowerment advocacy support service in Northland. Manager Jonny Wilkinson says: "We want to foster and demonstrate leadership by disabled people. We can still see examples of disabled people employed in organisations and not given full responsibility, given token roles and not valued for their participation. We want to demonstrate a functioning organisation where disabled people are not a reference group, and are not junior administrators but are fully participating in all roles, and everyone is valued for their contribution and paid appropriately. All our trust board members are disabled, and so are all our staff bar one. Our trust board members are widely experienced people with management experience, and provide quality governance and management.

"We want a single person or an organisation to know they can come in here and discuss an issue and it will result in appropriate and professional action, either on a personal level or in a meeting, hui, or in consultation with a service provider, the community or a local council. Where possible we are promoting self advocacy and have supported a number of individuals as they have worked through issues with government agencies or service providers. We have worked in longer term mentoring with individuals who were either working and needing mentoring to establish what they wanted from their career and how to achieve this or were transitioning from home to independent living.

"We are able to share our knowledge of working in the sector, of governance and management, of communicating effectively at political and local government level and in running community events. Of course all our staff are members of DPA."

The Office for Disability Issues aims to help develop the capacity and leadership of the disability sector. As part of this policy the Office supports the attendance and participation of disabled people and their families at conferences and funds capacity building and leadership initiatives. During 2004–2005 the Office provided funding to:

- DPA for development of regional leaders
- Standards plus and Parent to Parent to support participation by disabled people and their families in their Coming of Age Conference
- the Carers Alliance to support carers to attend the Caring for the Carers Summit
- Inclusion International New Zealand to help ensure a New Zealander with an intellectual disability participated at the United Nations ad hoc committee meetings on the Convention on the Rights of Disabled People in New York
- Standards and Monitoring Services (SAMS) to part fund the first Partners in Policymaking course for family members and disabled people
- People First to train leaders and assistants and for development of resource material to support their local groups
- Global Entrepreneurs Network for "Blindness: Dare to be Entrepreneurial", a UNITEC SIFE project for blind entrepreneurs.

### *Gaps and opportunities to improve the funding security of disability organisations*

Several not-for-profit disability organisations provide advocacy, advice, awareness promotion, peer support and information services, which are central to the effective implementation of the Disability Strategy. However, the funding arrangements are often not appropriate or adequate. They do not often allow for capacity building or for security to maintain an organisational infrastructure.

The Office for the Community and Voluntary Sector is working to improve cohesion across government funding schemes and funding security for community organisations, to enable them to focus on their core activities rather than constantly seeking funding. The Ministry of Social Development is also looking at this issue in relation to contracts for vocational services. However, there is still a lot yet to do, particularly in relation to appropriately and adequately funding disability advocacy and leadership.

## The right to vote and activity to improve participation in the electoral process

The Chief Electoral Office developed an action plan to improve the level of service for disabled voters. This included:

- contracting the Royal New Zealand Foundation of the Blind to produce information in Braille, large print, audio cassette and email
- making information available at the Chief Electoral Office website in New Zealand Sign Language
- contracting the Barrier Free New Zealand Trust to develop accessibility checklists for voting facilities and polling places, and providing training for Returning Officers
- providing disability training for Returning Officers and national office staff by trainers with lived experience of disability.

# Chapter two: Building government capacity

Putting disability issues on the agenda

The government directly affects the situation of disabled people through an array of services, legislation and regulation. Historically much of this activity was confined to the health and welfare sectors. However, movement from a needs-focussed approach to an emphasis on strengths and participation has improved the government's ability to respond to disability issues. A challenge remains to promote understanding of disability while working within structures with a legacy of historic and often institutional settings.

Part of the challenge is to keep disability issues on the agenda of government agencies outside traditional settings. The Disability Strategy and its various levers have had some success but there is much further to go.

## Objective 6: Foster an aware and responsive public service

### Improving access to government information and services

> Indicator 5: Proportion of government websites that are accessible to disabled people.

The internet is increasingly becoming an essential method to access government information and services. This trend is an opportunity for the many disabled people who found significant barriers with historic channels to improve accessibility. Work is under way across the state sector to improve government websites in line with the E-government guidelines and this will improve access for disabled New Zealanders.

Progress will be evident as the barriers to accessing web-based information and services are minimised for everyone, regardless of physical, sensory or cognitive impairments, or technological barriers.

#### *Latest trends and data*

Government agencies have been working to improve the accessibility of their websites over the last four years, as reported in the annual Disability Strategy progress reports, but we have not been able to check the outcomes of this work until recently.

The Office for Disability Issues has commissioned a survey of websites owned by government agencies or agencies funded by government. Survey findings indicate how accessible government websites are overall, at a particular point in time, providing a baseline against which to measure future progress. The survey also provides guidance on how to best target future website development.

A selected sample of 149 key sites was put through an automated tester. Thirty-five of these sites were not substantively meeting important accessibility criteria in the E-government guidelines. The most common fault was a lack of text alternatives provided to describe images or graphics. Of the remaining 114 sites fifty-eight were found to exclude some disabled people from important information, such as a statement of intent, annual report or consultation document. This was often because they only provided the information in a PDF format.

Fifty-six sites were considered sufficiently accessible to be tested in phase two of the survey, which comprised a technical test of key E-government guidelines that had not been checked by the automated tester, and a user test. Sites were assessed from the perspective of four disability groups (vision impaired, blind, mobility impaired, reading impaired).

The following twelve sites were found to be the most accessible:

| | |
|---|---|
| 4 million careful owners | www.4million.org.nz |
| Bioethics Council | www.bioethics.org.nz |
| E-government | www.e-government.govt.nz |
| Families Commission | www.familiescommission.govt.nz |
| Ministry for the Environment | www.mfe.govt.nz |
| Ministry of Transport | www.transport.govt.nz |
| New Zealand Embassies | www.nzembassy.com |
| Office for Disability Issues | www.odi.govt.nz |
| Office for Senior Citizens | www.osc.govt.nz |
| Reduce Your Rubbish | www.reducerubbish.govt.nz |
| Skill New Zealand | www.skillnz.org.nz |
| StudyLink | www.studylink.govt.nz |

Testers with low vision found at least one question impossible to answer for three-quarters of the sites tested in phase two. Best sites in this group included the Ministry for the Environment, the Bioethics Council and the E-government Unit.

Blind testers found the widest range of accessibility of the four disability groups, with some sites very difficult to access and some very easy. Best sites here included the E-government Unit, the Office for Senior Citizens and Reduce Your Rubbish.

Mobility-impaired testers were less likely than those with low vision to find a task impossible, but more likely to find it very hard. Best sites included the Ministry for the Environment, the Ministry for Culture and Heritage, 4 million careful owners, New Zealand Embassies and Reduce Your Rubbish.

Reading impaired users were more likely than any other users to find a question impossible to answer, and the survey found that this was the most poorly served of the four disability groups. Best sites were the Office for Disability Issues, Population Statistics, E-government and Reduce Your Rubbish.

Overall, the survey indicates that many government agencies are making efforts to meet E-government compliance requirements and create user-centred websites. However, further work is required. The Office for Disability Issues will be distributing information, including the technical findings of the survey, to each government agency to ensure that those who commission, fund, build and maintain websites can access the help they need to understand what the barriers are, who they affect and how to remove them.

Work to improve website accessibility is happening throughout the world as web technology develops. New Zealand can draw from and contribute to this international development as more of our websites become barrier free.

### *Activity during the 2004–2005 year to improve accessibility and responsiveness of government agencies*

- Most government agencies and Crown entities report development work on their websites. Many aim to meet E-government guidelines by 2006. The State Services Commission provides supplementary tools and material to help achieve this.
- ACC reports that all new building and refurbishments met accessibility requirements for disabled people. Key ACC information has been recorded onto audio tapes, and coded into Braille and five development managers were recruited to improve outcomes for disabled persons and other disadvantaged groups when accessing ACC services.
- Archives New Zealand has developed an accessible web-based search service. All their offices are accessible to disabled people.
- The Ministry of Education has developed guidelines for property modifications at schools for students with special needs.
- The Ministry for the Environment has moved into a building with good disability access. Of note are Braille lift buttons and a low section at the reception desk.
- The Education Review Office has implemented recommendations from a disability access review of accommodation.
- The Ministry of Health has introduced a disability awareness training module for their staff, using trainers from the Ripple Trust. Also, they have made their document *Living with Disability in New Zealand* available in Braille, audio cassette and plain English, and their *Disability Support Services in New Zealand – Service User Survey* is available in large font.
- The Ministry of Justice has developed a 10-year upgrade programme to make court buildings compliant with the disability access code by 2015. This will include voice enhancement equipment in courtrooms and signs designed for reading by those with impaired vision.
- The Department of Labour completed a disability accessibility audit regarding building accessibility in 2004. Feedback was provided to local managers and improvements made, but further remedial work awaits lease renewal or refurbishment opportunities.

- Land Information New Zealand provided a TTY (text telephone) device in reception areas so deaf people can phone the department.
- The National Library of New Zealand report that 75% of their buildings are accessible by disabled people and their Wellington auditorium has hearing loops.
- The Department of the Prime Minister and Cabinet has refurbished Government House in Auckland, which now has access and facilities for disabled people.
- The Ministry of Research Science and Technology considered access and mobility in their accommodation refit. This included a shower area for disabled people.
- The Ministry of Social Development trialled and evaluated voice recognition software.
- Statistics NZ developed several resources for the 2006 census; these include a Braille questionnaire, audio tape of the questions, screen reader, internet response option and a fax helpline. Also, their new Wellington accommodation has no accessibility barriers to disabled people.
- The Treasury ran a workshop for policy analysts and their managers to increase awareness of disability issues. Also a major refurbishment of the Treasury building resulted in several improvements recommended by a disability audit in 2004. These include an accessible toilet, signage and improved lighting.
- The Ministry of Agriculture and Forestry found two of their 11 buildings did not meet accessibility standards in a 2004 audit. One of the non-compliant sites has relocated to a fully accessible premise.
- The Ministry of Youth Development is working with the Ministries of Health and Education to increase participation of young disabled people in their programmes.
- The Department of Conservation established an internal disability reference group to increase the organisation's knowledge of disability issues and advise on Disability Strategy implementation plans. They have also developed an intranet information resource with links to disability implementation plans/reports, articles, external websites and issues from an internal disability reference group.
- The Human Rights Commission developed Braille, plain language and big print versions of material related to their public inquiry into accessible land transport. A marked-up version of the material is also available for screen readers. TTY access numbers are included in publicity material. A range of accessible material is also available about the Human Rights Action Plan and for accessing the Commission's disputes resolution service.
- The Police updated the chapter on mental illness in their best practice manual in response to survey findings on disabled people's satisfaction with police services.
- The Police and other agencies reported a number of initiatives to improve their services for people with hearing and/or speech impairments. These are described in chapter 4.

### *Gaps and opportunities for improving the accessibility and responsiveness of government agencies to disabled people*

Currently, there is a range of guidance documents for government agencies which help ensure accessible and responsive information and services for disabled people. These include the E-government guidelines, access standards in the Building Code and some other information standards for the public service. However, these are not comprehensive. Work could be undertaken to ensure all accessibility requirements for disabled people are consistently communicated to government agencies and monitored. Furthermore, in addition to the minimum standards, targets could be set for government agencies to achieve.

### Incorporating a disability perspective in policy development

The Office for Disability Issues has developed a disability perspective toolkit for government agencies to help them consider and address the impacts of legislation, policy decisions and programmes on disabled people. The kit is online at www.odi.govt.nz.

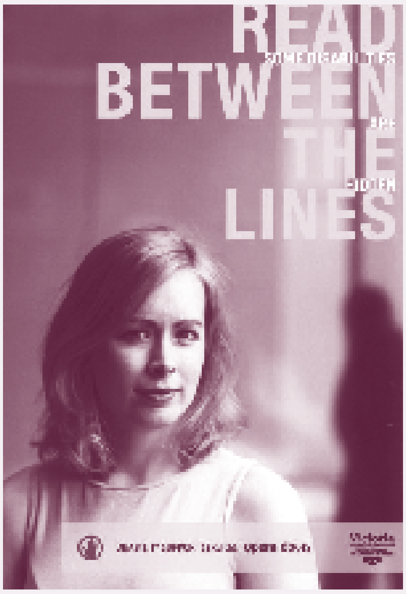
> … I see our society failing… because we, as disabled people, sometimes aren't recognised as normal individuals who are in the community…
>
> My view on the Disability Strategy is that we – disabled people – are doing a good job. We know what we want – **now it's time for people to listen to our needs** and it's up to us to make them listen.
>
> In my 19 years I have seen a lot of changes… I know it will get better because now I know we have a voice and we will be using our voices to get our messages out there. Kia Kaha, Kia Maia, Kia Manawanui!!!!!!
>
> Rebecca, *Life is for Living*, to be published at www.odi.govt.nz

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

### Improving the collection and use of information about disability issues

Indicator 6: Extent of quantitative and qualitative research about disabled people carried out by government and used to inform policy development.

There is a lot agencies do not know or understand about disability, or about how their policies and services impact on the lives of disabled people and their families. This seriously limits the capacity of government to improve its response to disability issues – "it does not know what it does not know". An increase in the amount of quality research related to disabled people and their families will not only enable the development of evidence-based policy advice, it will raise visibility of disabled people and improve understanding across the public service.



…I did research on hidden disabilities last year and presented it at a conference in Melbourne. I also appear on a poster promoting Disability Support Services at Victoria University… I have had some pretty good feedback on it. It has been interesting – some people that know me and then have seen the poster have asked, "Are you just a model?"

The most frustrating thing about my impairment is the invisible nature of it. …it is frustrating in that people don't recognise that I have a problem. You have to try so hard to get support. People aren't saying, "How can I help you?" They are saying, "Why do you think you've got a disability?"

Miranda, *Life is for Living*, to be published at www.odi.govt.nz

### *Latest trends and data*

The Office for Disability Issues and Statistics New Zealand have begun a comprehensive stocktake of data sources containing disability-related information. The work includes systematic identification, documentation and evaluation of the statistical potential of relevant administrative and other data sources, including those generated by the many and diverse disability-related service providers.

Initial investigation has found more than 30 reports containing disability related information published in New Zealand over the last 10 years. It is clear that over the last few years the use of disability information, in particular the post-census Disability Surveys, has increased considerably. Before the surveys there was a serious gap in information, but even after the first survey in 1996 the new information was not used to its full potential. Agencies were either not aware or did not understand the full significance of the new statistical information. This has started to change. In particular, the survey information has been used in a number of reports, such as the Social Report, a detailed analysis of employment statistics, various cabinet papers and the New Zealand Housing Strategy.

There is also a sense that disability related research has a higher priority than was previously evident. A new research project on the costs of disability, for example, should fill a major and longstanding gap in information.

### *Activity to improve the collection and use of relevant information about disability issues*

The government has approved funding for the post-census Disability Survey to be repeated in 2006 and 2011. Statistics New Zealand plans to incorporate conceptual and measurement developments from international best practice in the 2011 survey.

In October 2004 the Ministry of Health published a descriptive analysis of results from the 2001 Disability Survey entitled *Living with Disability in New Zealand*. This report is the most comprehensive ever produced on the status of disabled people in New Zealand.

The Ministry of Health's Disability Services Directorate also has a number of service evaluations under way. This includes a major evaluation of the lives of the Kimberley Centre residents pre- and post-de-institutionalisation.

The Health Research Council of New Zealand has partnered with the Ministry of Social Development to invest in a major research project to examine the cost of disability in New Zealand. This work is being undertaken by Auckland University, the Disability Resource Centre Auckland Inc, Diversity NZ Ltd and Fitzgerald & Associates. This group is developing an innovative economic model that accommodates the social model of disability and uses the concept of the standard basket of goods required for a particular quality of life. They will be using a disability reference group to steer development of the research.

The Health Research Council also has acquired money in the 2005 Budget, to build the capacity of disability researchers. Moreover, disability has been designated a priority research area for the Health Research Council and should secure some of the additional $70 million allocated over the next four years for priority research areas.

The Department of Labour has published research into the costs of injury in New Zealand to better inform future policy and decision-making. Further work is planned next year to make the data complete, integrated and useful for policy and research.

The Ministry of Education undertook a three-year research programme looking at integrated, effective service provision for students with physical disabilities. They have also published a study about the Māori perspective on autism spectrum disorder.

The Ministry of Health has a national mental health epidemiology study underway that measures the prevalence of mental illness in New Zealand. Approximately 13,300 interviews have been completed and the data are being analysed. The final report is due in June 2006.

In May 2005 the Centre for Housing Research Aotearoa New Zealand (CHRANZ) released its scoping research *Housing Choices for Disabled New Zealanders*. The aim of this project was to identify housing research projects that address key issues that impact on housing choices for disabled New Zealanders.

A Ministry of Social Development research project into sickness and invalids benefits aimed to identify approaches and interventions that support social and economic well-being and participation in employment. A resulting analysis of the post census Disability Surveys has led to presentations at conferences and publication of an article in the Social Policy Journal; *Work Participation Among People with Disabilities: Does the Type of Disability Influence the Outcome?*

### *Bioethical debates and research*

Bioethical issues around the value of a disabled person's life are of growing concern to disabled people. While there is no consensus on how to progress these issues, there is agreement that disabled people must have a voice in discussions that explore our society's collective values and the concepts that underpin these issues. The New Zealand Human Rights Action Plan echoes this view with a recommendation to "ensure effective representation of disabled people on national bodies such as the Bioethics Council, National Ethics Committee on Assisted Human Reproduction, and ethics committees at research centres and universities".

Two committees, recently established under the Human Assisted Reproductive Technology Act 2004, include a requirement in their terms of reference for a person with a "disability perspective" in their membership. The Advisory Committee on Assisted Reproductive Technology provides advice and guidelines on assisted reproductive procedures and human reproductive research. The Ethics Committee on Assisted Reproductive Technology assesses applications on a case-by-case basis to carry out assisted reproductive procedures and human reproductive research, and to ensure the protection of participants in those procedures or research.

### *Opportunities for debate and knowledge sharing about disability issues*

Conferences and seminars attended by diverse communities of interest are important forums for improving our understanding of disability. They provide opportunities for sharing knowledge and for constructive debate, which can help develop common understandings and communication bridges about disability. Such forums in New Zealand during 2004-2005, included:

- Deaf View II, July 2004, Auckland
- Epilepsy NZ Annual Conference, August 2004, Auckland
- Coming of Age: Exploring futures for young disabled people and their families Conference, September 2004, Wellington
- Parent to Parent Annual Conference, September 2004, Wellington
- International Conference on Mental Health Promotion and Prevention, September 2004, Auckland
- Post Polio Support Society National Conference, September 2004, Wellington
- 3rd National Dyspraxia Conference, October 2004, Christchurch
- DPA National Conference, October 2004, Palmerston North
- CCS National Conference/AGM, November 2004
- Like Minds Providers Seminar, November 2004, Hamilton
- Muscular Dystrophy Association Conference on Neuromuscular Conditions, November 2004, Auckland
- Injury Prevention & Rehabilitation Conference, March 2005, Auckland

- Carers' Summit, March 2005, Wellington
- 2nd National Guillian-Barre Syndrome Conference, April 2005, Wellington
- NZ Hearing Association 2005 National Conference, April 2005, Lower Hutt
- Cystic Fibrosis Association Conference, May 2005, Palmerston North.

### *Gaps and opportunities to use or collect better information about disability issues*

Many agencies collect data on disability for their own administrative purposes. There is, however, a gap in the availability of such data in a format that could usefully inform cross-agency evaluation and policy development. In particular, there is a lack of detailed and consistent information across agencies on how many people access services, how much they access and how frequently.

This variance across agencies in definitions, eligibility criteria for services and general approach to disability limits the ability to collate, compare or otherwise analyse information from a whole-of-government perspective. Developing consistency across government agencies that fund the majority of disability support services – Health, Social Development, Education and ACC – and their administrative databases might be a worthwhile investment.

There is a need to build the capacity of disability researchers and the users of this research. This should mean increased opportunities for sharing findings, and forums for accessing information.

# Chapter three: Improving disability support services

Investing in sensible support systems

The 2001 Disability Survey found slightly more than half of disabled New Zealanders (an estimated 432,100) require access to some form of disability support. Of these:

- about 110,700 people received or 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 used or needed an assistive device and/or help with heavier or more difficult household tasks (including 4,400 people in residential facilities).

Disability support services comprise a wide range 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 or subsidies
- housing support, such as housing modifications
- equipment support, such as wheelchairs, hearing aids, Braille machines
- communication support, such as NZSL interpreters and communication equipment
- 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 specific costs of disability but not including general income support.

Adequate and appropriate provision of support services can complement the social and environmental changes discussed in the first two chapters of this report to enable the full participation of disabled people in the economic and social lives of their communities.

Without the provision of support services some disabled people lack the opportunities to reach their potential. These are opportunity losses to the individuals, but they also cost the whole of our society. Moreover, there are major inefficiencies and costs to government and society through not adequately providing support services; these can include extra income support and healthcare requirements.

…Two years ago my electric wheelchair had its seat changed. The new seat is very uncomfortable for me. My occupational therapist has written to our service provider about it, but I've been waiting for it to be fixed for over two years.

It's an added insult when we get regular letters from that provider inviting us to contact a named person if we want to talk about ongoing issues; you phone repeatedly but he is never available and never responds to messages you leave.

My OT is concerned that I have to use a strap and physically lift my legs up onto my chairs or scooters. She can see this is aggravating my shoulders. She wants me to try powered leg lifters.

I have waited two years for an assessment to see if I could use them, let alone be on a waiting list to have them fitted. I try hard to get the help I need to be independent but they just say it's a shortage of therapists and you have to wait your turn.

I think that by the time that happens you're going to be much worse off and need more care and equipment. It is not good money sense to me.

Jean, *Life is for Living*, to be published at www.odi.govt.nz

## Objective 7: Create long-term support systems centred on the individual

### Indicator 7: Perception of people accessing disability support services of how simple to access, flexible and fair the system is.

If disabled people are to have the opportunities that others expect in their life they need a similar level of control over their lives. For this to happen, many disabled people need support and they need the systems for providing the support to be centred on meeting individual needs. Improvements will be evident when people find the system makes more sense for them and feels simpler and fairer to access.

The themes of the Disability Strategy and other messages from the sector have been translated into key principles, to guide disability support services.These principles are:

- the administration of support services should concentrate on long-term, whole-of-life needs and outcomes, and on the participatory roles of disabled people within their community

- the provision of supports by central and local government should use and build upon supports occurring naturally within the family and local environment
- funding systems should be centred on disabled people and their families, not the provider, allowing for stable and lasting support for active community living
- funding should be applied at the individual level in an equitable manner
- rules governing the allocation of funding and resources should be consistent in their approach and application, and flexible enough to address individual circumstance
- systems for providing supports should be simple to understand, straightforward to access and easy to interact with throughout the length of engagement
- disabled people and their families should be appropriately supported and empowered to make decisions for themselves, and to exercise choice, control and responsibility over these choices
- disabled people and their families should be supported and encouraged to advocate for themselves or, if they choose, have access to quality advocacy services
- innovation and forward thinking should be celebrated. Overall quality of life should be a measure of success.

…We are all on a learning journey… to get the right equipment for the boys. We need to have standing frames, wheelchairs with full headrests, boots, and splints; all customised for them. It's a matter of trial and error and I have to take a lead role in getting people to modify the equipment until it works well for Sam and Callum. I go onto the internet and see what is available overseas and try to get it made here. We need people modifying equipment to step out of the ordinary and be creative as the boys' needs are pushing boundaries…

We have carers for the boys. Each boy gets eight or nine hours care a week. It has been a struggle to get suitable carers. There is lifting involved, and a need to understand some medical procedures like using tube feeding and administering oxygen. We need to know the boys are safe with the carers. We have been given carers with bad backs, some who are very young, in their first job and with no experience of severe needs. Sam has had bones broken by carers who were not careful with him. In the end I went out and found a great carer for Callum, and persuaded our service provider to employ her. She is a woman with a family of her own who Callum adores.

… We have our own house modified for the boys. We need things like wheelchairs, hospital beds, hoists, oxygen machine, feed pumps. We applied to get a modified van from Lotto and, believe it or not, we got the hoist but not the van. Our family helped us purchase the van and we are paying back a loan to them, but the van lets us get out and about as a family…

*continued over...*

*continued from previous page...*

It is surprising in this world where we need to apply for funding and benefits how significant it is that the medical profession can put a name to a condition.

**We live in a "compartmentalise and tick the box" society and when you don't fit neatly you are difficult**. Another example is our request for respite care. When we applied for high needs respite care allowance we were told it was $2,500 per child, but no, it's a per family allowance, there is no additional money for a second child with an impairment. There is no respite care in Northland. When we realised that we needed a break away from the boys there just is nowhere here they could be placed. Options suggested to us included Sam being placed in a rest home. How could you leave a six-year-old with rest home staff who aren't trained to deal with a young boy with his specific needs? It was suggested we could pack the boys in the van and drive the three hours to Auckland and place the boys at Wilson Centre Family Unit for a night off then drive back home to Whangarei the next day!

I took the initiative and we have found a way to use our $2,500 respite care allowance that works for us. Because of the need to rely on specialised equipment in our home it is practical that a carer comes to our home and we have some overnight time away…

… What would be wonderful on this journey of discovery would be a "one-stop-shop" care provider instead of having to work through a large number of service providers, always having to explain or justify your situation and explain why offered solutions are not practical. One person or organisation that you can establish an ongoing relationship with would be great. **Currently we have dealings with 14 different organisations**.

Sam and Callum, *Life is for Living*, to be published at www.odi.govt.nz

## *Latest trends and data*

The current systems for funding and providing services are complex. Funding for support services comes from 10 different Government Votes and the ACC account, as well as from charity, proceeds from gambling and volunteer services. Each of these funding channels has its own goals, priorities, mechanisms and logic around the purpose of funding support.

During the 2004-2005 year the Office for Disability Issues connected with key stakeholders in the disability sector, examined findings from government consultation exercises and reviews of service provision and used data from government agencies to construct a comprehensive picture of disability support services in New Zealand. The Office also sought to reaffirm and elaborate the disability sector's vision for the future delivery of these services, as signalled in the Disability Strategy.

The Office found many issues identified in a 2001 stocktake of support services remain unresolved. This includes gaps, overlaps and inconsistencies in service provision. While there is evidence of minor improvements there is clear consensus amongst the disability community that the current framework for providing disability support services is still unable to support the whole-of-life outcomes disabled people aspire to. The likely reasons include that:

- control rests disproportionately with the delivery system and those who administer it rather than with disabled people and their families
- there is no common logic for providing supports across different agencies, resulting in diverse delivery mechanisms, inconsistent entitlements, an associated inability to transfer support across different settings, life stages or regions, and inequities in terms of the level of support available to different individuals.

My quest for a wheelchair resembles a nightmare. My first request was declined although I was falling up to five times a week and hurting myself. When an occupational therapist came she completed the assessment form "in the right language" and I've been assessed as urgent. I've been on the urgent list for six months now. I have politely tried to get myself a wheelchair as I am worried about my increasing fall and injury rate, but I am told I'm on the urgent list. Is there a list above urgent, and what hope is there for those on the non-urgent list? While I was at QE Health I saw someone in a different area get a wheelchair within a week. Does where you live influence when you get a wheelchair?

…I will soon need to have assistance with showering and it is important to me that I have a male carer. My service provider has indicated they will be unlikely to provide a male carer. What is it with our society that we value carers so lowly on the pay scale when they offer practical assistance and companionship, laughs, etc for those they work with? For some of the elderly I know their carer is the most constant visitor, the "light in the day" and the person who watches out for them.

I need home physiotherapy. I have heard that my service provider is considering training carers to deliver home physiotherapy… I risk pain, and further injury that could result in the loss of my remaining mobility. My need is for a trained physiotherapist who can make ongoing and constant assessment of my situation – not someone quickly trained in a few techniques.

Max, *Life is for Living,*
to be published at www.odi.govt.nz

### *Activity to improve the provision of disability support services*

Not surprisingly, given the number of agencies with responsibilities for funding disability support services, there is a wide range of activities that relate to this area. We report on some of these in the next chapter (as part of specific areas of life such as education or employment).

Budget 2005 allocated an increase of $18.7 million for home-based support services for older people, funded by district health boards, and younger disabled people, funded by the Ministry of Health (Disability Services Directorate). An additional $71 million was provided to district health boards for residential care for older people, and $93 million was provided to cover changes to asset test thresholds exempting thousands of older New Zealanders from paying base fees.

An extra $59 million was provided in 2005/06 for residential disability support services funded by the Ministry of Health (Disability Services Directorate) to cover demographic and inflation adjustments. This has been allocated to a variety of services and initiatives, including the de-institutionalisation of Kimberley Centre residents, younger people receiving residential care, and to help improve needs assessment and service co-ordination services.

In November 2004, the Ministry of Health reported on the findings of the *Quality and Safety Project: Improving the Care and Support for Older People and Disabled People*. The project provided recommendations to government on policy and purchase frameworks and the service development required to ensure safe, quality residential and community disability support services for people of all ages. The project looked specifically at workforce issues and how these may impact on the ability to deliver safe and quality services to clients. Consultation, a literature review and workforce and service user surveys were completed. The surveys are now available on www.moh.govt.nz

The Ministry of Health has a number of policy, evaluation and service development projects related to the provision of disability support services. In the 2004-2005 year this work included:

- a comprehensive national consultation process to inform the development of an environmental support services framework
- initial work to investigate and address boundary issues across the health and disability support sectors
- evaluation of befriending services for older people and of ageing in place initiatives
- contracting three organisations to trial ways to improve collaboration and co-operation between agencies that provide needs assessment and service co-ordination. These trials are part of an interagency project led by the Ministry of Health. Advice to government will be provided by 31 December 2005.

The Department of Child, Youth and Family Services and the Ministry of Health have started a review of their memorandum of understanding. They have started to develop staff guidelines on interagency collaboration and training, including two regional workshops to clarify operational policy and encourage greater collaboration between the health and child protection sectors.

The Office for Disability Issues is leading a cross-sector review of long-term disability support services. The first phase has focused on identifying the issues with existing support services. It has also developed a picture of what a system that was working well would look like and what the key components might be to achieve this.

Activity to improve support services for people with an intellectual disability is outlined in chapter five in the last section titled: Progress for New Zealanders with an intellectual disability.

### *Gaps and opportunities to improve disability support services.*

An undervalued and casualised support workforce will make any improvement in the policy and funding of disability support services difficult to implement. Turning this situation around requires more than simply increasing funding for “more of the same”. The workforce needs to be skilled and empowered to do a different and better job consistent with the Disability Strategy.

> We can get a carer for Darren but we cannot get a carer for Sam. People, including our wider family, are daunted by the responsibility of caring for a boy who can stop breathing and need oxygen. The shortage of trained carers able to deal with severely impaired or unwell young people has to be related to the pay rate. The carers get $64 for 24 hours of care. With shared care they get $40 for a 24-hour day. This is a low pay rate for work with high responsibility.
>
> Sarah and her great family, *Life is for Living*, to be published at www.odi.govt.nz

Separate sectors have projects under way that address their particular interests, such as initiatives arising out of the Ministry of Health’s quality and safety project, which includes a new position of disability workforce development manager.

However, workforce issues would perhaps be better addressed as a larger, cross-government exercise. It would then be possible to consider training and more attractive career pathways across a wider field. The Health Workforce Advisory Committee has been considering how best to progress this work, their reports are available at www.hwac.govt.nz

I am a community support worker, my role is to support disabled people as they reintegrate into the community. I work with someone as they extend their opportunities and capacity to be out there, participating in the community. I might accompany them on public transport, into town or to the gym as they are meeting and interacting with people. For example I've had one client I've been with for about five years. He has some anger issues so my role is to be with him as he is out and about and make sure he is behaving within "society norms". We've set some parameters and mostly now it's just a matter of drawing attention to his behaviour by asking if he thinks it's appropriate and he modifies it appropriately himself. He is relearning how to behave in our society so he can get a job…

There is a bit of a parallel with my own journey, and this allows me to see where my clients' frustrations are coming from. However, everyone is different and everyone has their own experiences. I know firsthand how annoying, frustrating, demeaning and inappropriate it is for someone to say "I know how you're feeling". You don't necessarily know and it's better to say "I can try and understand where you are coming from".

Kent, *Life is for Living,*
to be published at www.odi.govt.nz

# Chapter four: Promoting participation in all areas of life

The Disability Strategy is a “whole of government” strategy because disabled New Zealanders will potentially interact with every government department.

If disabled people are to have ordinary choices and responsibilities in their lives they need better access to education, employment, decent levels of income, housing, transport, health care, communication and information and recreation, and they need the freedom to make lifestyle choices, including choices about culture and relationships.

*Ordinary choices and responsibilities in all areas of life*

Work to enhance access across any of these areas of life may involve the provision of individual support services, individual modifications to the environment, or may be about changing aspects of the whole environment or society to be universally accessible.

Any particular activity is likely to impact on more than one area. To ensure comprehensive coverage, however, this chapter considers each area of life as a discrete setting.

## Objective 3: Provide the best education for disabled people

This section on education contains three indicators. The first focuses on an aspect of the compulsory school sector, the second on adult participation in education and the third on the overall education achievements.

### Providing the best education for disabled children

Positive and appropriate childhood experiences can help to build the expectations as well as skills of young disabled people to lead a life with the kind of ordinary opportunities and responsibilities most of us expect. The aspirations for children with special education needs are the same as for all children, including: “to reach their potential; to feel valued and accepted; to have the opportunity to experience success; to feel included, not marginalised; to enjoy a broad range of experiences and to enjoy quality learning experiences...” (LetsTalk, 2005).

DISCUSSIONS IN NEW ZEALAND SIGN LANGUAGE AT TE ARO SCHOOL

Presence and participation in the classroom is a first and essential step to meeting these goals and improving the education outcomes of disabled children.

### Indicator 8: Percentage of disabled children participating in some aspect of mainstream education.

The debate over what are the best settings for education continues, with views divided on whether special schools, units or regular class settings best meet children's needs. However, we can be sure that all disabled children need at least some time in mainstream settings that are inclusive and accessible. This ensures that all children have opportunities to interact with their peers. This idea is supported by the United Nations Committee on the Rights of the Child, which recommended, in October 2003, that New Zealand better integrate disabled children into mainstream education and other aspects of society.

Measurement of this indicator will not tell the whole picture but an increase in it over time will indicate that more disabled children are being included in mainstream education and gaining the life experiences and skills that go along with that.

> Sam goes to our local primary school and loves socialising and being at school. He is doing very well there when he is well. Sadly this winter term he has had about two-thirds of the term off sick. I taught the teacher aide how to deal with any medical emergency he might have. The school allowed me to be part of the interview process for the teacher aide and I feel comfortable with her. She is an older woman who has children of her own. She is brilliant with Sam, just like a second mum. We are so lucky because she is going to the intermediate with him next year. The school is magic; I am always singing its praises. Help is there for Sam but he is not cushioned or given an easy ride. They understand his capabilities. It's the whole school climate – the kids there are amazing – no bullying throughout the school. The staff and pupils are just great.
>
> I am fearful of Sam's transition into a much bigger intermediate school next year. At present Sam can move around the school as he can walk about 50 metres on the flat without a rest. At the intermediate, distances are much greater and he will have to use a wheelchair and lose some of his independence. It will be a big thing for him, as well as facing a new group of kids who don't know him.
>
> Sarah and her great family, *Life is for Living*, to be published at www.odi.govt.nz

It will also be important to measure the inclusiveness and effectiveness of the education received by disabled children. Group Special Education is developing measures for presence, participation, quality learning and achievement for an outcome framework. In future it should be possible to integrate the measures they devise with that of the Disability Strategy. The information associated with indicator 10 will also provide some insight into how effective education services have been for disabled children and youth.

> My schooling was not fun and I try not to remember it. When I was starting school my parents were told I didn't need glasses and I got off to a really bad start. Later on, when I had glasses, I sat in the front of many classes in many mainstream schools but I had no extra support and I missed out on a lot of learning opportunities. We later found out I could have gone to a school for the blind but I went to a state secondary school and got some support. I did not achieve anything like my potential and left with quite low self esteem. I do hope it's a different reality for mainstreamed students today.
>
> Gail, *Life is for Living*, to be published at www.odi.govt.nz

## *Latest trends and data*

The 2001 Disability Survey found that:

- approximately 97% (71, 600) of disabled children aged between 5 and 14 years who were living in households, were enrolled in some type of primary or secondary education
- 74% (53,300) of disabled children attended only mainstream classes; a further 16% (11,400) attended "mainstream" classes and a special unit.

In 2004, Group Special Education engaged with 5,000 parents, educators, students and other interested parties through 395 community meetings. The findings are published in a series of reports at www.minedu.govt.nz/goto/LetsTalk. There was consensus that there is a need to improve:

- funding to support all aspects of special education and accountability for the resources in special education
- planning and processes so support is available as children move through the system, and encourage thinking ahead and preparing for adulthood
- training of all staff, focusing on attitude change and skill building for those working with students with special education needs
- early intervention programmes
- co-ordination and co-operation of all those working with children with special education needs
- information on how the whole system works and how to access programmes and services
- communication between parents and those providing services
- relationships and networking between all the groups working in special education, particularly when it comes to access to schooling, services and resources
- the range of learning settings available and in some cases more options
- services for Māori and for Pasifika.

> I investigated a number of special schools and believed that he would be best placed in a special school a 30–40 minute drive from us. We enrolled him there and it has proved to be just the school for him, the teachers have transformed him. It was a difficult first year however, as he had to learn new behaviours. On regular occasions to begin with he spent time in a time-out room. However, the teachers liked him, and saw beyond his behaviours and recognised his frustrations and developed ways to deal with him. He learned not to hurt other children and adults. We so appreciate his teacher and the school that another parent and I nominated her and the principal for the Multi Serve Education Trust awards last year, but sadly they did not make the finals. The school has been wonderful in building positive relationships with Mark and with the families of their special needs students. We have to pay $40 per week to subsidise Mark's taxi fares to school as he does not attend the nearest special needs class or school – but finding the right school placement is well worth this.
>
> Mark's family, *Life is for Living*, to be published at www.odi.govt.nz

The 2001 Disability Survey showed that most caregivers of disabled children were able to enrol their child in the school of their choice. However, 7% (an estimated 5,000) said they had not been always been able to do so. The most common reason reported was that the school was unwelcoming.

## Promoting opportunities for education for disabled adults

### Indicator 9: Percentage of disabled adults participating in formal education.

Greater participation in tertiary study and other adult education is an essential part of improving education, employment and economic outcomes of disabled people. Participation can range from university courses or apprenticeships to finishing school or tailored courses to improve life skills, as long as the focus is on education outcomes and not "day care". Improvement will be evident when the percentage of disabled adults who are enrolled in formal education has increased.

> I finished college when I was 16 because I had to fight for so many things around schooling. I basically got tired and left to do a course instead.
>
> Rebecca, *Life is for Living*,
> to be published at www.odi.govt.nz

### *Latest trends and data*

The 2001 Disability Survey found that:

- an estimated 55,800 disabled adults living in households (9%) were enrolled in formal education
- 25% of these disabled adults were enrolled in polytechnics, 22% were enrolled in universities, 20% in secondary schools and 8% in private training establishments.

## Ensuring effective education for disabled people

### Indicator 10: Percentage of disabled people with a school or post-school qualification.

The attainment of formal qualifications will improve a disabled person's ability to compete in the labour market. If disabled people achieve a level of qualifications similar to non-disabled people this will be evidence that the education system has been effective for disabled people on an equal basis with others.

### *Latest trends and data*

The 2001 Disability Survey found significant differences in education outcomes for disabled people compared to people without impairments, as shown in the table below.

| 2001 Disability Surveys | Disabled adults in households | Non-disabled adults |
|---|---|---|
| No educational qualification | 39% | 24% |
| Highest qualification a school qualification | 34% | 42% |
| Post-school qualification | 27% | 34% |

> I can only do my studies part-time. The Disability Support Services (DSS) at university are fantastic. I don't think I would be where I am now if they hadn't supported me. If I have a bad day and I am at uni, there are people there who will help me out. There is a bed there where I can go and have a rest. The DSS will come and advocate for me with course co-ordinators – this is really important for me because the psychology course co-ordinators are the most sceptical – they know so much about the brain. One of my co-ordinators questioned why I was getting support but once DSS came and sat down with me and spoke to the co-ordinator about why, then he couldn't do enough for me. I had to explain myself because my disability is hidden, my exam results were good and I looked normal. That was frustrating for me…
>
> Miranda, *Life is for Living*, to be published at www.odi.govt.nz

### *Activity to improve education services for disabled people*

The Ministry of Education reports a number of initiatives to improve delivery of education services in New Zealand:

- Budget 2005 announced an increase of $30.7 million over the next four years for special education services. Of this $16.9 million will go to expand special supplementary learning support, $9.8 million for teacher aides and $4 million to develop effective special education assessments.
- Group Special Education has been preparing a set of local profiles of services and resources for each of their 16 districts. The information will provide a basis for more effective planning of local services. A newsletter, Let's Talk Special Education, was launched to provide information about national Group Special Education initiatives.
- An action plan is being developed to set the strategic directions related to education for children and young people with special needs. This first action plan focuses on improving the core services that Group Special Education is responsible for.
- A transition website has been launched to help ease the transition from school to work/further education/the community for young disabled people. It was designed with input from Emerge Trust and IHC (www.transitions.org.nz).
- The Advance Centre of Deaf and Hearing Impaired Tertiary Students is now in operation and gives deaf and hearing impaired tertiary students in Auckland access to support, resources and services. These include training for support staff, advice on equipment for studying, information to teaching staff on student needs and access to bridging and transition programmes that assist participation in tertiary study.
- The New Zealand Code of Practice for an inclusive tertiary educational environment for students with impairments has been launched. The code is designed to assist tertiary education providers achieve a fully inclusive environment by identifying and removing the barriers of campus life. The code was developed by ACHIEVE, a national post-secondary education disability network.
- The Ministry of Education has completed a literature review and developed a project plan for improving information and early action to address barriers to learning faced by children with additional support needs.

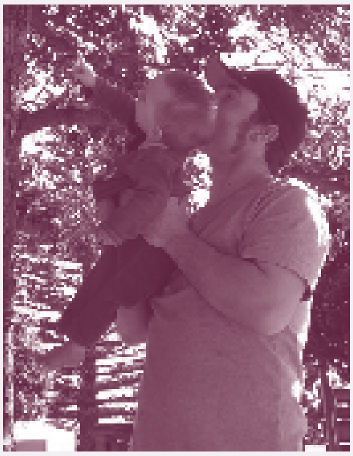
ACHIEVE was established to ensure equal opportunity and access to post-secondary education and training for people with impairments. The national network advocates and lobbies for people with a range of impairments who are transitioning into or studying in post-secondary education or training; for example at a university, polytechnic, private training establishment, wānanga or college of education.

# Objective 4: Provide opportunities in employment and economic development for disabled people

## Promoting employment opportunities for disabled people

### Indicator 11: Percentage of working age disabled adults who are employed.

Access to quality employment is a priority for the disabled population. It is seen as key to breaking the cycle of deprivation and creating a more inclusive society. Improvement will be evident when the proportion of the adult disabled population aged 15–64 who are employed (full or part-time) has increased.



> I was a successful chef for many years but eventually I was unable to maintain a consistent mood in order to remain employed. My employment will always be governed by my ability to manage my health in negotiation with employers.
>
> I would love to be able to support my family better, but I don't want to pressure myself about it. I'm about to begin some voluntary work with Amnesty International. I have not worked in four years so it's a bit of trial and error. In the future I hope to work full-time…
>
> I'm unsure about what resources or support I would need to achieve this. I guess someone who could facilitate (advocate) between employers and myself would be best.
>
> Craig, *Life is for Living*, to be published at www.odi.govt.nz

### *Latest trends and data*

The 2001 Disability Survey found that 58% of disabled people aged 15–64 living in households were employed (full and part-time). Six percent were unemployed and actively seeking work, while 36% were not in the labour force.

Twenty-two percent of unemployed disabled adults aged 15–64 had been looking for work for more than a year.

The 2001 Survey also observed significant differences in labour market outcomes for disabled people compared to people without impairments. The difference is particularly pronounced for full-time employment outcomes, as shown in the table on the following page.

| 2001 Disability Survey | Working age disabled population | Working age non-disabled population |
|---|---|---|
| Any employment | 58% | 77% |
| Full-time employment | 29% | 65% |
| Benefit receipt | 30% | 11% |

## *Activity to promote employment opportunities for disabled people*

This area of life has seen a very significant increase in activity for disabled people since the launch of the Strategy in 2001. This is partly because of the current shortages of skilled labour. The government has used this shortage to motivate employers to engage in discussions about why and how they could better harness the untapped potential of disabled people.

- The Department of Labour focuses on improving the overall employment environment. It has launched PeoplePower: a project highlighting the employer benefits of increasing diversity in the workforce, including disabled people. The Department has produced a list of "frequently asked questions" for employers regarding the employment of disabled persons. The Ministry of Social Development and the Department of Labour held a summit for employers in March 2005, hosted by the Minister for Social Development and Employment and the Minister for Disability Issues.
- Current development of the Work-Life Balance programme, which promotes flexible work environments, could also improve employment options for disabled people.
- The Pathways to Inclusion Strategy launched in 2001 aims to improve the quality of employment opportunities for disabled people. It promotes a shift in emphasis within some vocational services away from sheltered work and day activities to supporting disabled people to have meaningful participation in their community and into real jobs (although sheltered workshops remain an option in some circumstances). In the 2004–2005 year the initiative helped 1,100 disabled people into more open employment.
- An important element of the Pathways to Inclusion Strategy is a repeal of the Disabled Persons Employment Promotion Act 1960. The policy around the repeal includes a transition period (2001 to June 2007) for sheltered workshop providers. As part of this process Department of Labour officials participated (over the last year) in a variety of workshops, presentations, conferences, consultations and discussions with advocacy and disability sector groups.

Virginia says "I work in the grocery department of the local Countdown supermarket. I've been there four years and I'm one of their best workers. I work from Monday to Friday, from 9am–3pm. I get heaps of work experience. We try to get more people like me to get out there and get work experience. Someone comes once a week to see us doing our jobs and checks how we are going. In Countdown we see lots of people with special needs and I help them. Countdown has disabled car parks for people in wheelchairs but sometimes it's hard for people in wheelchairs to get out when there aren't ramps on the trains and there aren't enough taxis. I like my work."

Douglas says "Virginia is a first class worker and I'm really proud of her. I work too. I've had heaps of jobs – I used to work at Pizza Hut, now I'm at KFC. I do the rubbish outside. I keep it all tidy out the back and I also do the potatoes and gravy."

…Caregiver Debbie says "Douglas only works two and a half hours a day so he really has to watch his spending. He really loves spending money. He loves going to the shop and buying muffins." Douglas says: "I spend some of my money on my art stuff. Virginia likes to save her money for going on holiday".

Virginia and Douglas, *Life is for Living*, to be published at www.odi.govt.nz

- The Ministry of Social Development provides general assistance to disabled people to help address barriers and move people towards sustainable employment. They are continuing to develop the New Service for Sickness and Invalids Benefit Recipients. Budget 2005 allocated an extra $27.7 million over the next four years to this development. Initiatives include:
    - support for employers so they can employ people with ill health or disabled people
    - changes to the 15-hour and stand-down rules to make it easier for people receiving the Invalids Benefit to move into work
    - a new and better case management model
    - an extension of employment related support funds for disabled people (administered through Workbridge), which are now available to employees in the state sector.

I am hoping to be completely off the invalid benefit and working fulltime. It would help if there was more care in place for my son to enable my husband to get more regular employment as his role is often that of carer. He is self-employed so is able to be flexible in the care he provides for Thomas. Costs of specialist visits for my husband and I, and medication, is significant for us. More spare cash to let us go to the movies or out to dinner once in while would be great, however there are great things we do as a family – like fishing.

Kathryn, *Life is for Living*, to be published at www.odi.govt.nz

- The Ministry of Social Development also provides services for school leavers with high and complex needs. Budget 2005 allocated an extra $9.9 million to meet the growing demand for these services. Transition services that focus on supporting disabled people in the move from school to work and/or community participation are currently being piloted.
- District health boards also fund a range of supported employment options for disabled people. These are provided through the district health boards' mental health services and contracted non-government providers.
- The State Services Commission runs the Mainstream Supported Employment Programme, a subsidised employment programme for people with significant impairments working with selected state sector organisations.
- The Equal Employment Opportunity Trust and the Human Rights Commission are founding partners of NEON (New Equal Employment Opportunity Network), and four issues of an electronic newsletter, which includes disability-related news, have been published to over 600 subscribers. The network's next activity is the development of an electronic portal aimed at better connecting people and organisations working to further equal employment opportunities in New Zealand.

Government agencies report that over the 2004–2005 year:

- ACC contracted with the Spinal Injury Trust to provide vocational services for people with a spinal injury in Christchurch area. The service is to be reviewed and, if found successful, will be developed nationally.
- School boards that seek information resources for new trustees from the Ministry of Education are supplied with advice on "Mainstream" placement opportunities in schools. An information handout was distributed to trustees at the annual New Zealand School Trustees conference.
- The Office for the Health and Disability Commissioner has a new policy, where every person identifying themselves as disabled who applies for a job with the Commissioner, and who has the minimum qualifications and experience, will be interviewed. All vacancies will be notified to Ripple Trust and Workbridge.

## Ensuring an adequate income level

> My disability doesn't affect my earning capacity and I'm sure it never will, but it does impact on finances. I bought a van recently and I had to get a loan for it because it was wheelchair modified with hoist, hand control etc. The previous owner had it modified for $30,000 – for the modifications alone. I bought it for $20,000. I love it and the independence it has given me, but it annoys me that because I'm in a wheelchair I had to pay out this kind of money. I can't go and buy a bomb for $500.
>
> Other costs related to my disability are for physiotherapy (yoga, stretching) once a week, home care support services, and gym fees. I go to a gym that's modified for people with wheelchair disabilities. I receive home care service – a guy comes in every morning and helps me put my clothes on. I can get out of bed, shower and dry myself but I can't put my clothes on. He comes to the gym with me sometimes as well. It's a really important service that gives me a bit more independence and I'm really pleased with that service.
>
> Red, *Life is for Living*, to be published at www.odi.govt.nz

### *Latest trends and data*

Many disabled people not in paid employment or in low paid work rely on income assistance to meet the additional disability-related expenses that would otherwise consume their income and erode their standard of living.

A decrease in the proportion of the disabled community reliant on benefits or ACC compensation might indicate increased levels of employment income. However, it could also indicate that disabled people and their families are bearing more disability-related costs themselves.

The 2001 Disability Survey found that:

- almost half of disabled adults aged 15-64 years had incomes of less than $15,000
- 7% of disabled adults received the sickness benefit, 7% received the invalids benefit, 2% the war disablement pension and 2% the special needs grant
- the disability allowance was provided to 13% (84,000) of disabled adults
- 18% of disabled children (16,500) received the child disability allowance while 6% (5,400) received the disability allowance.

### *Activity to improve the provision of income support*

The Ministry of Social Development through its Future Directions Benefit reform is developing proposals for a single core benefit; this is complementary to the work developing a new service for clients currently on sickness and invalids benefits.

One of the goals of the benefit reform is to help beneficiaries successfully make the transition from benefit to sustainable employment; another is to make the benefit simpler by improving people's access to the correct amount of assistance. It intends to re-focus Work and Income staff on the abilities of people rather than on what they can not do.

Research commissioned into the costs of disability will inform the further development of this work.

> Our family issues sadly often revolve around finances and I worry about how this will affect our girls' future. We live on benefits, an invalid benefit, a disability cost benefit and a child disability allowance. Money is very tight. Our big investment is our house on a bit of land. It's a good place to live, but I worry about the mortgage payments. We own a van with a wheelchair hoist but it is so costly to run. For example we spend a lot of time and money travelling into a major hospital for specialist treatment for Sam. It's a three-hour drive and we are doing three to six trips a year. The trips cost. Although we get 20 cents a mile, there is parking for the van, meal expenses etc. I stay with Sam in hospital and do all his individualised care. It's hard as there are no beds, no meals. At our local hospital if I stay over they manage to give me meals, and it means I can cope better…
>
> On a bad day I worry about the future, the money aspect of it, the fact that I'm getting older and I'm tired by the physical caring, what would happen if I couldn't do it? I go to our Down Support Group and it's great to share our concerns, have a laugh and support each other. Our group has widened to welcome other parents with children with severe impairments so I am among others who understand our day-to-day reality, and it helps.
>
> Sarah and her great family, *Life is for Living*, to be published at www.odi.govt.nz

## Objective 8: Support quality living in the community for disabled people

### Providing accessible housing in the community

**Indicator 12: Percentage of public housing stock that is accessible to disabled people.**

Disabled people have a number of extra requirements for housing. These include the need for easy physical access, locations near public transport and/or services, adaptations to meet a variety of needs including for people with sensory, mobility and intellectual impairments. These requirements narrow considerably the market of houses some people can choose from. Put this together with low income levels and there are some very serious housing issues for many disabled people.

Improvement will be evident when there is an increase in the percentage of Housing New Zealand Corporation properties already modified or suitable to be adapted for people with physical impairments.

### *Latest trends and data*

- The Housing New Zealand Corporation has more than 64,000 properties. These include accommodation for disabled people. It is estimated that about 10% of their housing stock is currently modified or suitable to be adapted for people with physical impairments. This includes 2,500 properties (3.8% of all rental stock) that have already been modified.
- A further 3,500 properties (5.4%) are suitable for modification for people with mobility or other impairments. The balance of their housing stock is ill-suited for disability modification for a variety of reasons associated with design and location.

The 2001 Disability Survey found that disabled adults were less likely than adults without an impairment to own or partly own their home. Comparisons between the 1996 and 2001 surveys do not show an increase in housing ownership for disabled people.

Consultation undertaken by the Housing New Zealand Corporation in 2002 in preparation for the New Zealand Housing Strategy found not enough choice in accessible housing for people with mobility and sensory difficulties, and a lack of suitable rental-housing stock, particularly single units for people for whom living alone is the most appropriate option.

The process of the de-institutionalisation of the Kimberley Centre will be complete in 2006; in June 2005 there were 96 people remaining.

> Virginia has been living at Debbie and Steve's place for three years and Douglas for one… They both say: "We like it here. We're happy and we want to stay here".
>
> Douglas comments: "We have our moments but everyone has their moments. This house is good. I help with the dishwasher and the rubbish and do the bottles for Steve. Ginnie folds the washing. We've all got our chores."
>
> When comparing their current living situation with their experience in residential care they explained: "In residential care you don't get to go out much. You get told you are not allowed to do this, you are not allowed to do that. Here we can get out more and do a lot more things. We don't do any courses or any training but we go to the Cossie (Cosmopolitan) Club once a fortnight. We do lots of dancing at the club. We know lots of people at the club. It's within walking distance.
>
> "This house is really close to work and close to the shops. On Saturday we go out for lunch or dinner together. Douglas goes to church on Sundays and gives out the pamphlets. Ginny watches Coronation Street. She doesn't like to miss that. We both love dancing and wining and dining too …"
>
> Virginia and Douglas, *Life is for Living*, to be published at www.odi.govt.nz

### *Activity aimed at improving housing choices for disabled people*

In May 2005 the New Zealand Housing Corporation launched *Building the Future: The New Zealand Housing Strategy*, which outlines a broad approach for lasting, positive housing solutions for families and communities, including disabled people. The Strategy includes specific activity related to improving housing choices for disabled New Zealanders, such as promotion of universal design principles.

The corporation continues to provide a "Suitable Homes Service" to meet the housing needs of people with physical impairments:

- over the last year the service assisted 361 people into modified homes
- an additional 126 units were made available to the social housing and disability sector through the provision of loans to community-based organisations and local councils
- 19 houses were provided to support the de-institutionalisation and resettlement of former Kimberley residents.

A total of 406 properties were modified during the year. Modifications are done on a case by case basis to suit the specific needs of the tenant where appropriate housing is not locally available. All disability modifications comply with *New Zealand Standard 4121: Code of Practice for Design for Access and Use of Buildings and Facilities by Disabled Persons*.

The Housing Corporation's development guide applies to all new and modified housing to ensure that increased housing is accessible to disabled people or requires only minor modifications to be made suitable; for example, many units in new post-family housing developments have no internal stairs, have level access or access by lifts.

The Corporation worked with health agencies and service providers to establish a not-for-profit disability sector housing association in Auckland. A peak body (Community Housing Aotearoa Inc) was established through the provision of funding and support to support housing providers in the social housing and disability sector.

### Community trust management and ownership of social housing in Kaipara

There is an identified need for low-income housing catering for disabled people and elderly people in the Kaipara area. The Kaipara has above the national average of people over 65, and the mean income of the area is $4,000 to $5,000 below the national average. There are an identified 477 disabled people in the Kaipara area, with 386 people receiving the invalids benefit in the Dargaville central area.

The Kaipara District Council decided community-based organisations could better provide for social housing needs. They invited local community organisations to tender for the management and eventual ownership (within five years) of 34 self-contained housing units in Dargaville and Ruawai. In 2005, the Kaipara Community Health Trust won the tender with the intention of renting the units to low income disabled and elderly people.

An assessment of the units indicated that modernisation and modification was needed to make the units accessible for elderly and disabled tenants. The work includes installing wet shower areas, kitchens specifically designed for wheelchairs, decks to extend living spaces, off-street parking including parking for mobility scooters and, on one site, paths to join units to the nearby community hall.

The trust and the council are working in partnership to access an interest-free suspensory loan of $30,000 per unit from the Housing New Zealand Corporation innovation fund to complete the required work. Specifications for the modifications will be worked out in conjunction with the local CCS.

Funding from Housing New Zealand is also being used to build the trust's organisational capacity. The trust has 12 volunteer trustees who represent all sectors of the Kaipara community. A full-time CEO has been appointed and the appointment of a housing manager is under way. Strategic and business plans are being developed. Debbie Evans, CEO, indicates that "a key task will be to develop a social housing policy that sets criteria for allocation of units to tenants. The trust sees it has a role in providing support for tenants. We are strengthening our working relationships with all the service providers in the Kaipara area so we can work with them to support our tenants. We want an integrated approach to meeting our tenants' needs.

"Although the loan for the modifications has not yet been finalised we are placing people in the units. We have three wheelchair users in the units and six people with scooters. At one site the council has made accessible scooter and wheelchair access from the units to the nearby hospital and to the local supermarket."

Sarah and Bill Grayson have moved into one of the units. Sarah comments: "I've recently had my leg amputated and we had to leave our house in Tinopai. Our house was not suitable for a wheelchair and access to the services I need would have been difficult. We are missing our family, but living in town is the best for us now. We don't know where we would be without these units."

### *Gaps and opportunities in housing research*

In March 2005 the Centre for Housing Research, Aotearoa New Zealand (CHRANZ) released scoping research on the housing choices for disabled New Zealanders. It identifies a set of housing research projects that address the key issues impacting on housing choices for disabled New Zealanders:

- location-specific data on numbers of disabled people experiencing housing challenges
- location-specific data on the supply of houses already modified for disabled people; and the type of impairments they have been modified for

- the New Zealand Housing Corporation's public sector housing modification demand and supply monitor covers their own stock only, and should be extended to private and local government housing stock to identify net need for housing modifications.

Based on these needs the following research projects have been proposed:

- upgrade the analysis of households' data in the Disability Survey and census data incorporated in the database
- current and projected supply of, and demand for, accessible housing in relation to disabled people with physical impairments
- projecting need for new housing or modified housing for the future ageing population
- number of disabled people living in transitory/temporary or inappropriate housing.

CHRANZ intends to commission research related to these proposals.

## Improving access to public facilities and environments

### Indicator 13: Proportion of public buildings, facilities and environments that are accessible.

Access to public buildings, facilities and environments is critical for participation in work, education, social life, recreation and community activities. Improvement will be evident when there is a marked increase in the percentage of public buildings and facilities universally accessible.

### *Latest trends and data*

Information regarding the rates of universal access to public buildings is not currently available, so progress towards the target is not measurable at this time. However work to improve compliance with the Building Act 2004 and the Building Code is under way.

### *Activity and opportunities to improve access to public facilities and environments*

Building regulation in New Zealand requires that any building work on public facilities ensures that new building or alterations will be accessible to disabled people. This requirement is managed through the building consent processes.

While this system has been in place for many years there are ongoing issues with compliance. However, there has been a number of changes in building regulation over the last year that have provided opportunities to bring improvements in the regulations around accessibility and monitoring compliance.

The Building Act 2004 resulted in dissolution of the Building Industry Authority and the establishment of the Department of Building and Housing as the new administrator.

The new department is required to undertake consultation with the disability sector in matters that affect disabled people. To fulfil this requirement it has established an access advisory panel with members from the disability community.

The panel is required to provide advice that contributes to:

- an enriched understanding of disability issues
- efficient and effective building regulation that supports the development of a universally usable built environment accessible for all, including disabled citizens.

The panel produced two reports in 2004–2005 (November 2004, April 2005). A result of the first report to the Department of Building and Housing was an amendment in April 2005 to the Building Act to clarify that no waivers or modifications relating to access and facilities for disabled people can be granted for new buildings. For existing buildings, such waivers or modifications can be made only by the department's chief executive.

The Building Act 2004 requires that a major review of the New Zealand Building Code take place by 30 November 2007. This review offers the opportunity to get a number of things right for disabled people and the access advisory panel, along with the Office for Disability Issues, will be working with the department to ensure this happens.

The Association of Credit Unions now provides voice-enabled ATM machines nationwide. The "talking" ATMs have been developed for use by blind and vision-impaired customers and are used by plugging personal headphones into a universal audio jack. The ATM then delivers step-by-step audio instructions to the customer.

## Moving around the community

### Indicator 14: Percentage of disabled people who are able to undertake independent journeys.

Independent mobility is critical to the full participation of disabled people in society. Appropriate transport is needed for participation in work, education, social life, recreation and community activities. Improvement will be evident when the percentage of the disabled population who are able to undertake short trips without personal assistance has increased.

> Access to affordable public transport would be great. My vision impairment means I am not able to hold a driver licence so I rely on my family, friends and co-workers and sometimes the local school bus to get to and from work. I miss my independence sometimes, when I lived in Sydney there was public transport to get around. I am lucky to have the support I do, because if I didn't, my work and living options would be even less.
>
> Gail, *Life is for Living*, to be published at www.odi.govt.nz

### *Latest trends and data*

Many disabled people rely on public transport as their only means of transport. The main difficulties for disabled people using public transport are boarding and getting off trains, buses or aeroplanes, and inadequate seating. And, because most disabled people are on low incomes, the cost of more accessible transport, such as taxis, is a barrier to their use.

The 2001 Disability Survey found that:

- only 3% of disabled adults and 2% of disabled children had not made any short trips (less than 80 kilometres) in the previous 12 months
- of those who had not made any short trips, most (adults, 91%; children, 75%) indicated their condition or health problem was not a factor preventing them from making short trips
- of the disabled adults able to make short trips, an estimated 49,500 (9%) needed someone to help them. Similarly, of the disabled children able to make short trips, an estimated 9,500 (11%) needed someone to help them on these trips
- amongst adults, the need for help on short trips increased with age, with 16% of adults aged 75 and over able to travel short distances with assistance, compared with 8% of adults aged 15–24 only able to travel short distance with help.

> I have spastic quadriplegia and get around in a power chair… I face barriers to the places I can go and how I get there. Transport is a huge barrier. Part of this is an attitude problem – it seems that some service providers don't really want to provide a service but feel they have to, to be politically correct or because the council tells them they have to.
>
> I catch a bus to and from work every day. When that doesn't work out I'm in trouble. In fact, last night the midnight bus that I usually catch home from town didn't come so I had to drive myself home in my chair. To catch a taxi you generally have to book it at least a day in advance so that's impractical.
>
> The attitudes of drivers are something I have to deal with – I've found that most bus drivers, and even some cab drivers, have a begrudging attitude and appear as if they don't really want to help. You can't really blame them – they have to put the ramp down for me and that is an inconvenience.
>
> When I go out with friends it's usually to a bar or to the movies. It can be a pain if a bar has stairs. I sometimes feel like a liability when we go out because the places we can go are limited by me. I sometimes say, "Don't worry guys, I'll go home. You guys can carry on." That doesn't happen because my friends won't let it. But in an ideal world everywhere would have ramps and it wouldn't be a big deal.
>
> Red, *Life is for Living*, to be published at www.odi.govt.nz

### *Activity aimed at supporting access to transport*

The Human Rights Commission has undertaken an inquiry into accessible public land transport. Submissions were invited (until August 2004). Hearings were held in Dunedin, Wellington, Palmerston North, Hamilton and Auckland. Draft recommendations were developed, stakeholders consulted and further information sought from some participants. The final report recommends direct participation of disabled people in planning processes, mandatory design standards for public land transport premises, conveyances and infrastructure, and service information and industry wide training in disability awareness and disability competency.

The government's Transport Strategy 2002 includes a commitment to improve the consistency and quality of the Total Mobility scheme across New Zealand. Improvement in this scheme may foster more independent travel for the disabled community.

The Total Mobility review, led by the Ministry of Transport, will report back to their Minister in 2005. The report will review the system of targeted transport assistance to disabled people with the aim of establishing a system that is nationally consistent, portable and secure. An extra $9.5 million was allocated to the Total Mobility scheme from August 2005.

Local authorities play an important role in supporting disabled people to get around their communities.

### Absolutely Positively Accessible Wellington

In 2005 Wellington City Council (WCC) introduced a mobility parking policy after consulting with mobility card holders, completing an audit of existing mobility parking and consideration of worldwide best practice. Implementation of the policy will see the number of mobility parks in the central business district increase from 23 in 2005 to 60 by 2008. Future planning must incorporate a baseline of mobility parking being at least 2% of standard car parks. Mobility parks in both city and suburban areas will be situated where they are most needed, determined in consultation with users.

All car parks are being designed so they are suitable for people with a range of impairments; for example, wide enough for safe wheelchair access and with kerb ramps, easy to manoeuvre in and out of and on a suitable gradient.

Methods of payment for parking will be easy to access and easy to use with wheelchair-accessible coin meters at each park. Mobility card holders will be encouraged to use a pre-paid electronic meter. Smart Park, a prepaid electronic meter that users rent, has just been introduced in Wellington, and a trial of providing free rental for mobility card users is currently under way.

*continued over...*

*continued from previous page...*

The council recognises that disabled people may need more time to reach destinations so allows mobility card holders to be one hour over the time restriction before they are fined.

Wellington, like all other cities, has faced the issue of people who do not hold mobility cards parking in mobility parks. WCC has adopted a strong enforcement policy on towing and fining to ensure mobility parking is accessible at all times to mobility card holders. They are currently engaged in a publicity campaign on towing and fining where people are invited to phone the council to initiate action if they see people illegally parking in mobility parks.

All council buildings with car parks attached will provide mobility car parks. Future city planning will need to consider accessibility for disabled people in the design of streets and amenities. This will include the provision of accessible routes to major amenities, with kerb ramps, audible crossing sounds and tactile tiles at crossings.

A partnership with Taranaki Savings Bank (TSB) has meant that eight mobility scooters are available for free use within the Wellington CBD. The TSB donated the scooters and the council operates a booking service and management for the scheme. Jennifer Rains says: "The scooters have been in use since early July 2005 and there has been an amazing take up, they are widely used and the scheme is working well. More central city locations are keen to be pick-up points for the scooters. As well as making the city accessible we need to inform people, and an 'accessible Wellington' map has been produced. This is just the first in a series of brochures."

The WCC, through the disability reference group, is in discussion with local bus and train operators to make public transport more accessible to disabled people.

## Improving communication for disabled people

### Indicator 15: Percentage of disabled people who report their communication needs have been met.

Communication is fundamental to participation in any aspect of society. Appropriate assistance with communication for some disabled people can benefit them through all areas of life. Improvement will be evident when the proportion of the disabled population reporting unmet communication needs has clearly decreased.

Sam goes to a special needs school and has his own teacher aide. While he can't talk he can certainly communicate. He has a great sense of humour and is right out there, interested in the world around him and trying to get involved. He can communicate his needs and wants with his eyes; he can easily convey yes and no. At home we know he can recognise letters and we are experimenting with him spelling words of things he wants. Because he is unique we realise it is going to be us recognising the way forward for him and then bringing the school on board so that they extend their expectations of what he can participate in and achieve. This is all new territory and we are always experimenting with possible means of communication and ways he can physically extend himself safely. We are all on a learning journey. Callum goes to a special needs playgroup and that's a great time for him.

Sam and Callum, *Life is for Living*, to be published at www.odi.govt.nz

## *Latest trends and data*

The 2001 Disability Survey found that:

- an estimated 45,000 or 21% of adults with a hearing impairment reported unmet needs for hearing equipment, services and assessments. The types of equipment most commonly needed were hearing aids with a T-switch, other types of hearing aids and volume-control telephones
- an estimated 14,000 or 20% of adults with a vision impairment indicated they had unmet needs for equipment or services, most commonly unmet needs for glasses or contact lenses
- 80% of disabled adults had a working telephone or cellphone available in their home; and 26% (an estimated 162,200) adults had access to the internet at home (substantially lower than the 39% of non-disabled adults). Disabled children (77%) were slightly less likely than non-disabled children (81%) to have a telephone or cellphone in their home, and were also less likely to have access to the internet at home (34% compared with 40%).

## *Progressing the New Zealand Sign Language Bill*

For many deaf people, New Zealand Sign Language (NZSL) is an essential and first language. The historic lack of acknowledgement of this has resulted in a denial of some basic citizenship rights.

I attended Kelston School for the Deaf from age five to 18. It was very hard for me to understand why I had to leave my whānau to go to the school. I know that my Dad wanted the best for me and that my family love me very much. However, their lack of understanding of my culture as a deaf person, and because my family did not sign, meant that there were times when I felt lonely and I missed sharing my feelings with them. I did not have many hearing friends and stayed home a lot. I did have deaf friends and I worked with them as well. In high school I attended classes with non-hearing students in sewing, cooking etc. When we had to take exams I knew that our exams were not graded at the same level as hearing students and I felt that hearing students were smarter than me.

…I attended courses that did not have interpreters or communicators so it was very hard for me and I found them boring…

… I met my partner Mita when I was working as a seamstress. It was great to be able to talk to someone in my language, sign. We became very close friends and one day when I was over 20 Mita took me to the beach. That was so wonderful for me and I started to cry because that was the first time I had ever been to the beach…

My life now is wonderful. I know that I need to learn more but I also know that I have come a long way. I have a daughter who attends kura kaupapa. It is hard for me to attend parent interviews as there are not enough Māori-speaking interpreters or communicators who can support me. This is distressing for me as I can only rely on my child to sign to me about how she is doing at school. It is good that all my children know sign language...

Kathy, *Life is for Living*, to be published at www.odi.govt.nz

Government has developed a New Zealand Sign Language Bill to provide for:

- the official recognition of deaf people's language – NZSL – as a unique New Zealand language with equal status to spoken languages
- the right for users of NZSL to receive NZSL interpreter services in legal proceedings
- principles to guide government departments on the use of NZSL to promote and provide access to government services and information
- regular reporting on the progress made in implementing the Bill.

The first reading of the Bill took place on 22 June 2004 and was supported by all political parties. The Justice and Electoral Select Committee tabled its report in July 2005. Their main recommendation was to propose a new clause to review the legislation after three years.

Enactment of the Bill will be a first step in addressing the serious neglect of the needs of many deaf New Zealanders. Key ongoing work includes:

- developing the NZSL interpreter workforce, including consideration of mechanisms for ensuring competency standards
- reviewing funding mechanisms for NZSL interpreters

> …I love the interpreting work. I gave up a full-time job and took a big cut in pay to do this work. If a qualified interpreter came here I would have to give it up. It means I don't have total control of my career. However I see myself working as an interpreter a long time into the future…
>
> Because I have been deaf I know what an act of trust it is to use an interpreter. You rely on the interpreter to communicate really important and personal information. Interpreters are communicating at intimate or serious medical examinations, in situations involving legal interpretations, with the Police or with courts. The deaf person has to trust the interpreter has got it right. I really understand the responsibilities of an interpreter to be accurate, impartial and confidential. [Note: Tina has had a cochlear implant operation].
>
> Tina, *Life is for Living*, to be published at www.odi.govt.nz

- development of mechanisms to promote NZSL and for review of the NZSL Bill
- removing language barriers to deaf peoples' participation in education, health, employment, the justice sector and public broadcasting, using the Disability Strategy work plans and reporting processes.

The NZSL Bill specifies the Disability Strategy planning and reporting process as the monitoring mechanism for the Bill. Once passed into legislation government agencies will be required to report on how they will ensure, and have ensured, appropriate access to their information and services for deaf New Zealanders.

Some government agencies have already reported some activities supporting the objectives of the NZSL Bill. Several departments report that NZSL interpreters are available on request for their services and public meetings. The Office of the Health and Disability Commissioner has provided staff with regular NZSL lessons. The Chief Electoral Office has produced a film in collaboration with the Deaf Association using NZSL to explain enrolment and voting procedures to deaf people for the 2005 election. The Ministry of Justice are working to improve the interpreter services provided in Courts and this will include NZSL interpreter services.

The New Zealand Police report many initiatives to improve their services for deaf and hearing impaired people. These include:

- training for front-line staff on the use of NZSL interpreters
- producing a NZSL version of the Neighbourhood Support video
- a notice informing staff about a new communication system for deaf and the hearing and speech impaired was placed on the National Bulletin Board
- communication centres put 111 call procedures in place for telephone relay service (TRS) users and have set performance measures for emergency communication on teletypewriters and fax machines for the same response time as set for other emergency calls
- text is now entered for each event, which enables information to be pulled on number of calls to TRS or Deaf Fax, the nature of the calls, and the response time
- a deaf awareness training workshop has been designed to be delivered by the Deaf Association.

### *Establishment of a New Zealand telephone relay service*

The Ministry of Economic Development launched the New Zealand Relay Service in November 2004, a telecommunications service that will enable people who are deaf or have speech or hearing impairments to use the telephone. The relay service is available nationwide, 24 hours a day. Trained call centre operators convert typed text into speech, and vice versa, to enable live conversations between people who are deaf or hearing impaired and people who are not. Sprint New Zealand is the relay service provider.

The service was established under the Telecommunications Service Obligations (TSO) framework of the Telecommunications Act 2001. The Human Rights Commission had reported to the Prime Minister that the government should establish a deaf voice text relay service under a TSO. The Commission had previously received complaints from deaf people about the lack of a relay service and had issued its opinion that the failure to provide this service was discriminatory. It had not resolved the complaints.

Some organisations receiving relay calls have expressed concerns about confidentiality and privacy responsibilities. These concerns have been addressed by clarification of the relay service's confidentiality protocols and suggestions for how agencies can successfully accept relay calls. Some organisations have since successfully adapted their call centre policies or processes to be inclusive of deaf, hearing impaired and speech impaired people.

The New Zealand Relay Service Advisory Group, established in April 2005, includes deaf, hearing-impaired, deaf-blind, speech impaired people, and a parent.

The relay service is going well, with the target number of call minutes after two years of operation being achieved in the first eight months of operation.

> …I was mainstream educated with some technical support, but with no interpreter and no note taker. As I progressed through secondary school it got harder and harder. I struggled with the work and just thought I was stupid so I left school at 16 and got married a year later. I had no close friends in my school years – it was just too hard to connect with people. As I got older I had a circle of Deaf friends and a few friendships with a group of neat hearing people who bothered to learn how to communicate with me. In our family it was easier, because my Mum and another sister were deaf and we signed at home…
>
> When I was in my late 20s my mother and sister got cochlear implants and I decided to get one too… Before the implants I could not use a phone, I could not go to any appointment and be sure about what was said. If it was important I needed to take an interpreter, or my partner, or a hearing friend. If no one was available meetings were very stressful. I was limited in what work I could do in the community. Even everyday one-to-one communication required my full concentration and had difficulties. I limited the number of interactions I had. It was too hard, too tiring, so you end up feeling you do not belong with other people. Because the communication is difficult you feel stupid and limited.
>
> Tina, *Life is for Living*, to be published at www.odi.govt.nz

## Improving access to health services that meet disabled people's needs

### Indicator 16: Percentage of disabled people who report their need for health services have been met.

Disabled people tend to have higher needs for health services than non-disabled people. This is partly explained by the overall lower economic status and the vicious cycle of deprivation associated with this. Some higher health needs can be explained because of an older overall demographic and some are the result of health issues directly associated with particular impairment types.

I have cerebral palsy, which affects my left arm and hand. My left hand has a tendency to attack itself as the fingers constantly rub and dig into one another, causing the skin to break down and often become infected. To prevent the fingers causing any damage I have worn a splint, or some form of protection on my left hand since I was about four and have gone through many different types, styles, and versions. I'd love to find the perfect splint, but I don't know that it's out there. I've been looking for 20 years, and been to many different specialists. I've had the fingernails removed from my thumb and index finger, which is working well to prevent infection. I had a tendon transplant when I was 14, to try and combat the severe spastic diatonic movements; however that was nowhere near as successful as hoped. For almost 10 ten years now, three or four times a year I have botox injections deep into the muscles in my left arm, to relax them and combat the extreme spasms and this works well.

Anna, *Life is for Living*, to be published at www.odi.govt.nz

There is evidence that health services, including health promotion and illness prevention, are not always responsive to the needs of disabled people. International literature shows that the disabled population have higher mortality and morbidity rates than non-disabled people. It is necessary for health services to be more responsive and to better co-ordinate their services with disability support services.

Improvement will be evident when the proportion of the disabled population who report an unmet need for at least one type of health service decreases.

Managing my health can be really difficult so sometimes it's just too much hassle to do anything if I'm feeling unwell. I would like to access better healthcare to learn how to manage my health better and make the most of the time when I'm feeling good. I suffer poor physical health due to my impairment, high blood pressure, stomach complaints, and general stress-related illnesses. They make my life quite difficult and limiting on many occasions. I would love to be physically well so I could just concentrate on dealing with my mental issues. It would be great to have support in the form of some decent affordable healthcare and a doctor who could work with me in getting my health back.

Craig, *Life is for Living*, to be published at www.odi.govt.nz

## *Latest trends and data*

The 2001 Disability Survey found that:

- 15% of disabled adults, an estimated 94,900 adults, indicated that in the previous 12 months they had needed to see a health professional, therapist or healer but had not been able to (a slight increase over the 1996 survey)
- parents or caregivers of 17% of disabled children, an estimated 15,500 children, reported their child had needed to see a health professional, therapist or healer in the previous 12 months but had not been able to.

Research undertaken by the National Advisory Committee on Health and Disability between 2001 and 2003 found that many adults with an intellectual disability have health conditions that are treatable, relievable or able to be cured but for which they are not receiving appropriate medical care or management.

> In addition to the significant barriers to receiving health care, the National Advisory Committee on Health and Disability is very concerned about prescribing practices for this group [adults with an intellectual disability]. Many people are over-medicated, use outdated medication and are unable to access specialist review. The committee was given access to an analysis of the pharmaceutical records of more than 2,500 adults with an intellectual disability. The records showed some very worrying prescribing practices. For instance, 40% of people being treated with psychotropic medicines had never been diagnosed as having a psychiatric condition. It appears that in many cases medications are being used to deal with behavioural problems, rather than the cause of behavioural issues being addressed.
>
> National Advisory Committee on Health and Disability (2003)

## *Activity that will improve health outcomes for disabled people*

The Ministry of Health reports that in the 2004–2005 year:

- the national breast screening programme aimed to ensure all screening and assessment services it provides are responsive to disabled women and their facilities are physically accessible
- a clinical guideline for the diagnosis and management of Autism Spectrum Disorder is near finalisation
- the second *New Zealand Mental and Addiction Plan: Te Tāhuhu – improving Mental Health 2005-2015* has been released. The plan provides an overall direction for investment in mental health and addiction services.

> QE Health is a vital place to me, it's a lifeline. It has the only post-polio clinics in the country. Here we get up-to-date information about our degenerative condition, physiotherapy, occupational therapy, mud baths and wheelchair assistance. Going there each year is a chance for all of us to give each other support, maintain friendships and gain energy and renewed mobility to keep going. Our local DHB has not renewed its contract with QE Health. I don't think they realise the holistic value of what is offered, because they are saying a physiotherapist in Auckland can offer the service. There is no value on the mutual support, friends who understand, experts who use a range of treatments to maintain our limited mobility. This is pretty devastating for us and I am currently advocating for continuing the treatment with senior management at the local hospital.
>
> It's tough living on a $200-a-week benefit and needing frequent doctor's visits. There is no PHO (primary health organisation) near me, so its $45 a visit. At a time of rapid changes in my health that could be fortnightly or monthly, then there are frequent visits to the hospital. The car parking is $12 a visit. No appointments at the hospital can be co-ordinated so it could be there on two consecutive days. The costs mount up.
>
> Max, *Life is for Living*, to be published at www.odi.govt.nz

There is an opportunity in the Primary Health Care Strategy to better meet the health needs of disabled New Zealanders. The new funding approach provides incentives for primary health care organisations to better promote good health and wellbeing for its enrolled population, including disabled people. In particular, there is an opportunity to improve the health care of adults with an intellectual disability through more effective illness prevention, health promotion and regular review.

As part of the development of primary health care organisations, the Ministry of Health has introduced a Care Plus initiative to make primary care cheaper and better organised for people with chronic conditions. This programme will soon be evaluated and access for disabled people including those with an intellectual disability will be an important issue to consider.

There is sometimes a need to better co-ordinate primary health care with support services. For example, if a general medical practitioner carries out a review of the medication for clients with an intellectual disability and finds a need to reduce the dosage there may be a need to work closely with support workers and other care providers to manage any changes effectively. The Ministry of Health is working with the two primary health care organisations that many ex-Kimberley residents are enrolling in. This may help develop practice models for other places.

More work is required to make best use of these opportunities. There is a need to raise the knowledge of primary care practitioners of the health issues for disabled people and about disability issues generally. For example, practitioners need to ensure disabled people can communicate directly about their needs rather than only through a provider or family member.

An article in an Australian medical journal commented that "although evidence has existed for decades in the literature that people with an intellectual disability have poor health, there has never been a loud call for this injustice to be redressed, not even from the organisations which exist to improve their welfare" (Lennox et al, 2000 in National Advisory Committee on Health and Disability, 2004).

In New Zealand this situation has changed. The *To Have an Ordinary Life* report, released in September 2003 by the National Advisory Committee on Health and Disability, makes strong recommendations to address the health issues of people with intellectual disability. Moreover, the Ministry of Health has undertaken to progress this work. It will be very important, however, to keep the momentum of commitment inspired by this report and capitalise on the opportunities in primary health care to make real change in the lives of disabled New Zealanders.

## Objective 9: Support lifestyle choices, recreation and culture for disabled people

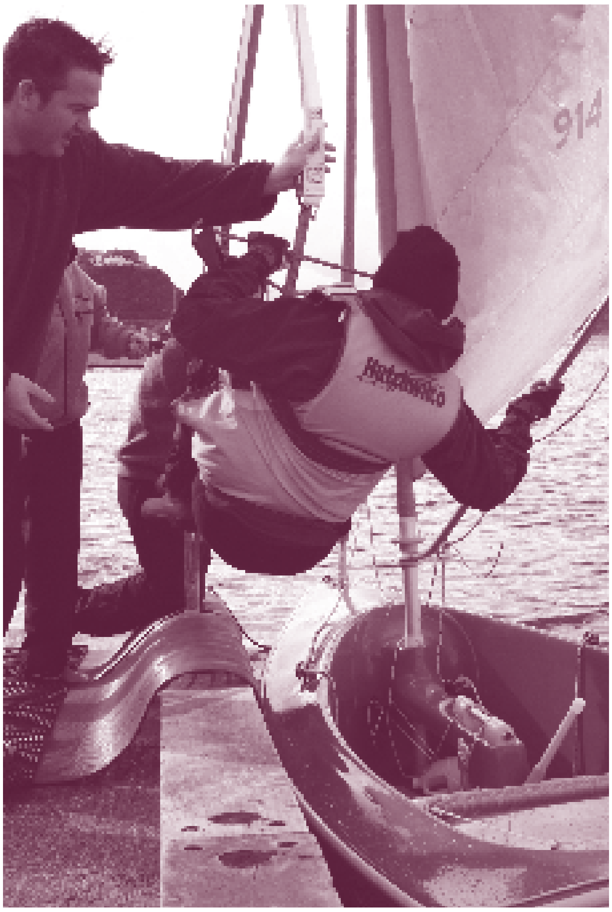
> Alma is well known in our community. I take her out with me shopping etc. Alma goes to a voluntary job at the Salvation Army shop one day a week. She loves the job and always goes. She goes to Gracelands five days a week with two of those days spent at day care. She was one of their first clients so it's like a second home for her. She likes the gardening group there, and does art too. She is great with children. Once a month friends take her to a country music club and she loves it. It is emotional for Harold and myself to see her up there singing with a very supportive group of friends. Alma loves being with people, she likes being part of a group, both to contribute and to have fun in her own way.
>
> Alma, *Life is for Living*, to be published at www.odi.govt.nz

### Promoting participation in sports and recreation

**Indicator 17: Proportion of the disabled population involved in sports and recreation.**

Participating in recreation activities is an integral part of active involvement and inclusion in society for all people. It can also contribute towards rehabilitation and other health and wellbeing goals. Improvement will be evident when there is an increase in the proportion of the disabled population who actively participate in sports and recreational activity.

## *Latest trends and data*



EVANS BAY YACHT CLUB: SAILABILITY

- Sport and Recreation New Zealand (SPARC) undertook sport and physical activity surveys between 1997 and 2001. They found that 28% of disabled adults were active members of a club or gym, 19% took part in at least one organised sport/active leisure competition, and 19% received some coaching or instruction for at least one of their chosen sports or activities. In comparison the national figures are 36%, 26% and 23% respectively.
- Twenty-two percent of all disabled adults were involved in active leisure in a capacity other than as a participant, compared with 27% of all New Zealand adults. This includes being involved as a coach, referee, official administrator, or parent helper, either paid or unpaid.
- Just over half of young disabled people (53%) received some coaching or instruction to help them improve their performance in their chosen sports and activities, which was lower than the national rate for young people of 62%.
- Sixty-three percent of disabled young people are active compared to 68% of all young New Zealanders.

## *Activity to increase participation in sports and recreation*

As a result of the Sport and Recreation Act 2002, SPARC is required to encourage participation by disabled people and to recognise the rehabilitative nature of physical recreation and sport. SPARC reports that in the 2004-2005 year:

- Through the Halberg Trust, and its team of 12 sport opportunity advisors, 1,306 disabled school students and 534 disabled adults have been assisted to engage in sport or physical recreation. Also 2,032 disabled people have been involved in events run or facilitated by the regional sports trusts throughout the country.
- In the Auckland region, the Halberg Trust and the ASB Charitable Trust developed a resource called Sport Access that promotes the inclusion of disabled people into clubs, and sport and recreation facilities. Sports Access incorporates physical access audits as well as a toolkit to establish the organisation’s readiness to include disabled people. It culminates in an award for compliant facilities/organisations. Several territorial authorities have already begun to use Sport Access and the initiative may well be developed in other regions.

- In conjunction with the Christchurch City Council, the Halberg Trust developed a DVD illustrating best practice models for community inclusion. Entitled Get Onto It – Community Inclusion At Its Best, it shows predominantly teenagers participating in sport, recreation and dance alongside their non-disabled peers.
- SPARC created a new disability advisor position. A key role for this advisor will be the implementation of the No Exceptions Strategy and Implementation Plan, which promotes disabled people accessing sport and recreation activities.

The Department of Conservation reports that they have added information about accessible walking tracks to their website.

EVANS BAY YACHT CLUB, MAUREEN AND ALEXANDER

## Promoting access to arts and culture

Disabled people should have opportunities to develop and use their creative, artistic and intellectual potential, not only for their own benefit but also for the enrichment of society.

The Giant Leap Disability Festival ran from 28 February to 6 March 2005 at Western Springs, as part of the Auckland Fringe Arts Festival. It featured disabled professional performers from London, Vancouver, San Francisco and Singapore, as well as local artists. This may have been the first truly international disability arts festival.

The festival highlighted and celebrated the distinct perspectives and creativity of disabled artists and performers. The organisers wanted to create a platform for disabled New Zealand artists to work with more established international performers. They hope that the festival will develop into a biennial arts festival and conference event.

The festival received funding from the same organisations as did the mainstream Auckland Arts Festival. These included corporate sponsors, in partnership with local authorities and Creative New Zealand.

> Art and performance are magic and creative forces. Mix them with the experience of disability and they become a miraculous expression of the illusion of limitation and proof of the existence of infinite human potential.
>
> Philip Patston

The first Deaf Short Film Awards were launched at the July 2004 Deaf View Conference in Auckland. Entries were produced, directed and/or written by a deaf person. The content was also related to deaf issues.

The National Library of New Zealand is a key provider of audio books to local authority libraries, and issued 32,000 books during the 2004–2005 year.

Arts Access Aotearoa is a charitable trust that promotes access and participation in arts. In 2005 they undertook a survey of “creative spaces”; arts programmes or gallery spaces targeted at marginalised population groups. The survey found that 84% of the people using creative spaces were disabled, predominantly with an intellectual impairment and/or mental health problems. Fifty-three creative spaces throughout New Zealand were identified in the survey. Wellington had the highest concentration with 10 providers; Waikato and Canterbury were next with four each.

Creative spaces are currently funded from a mix of funding sources; these include district health boards, the Ministry of Social Development, the Ministry of Health, local government, educational institutions and charitable sources.

There are numerous small recreational, cultural and artistic initiatives or projects undertaken in communities throughout New Zealand – from poetry clubs, open mike evenings to bingo or card playing bridge clubs etc. Sometimes these go out of their way to involve disabled people; sometimes they are set up by and for disabled people. Participation in these sorts of events and activities can make a real difference to someone’s quality of life.

## I live in Sevenoaks and, once upon a day, I remember

The Sevenoaks Lodge poetry class began in February 2002 and meets once a fortnight to read poems aloud. Julie Leibrich, who takes the class, says: “Since 2002 we have heard hundreds of poems and we also learn something about the lives of the poets and discuss what the poems mean to us. The class enjoys all kinds of poetry – we listen to ballads and sonnets, poems which rhyme and poems which don’t, funny poems and serious poems. Sometimes people know a poem and they join in the reading. Many poems are also songs so sometimes we break into song and we are lucky that several people in our class have good voices.”

What is unusual about this poetry class is that the up to 25 participants are Sevenoaks Lodge elderly residents, many of whom have Alzheimer’s disease, other dementias or other disabling conditions. Membership of this group is not constant as individuals die and new friends join. Some members cannot communicate, but move their lips and follow with their eyes.

In 2004 Julie, a Sevenoaks volunteer, and the diversional therapist Trish Howard decided to encourage the group to write some poems. As Julie says: “For some with no language problems writing a poem was an easier task; for others it was more difficult and we had to find ways to find the words. Some cannot speak but wanted to write a poem. One person wanted to write about her garden, so we typed out many individual words about seasons, plants and growth and she indicated the ones she wanted to use and how she wanted them placed to make a poem. Some poems, like Looking at a Snow Wizard, were written in groups as members looked at and spoke about objects. We wrote down everything anyone said and then chose phrases exactly as they were to construct a poem. Some people were able to dictate their poems and one or two could write them down.

“When I started I thought poetry which had good rhythm might unlock thoughts and memories in the way in which music can. I had no idea how powerful the experience would be for the group and myself. Some of the last memories that we lose are memories of things with rhythm and things learned when we were young.

So many of our group recall nursery rhymes, poems they learned at school and songs they sang when they were young. This brings back memories, thoughts and pictures. You can see when I read a poem who in the group is moved by that poem– it’s in the eyes or a nod of the head or a look of engagement.”

Trish and Julie believed that most of the group could write a poem if they were encouraged. They gathered the poems together and published a book called Finding the Words. Families and friends came to the launch and every poem was read aloud. Each poet received a rose. To have their families with them as their

*continued over...*

poems were read was emotional. Families were very moved at what had been written and the occasion was a great celebration.

Julie and Trish comment: **"We can all make false assumptions about the abilities and interests people who have difficulty communicating.** The poetry book gave the Sevenoaks poetry class an opportunity to express themselves."

When asked "What is poetry?" members of the group say: "It uses words to tell a simple truth." "It's harmonious with things going round." "Health-giving, rest-giving, pretty good stuff." "A good poem makes the pictures and the pictures unfold."

## Poets and poems at Sevenoaks

RESIDENT POETS

### ONCE UPON A DAY

Shall we do it?
Shall we not?
In never-never land

There was so much to do.
Life had changed.
Being in love.

She cut the cake
He was nice
I felt great.

He looked lovely
She loved it.
We were both smiling.

It was full love.
Yes, a very nice day.
The best wedding for a long time.

Once upon a time.
Once upon a day.
I remember.

*Written by Ben and Jessie van den Brink*

### LOOKING AT A SNOW WIZARD

(Looking at a snow wizard in a bubble that can be shaken.)

It sparkles, as though all gems
Have come down out of the sky
To help shake it up a bit.

It's for semi children
– not too young but not too old.
They have come into a new world.

Hoping to see a better place.
It's swirling whirling round.
Going in and out.

*A group poem by Muriel Callaghan, Dinny Lincoln, Marion Raymond and Joan Tooley*

### SEVENOAKS

I live in Sevenoaks
Which is full of old folks and blokes.
We're surrounded by lawns, shrubs and trees
Waving in the Kapiti breeze.

*Written by Tony Nelson*

### *Gaps and opportunities around funding for access to recreational, creative and cultural programmes*

Historically, some disabled people participated in art and other creative activities in workshops set up within institutions. When the institutions closed some funding was channelled, in a relatively ad hoc manner, into art programmes in the community for disabled people. The programmes were originally intended to provide "meaningful activity" and to achieve a therapeutic purpose.

A review of vocational-type services, including art programmes, resulted in the 2001 Pathways to Inclusion Strategy to improve vocational and community participation outcomes. The intention now is that this funding should be targeted at supporting people to gain real jobs for real pay and/or community participation as others expect – an ordinary life.

A consequence of this policy, although not the intention, is uncertainty about the funding of services designed to enhance access to recreational, cultural and creative activities. Pre-existing services continue to receive funding from their historic funders. This may not be appropriate in the longer run but there are currently no opportunities for development or growth from this funding source.

> I enjoy embroidery and used to belong to the local Embroidery Guild. My grandmother was an embroiderer and I liked it and thought it would be a good hobby for me. I've exhibited some of my work. I also do artwork, mostly painting in acrylics and using pastels. I've exhibited and sold some of my artwork too. When there was a gallery here in Te Awamutu my work was displayed for sale, but the gallery closed down.
>
> I used to enjoy going to an evening art class. It was a smallish group and very social, as well as learning new art techniques, but the class is no longer on. It was great to get out to it one evening a week as you need something like that when you live on your own.
>
> Andrea, *Life is for Living*, to be published at www.odi.govt.nz

There is a continuing need for policy work on how to better support the participation of all disabled people in the recreational, cultural, and creative life of New Zealand.

## Supporting relationships

Sometimes people do not expect disabled people to have the same kinds of relationships that others have with their community, family, friends and intimate loved ones. This is an inaccurate and very unfortunate assumption.

Virginia and Douglas are a couple who share a special bond. They both have an intellectual disability and, in the past, have lived in residential care. They now live in a contract board situation with a family (Debbie, Steve and pre-schooler Chelsey) in Upper Hutt, and they are actively involved in their local community.

Debbie and Steve support Virginia and Douglas in caring for themselves. Douglas says: "Steve helps me to have a shave. I have epilepsy and I have had help to get my medication right. I take my medication myself and I keep control of it. I haven't had a seizure for ages." Debbie adds: "I take Douglas swimming often – he just loves it and would love to go more often but he would need support to do that. He needs to be able to get there and he needs to be watched all the time because of his seizures." Virginia explains that: "the only thing we don't do now is meet with our friends at People First. We can't get there now since People First moved to Lower Hutt. We miss going there. We would need to get transport to get there. It would be good if they could arrange some transport for us to get there."

Both Virginia and Douglas say they feel good about themselves. They have a good relationship with their own families. Virginia comes from a family of 12. She has two brothers with special needs and one of them is in residential care not far away. She keeps in touch with him and supports him as best she can. Virginia also has a sister living close by who "supports her and helps to keep her on the right track".

Virginia and Douglas are both positive about how people treat them and say that no-one treats them rudely, although Douglas commented: "If someone upsets me at work I just tell me boss and he has a talk to them..."

Virginia (now 47) and Douglas (now 41) have been engaged for 11 years. They are very happy in their relationship and they are happy being part of Debbie and Steve's family. The future looks bright for them and they have no plans to make any changes to the way they are currently living.

Virginia and Douglas, *Life is for Living*, to be published at www.odi.govt.nz

Sometimes disabled people need extra support to find friendships, and a small number of innovative initiatives around the country do this.

## Friendship Links - Nelson Trust

The Nelson Trust matches volunteers with people who have an intellectual impairment in a one-to-one relationship for the purpose of lasting friendship and advocacy.

In 2005 there are 34 volunteer friendships, involving a friend from the community and a friend with an intellectual impairment. There are around 50 friends waiting for a community friend. Friendship Links Nelson has six trustees, including two with an intellectual impairment. A Ministry of Health contract allows Diane Ward to work for 15 hours a week as a paid co-ordinator. Friendship Links advertises widely for volunteer friends, using free advertising in newspapers and radio as well as advertising in community meeting places, at sports clubs, on work notice boards and in churches.

People who volunteer to be friends go through a screening process that involves checking references from two referees, a Police check and a discussion with the co-ordinator. Diane says: "This discussion allows me to make sure the person is suitable and is in a position to commit time to a friendship. I can then find out enough about the person to link the right people so the two friends will be able to develop a natural friendship built on some common interests. The friendship is monitored to ensure that it is mutual and that the person with the impairment has not had a friend imposed on them, and that the friends are not making unreasonable demands on each other. Training is provided for the new community friend, either individually or in groups and I'm only a phone call away if problems arise.

"We produce and distribute a regular newsletter. We have received funding from Nelson City Council to enable us to run social outings. We also have get-togethers three or four times a year, and these are great events always well attended.

"Currently our volunteers range from 23 to 65 years of age and choose to become a friend for a number of reasons. Some have a friend or relative with impairment or they have impairment themselves, giving them the empathy and interest to sustain the friendship. Others are just outgoing people with space in their lives for new friendships.

"The friends with intellectual impairment range in age from 23 to 90 and may have come from a background of a significant period spent in an institution before moving to community homes or supported independent living. Others may be living at home. Many people with an intellectual impairment also have a physical or sensory impairment that may limit their ability to move around or the sorts of interests they can pursue.

*continued over...*

*continued from previous page...*

”It is always easier for me to match friends who can speak and are mobile than those who are non-speakers and are in wheelchairs. Sadly a number of those waiting for the right friendship have multiple and more severe impairments. I may match up, for instance, younger people who want to go out with their friend and include them in activities with their other friends, or a person from the community who is content to just sit with their friend and chat or read to them.

“Our organisation has some other roles. We work to expand the social networks of people by assisting them to widen their circle of friends and contacts and by promoting acceptance and understanding within the community. We encourage friends with intellectual impairments to join groups and clubs. We have a number who have joined the local country and western club. I currently have someone interested in rugby looking for someone to make them part of a rugby club.

“We work with people with disabilities, alerting other agencies to disability issues, anything we can do to ensure their ongoing wellbeing. Often community friends become aware of issues of concern for friends and contact me. I can then contact the right person or agency to deal with the issue. We of course work in with our local volunteer centre and have a page on the Nelson community website. Lastly we assist in bringing people with intellectual impairment into circles of ordinary community life, to be included and valued, therefore adding to Nelson’s diversity and enriching its community.”

# Chapter five: Addressing the diversity of need

To address diversity of need it is important to acknowledge that, in addition to some issues in common, there is huge diversity among disabled people. It is also important to address the specific needs of disabled people's families.

*Disability is a common yet diverse experience*

## Objective 11: Promote participation of disabled Māori

Indicator 18: Percentage of disabled Māori who report their need for transport and special equipment has been met.

Disability support services need to be responsive to the needs of disabled Māori. Improvement will be evident when fewer disabled Māori report unmet need.

### *Latest trends and data*

The 2001 Disability Survey shows that, of all groups, Māori have the highest age-standardised rates of impairment. Compared with non-Māori they tend to have more severe impairments at younger ages. Māori are also more than twice as likely to report an unmet need for transport costs. Half of all disabled Māori adults living in households had a total annual income of $15,000 or less. Over a third had no educational qualification; considerably higher than their non-Māori counterparts.

The survey found nearly a quarter of disabled Māori living in households reported an unmet need for some type of health service (compared with 14% of non-Māori). Having an unmet need was particularly high for younger Māori (15-24 years) where the rate was almost double that of their non-Māori counterparts. Fifteen percent of disabled Māori had an unmet need for special equipment compared to 11% of disabled non-Māori.

### *Activity and opportunities*

ACC has completed a draft literature review to contribute to the development of a Māori research programme to explore Māori use, expectations and experience of their services.

The Ministry of Health has started fieldwork research for a three-year project headed by the Māori Health Directorate to gather information on the use and experience of Māori accessing health and disability services.

## The Northland Māori Deaf Project

Northland has one of the highest populations of Māori Deaf in New Zealand. A hui sponsored by Tai Tokerau DEAS in November 2004 identified the need for a service targeted specifically to Māori Deaf.

A project steering committee of six Māori Deaf was formed and funding obtained from the Māori Provider Development Scheme, funded by the Māori Health Directorate of the Ministry of Health. Committee chairperson Mita Moses says: "The Tai Tokerau DEAS Trust[1] continues to support us to achieve our kaupapa. They hold the contract and provide the organisational infrastructure, but the steering committee drives the project.

"Funding was received in July 2005 and they have begun developing terms of reference and business and action plans. Our vision is that Māori Deaf in Tai Tokerau receive a service that is culturally appropriate and gives us skills and strength. We want to have a Kaupapa Māori Deaf organisation.

"Our committee needs some capacity building. The committee is like a motor, more skills gained make the motor work more effectively. We want to make sure the training we receive is culturally appropriate and will teach us specific skills such as literacy, governance, workshop facilitation and advanced computer training. We want to be actively involved with issues relating to Māori Deaf within our own communities and want to develop our leadership skills and support Māori Deaf in Tai Tokerau. Most important is to be able to bridge the gaps between us and our whānau, hapū and iwi."

Committee member Mihirangi Marsters says: "What's important about this project is that this project is driven by Māori Deaf. It empowers us to share our culture with our own people, and receive training. It's about giving us access on the marae and growing leaders in our community.

"Literacy is a big thing for us. Many of us missed out on reading and writing skills because we did not have interpreters or at that time we were not allowed to sign. This was very frustrating and, when some of us had to attend mainstream schools, we missed a lot of the information because we were trying to rely on lip reading. It was hard for me and I left at an early age. New Zealand sign language is our language and I am very interested in becoming a literacy tutor using sign as a way to support Māori Deaf. I know that we will all gain more confidence in reading and writing and more employment and training opportunities.

---

[1] Note that, while the trust has maintained its name, from 1 July 2005 it is contracted to provide disability information and advisory services (DIAS) rather than disability empowerment, advocacy and support (DEAS) Services.

"For some of us older ones (over 30) we were sent off to Deaf schools when we were very young and did not see our families until the holidays. It was very hard for us to communicate with our families. We were not allowed to sign at school but we signed amongst ourselves. We had home signs, school signs and signs that we used with our mates. Later we learned New Zealand sign language. In my family all my whānau, down to my great grandchildren, can sign. My husband was Deaf and from the Cook Islands. He had his own sign language and so I taught him New Zealand sign language. In my home we could all talk together, but that's not the case for other Māori Deaf.

"The lack of Māori speaking interpreters or communicators has made it hard for us. I would rely on my children to support me as best they can, but many of us we lost the opportunity to understand our whakapapa, our Māoritanga. When there is a tangi, unless there is an interpreter present, many of us don't have the opportunity to say farewell or understand what our friends or families are saying. This is very hard for us. Most of us worked in the kitchen and missed a lot of korero. Māori signs are being used in different regions. We want to work with our whānau so we can share and develop signs for Tai Tokerau.

"Overall, as a committee we are proud of who we are, and this project will give us the strength to continue with our mahi and find our own pathways and a strong way forward for the Tai Tokerau Deaf whānau."

## Objective 12: Promote participation of disabled Pacific peoples

### Indicator 19: Percentage of disabled Pacific people who have received a needs assessment.

An essential step for ensuring improved access to services and acknowledgement of disability needs in the Pacific community is access to needs assessment and service co-ordination services.

### *Latest trends and data*

The 2001 Disability Survey shows that disabled Pacific children were much less likely to have never received a needs assessment than their non-Pacific counterparts and disabled Pacific adults were less likely to use equipment, including hearing-related equipment.

Compared to their non-Pacific counterparts, disabled Pacific adults living in households were less likely to have access to a car, less likely to have post-school educational qualifications and more likely to be using income support services.

Mathew Ngametua is 24 and lives with his Cook Island Māori family in Auckland and participates in a variety of work. He doesn't see his cerebral palsy as a barrier to doing the things he wants to do. "I have done three years tertiary study. I plan to do a business management course because I want to start up my own business – a clothing line for disabled people. I have decided on a name and I'm gradually getting my ideas together, writing them down and we'll see what happens!

"At the moment I am doing contract work for CCS in their Community Development team. I do motivational speaking and anything along those lines. I do the same type of thing with Ripple Trust. I'm also working as a sales assistant in a video store. With my work in the retail sector I am dealing with people every day and the only barrier I can see is with the attitude of some customers. The staff are really supportive and help me to do my job well – not only that, they are good friends.

"My disability does not really impact on my ability to earn money and live the lifestyle I choose. When I wasn't working I found it hard to have money in my pocket but since I started working it's been all good – now I can actually hold onto my money. I get involved in community work. A couple of months back I was involved in planning for a youth forum at the local community hall. I was planning how everything should be set up to make it comfortable and accessible for everyone.

"Before I got involved with CCS and Ripple Trust I didn't access any services because I did my own thing – I am really independent. I got around just fine but CCS and Ripple Trust have helped me with employment and living support."

Matthew, *Life is for Living*, to be published at www.odi.govt.nz

### *Activity and opportunities*

The Ministry of Education has produced information about special education services and how to access them in five languages for the Pasifika community.

The Health and Disability Commissioner has compiled a handbook for staff, *Guidelines for meeting with Pacific Island Peoples.*

In December 2004, the Ministry of Health published a Pacific Health and Disability Workforce Development Plan. It is part of government's strategy to improve health outcomes for Pacific peoples and foster leadership and promote participation by disabled Pacific people.

In April 2005, the Ministry of Health published *Te Orau Ora: Pacific Mental Health Profile*. This is the first specifically-Pacific document to be published by the Mental Health Directorate. It contains demographic and mental health information to provide an overview of the mental health status of Pacific peoples in New Zealand.

## Objective 13: Enable disabled children and youth to lead full and active lives

### Indicator 20: Number of disabled children and youth in residential care.

A fundamental right of all children and young people is to live with their family, or in a family setting. To ensure this happens for disabled children, adequate support services for families are required, including good innovative options for allowing family members some time away from each other.

If care within the family of origin is not appropriate or adequate, alternative arrangements should be as close to a family setting as possible. These include foster care and shared care arrangements. Improvement will be evident as less New Zealand children need to live in residential facilities designed for adults.


DISABLED YOUTH FORUM 2004

Since shared care began there has been a big change in Mark's behaviour. This year he has only been in time-out at school three times, and not for violent behaviour. Right from the start, Mark has fitted into Sue's family's routines. There he has his own room, he is trying different foods, shares space and interacts positively with her children – like letting them choose the TV channel to watch. He is still quite controlling about routines at home, but he is developing the capacity to handle more flexible routines in a new place and is more relaxed at home too. His anxiety levels when routines are broken have gone down considerably. The week when Mark is not home means we can have time for Claire and focus on her, and on fun things that we can not do as a family when Mark is there. There is much more space for spontaneous, noisy, different things.

CCS recently sent me and another parent to a One Person at a Time conference in Melbourne. It was an important time for me and Steve as, after the conference, I began to expand my vision of the kids' futures, and began to dream big dreams for Mark. We were worried about what would happen when he was adult, or when we passed on. We had been thinking perhaps of him living in a flat attached to our house.

*continued over...*

*continued from previous page...*

The conference expanded my thinking to establishing circles of support now that lead him to an independent adult life – perhaps, with the right support, flatting with a non-disabled friend and in suitable work earning an income independent of any benefits.

The conference focused on establishing new friendships, relationships and circles of support that encouraged young people to extend their contacts and slowly develop their independence. I wouldn't have believed it possible, but I have seen how Mark can progress through guided new experiences with Sue in his shared care. Mark has a non-disabled friend and I'm about to take him to some mainstreamed after-school classes. He can travel on public transport now and is much more comfortable out in the community. Big first steps, and maybe the dream is too big, but I can see significant steps being made to reaching it…

Shared care benefits us all, and it has made such a difference to our family that I will do all I can to lobby for shared care for families who have a child with very high needs.

Mark's family, *Life is for Living*, to be published at www.odi.govt.nz

## *Latest trends and data*

The Department of Child Youth and Family Services' disability data derives from reports by their social workers. From this data we can get some indication of the numbers of disabled children that are living in residential facilities. However, it is known that the data is not robust with respect to this client population and also that there may be other children placed in residential care not known to the department. For example, children may have been placed in a residential facility as part of a respite care arrangement through the Ministry of Health's Disability Services Directorate. Therefore, the numbers are likely to be an underestimate.

Under the Children, Young Persons and Their Families Act 1989, there are two pathways for placing disabled children in care arrangements outside their family of origin. The first provides for situations where there is a substantiated care and protection issue. The second provides for children that require specialist care related to their disability needs and typically arises when parents or caregivers are unable to continue to provide the necessary level of care in their home. In this latter case a Section 141 care agreement is used. Some of the children under both sections of the Act are placed in residential facilities.

In March 2005 there were 194 disabled children recorded as placed in alternative care. Of these 101 were under care and protection agreements or orders and 93 were under section 141 agreements. There is no knowledge of how many in the former category were placed in residential care. Of the latter group 35 were known to be in some form of residential facility, with the remainder in family based care.

The 2001 Disability Survey shows that 11% of children (90,000 0–14 year olds) living in households had an impairment. This was the same level as in 1996, and in both surveys boys had a higher rate than girls. Nearly half the disabled children in 2001 had more than one type of impairment. The most common was learning disability, followed by chronic condition/health problem, psychiatric/psychological problems and hearing impairment. Forty-one percent of disabled children had impairments at birth.

The Youth Development Strategy Aotearoa (Ministry of Youth Affairs, 2002) identified key issues for young disabled people. These included providing opportunities for connections with peers, in particular young non-disabled people, and opportunities for meaningful work and ongoing education.

> Thomas has been mainstreamed throughout his life but it hasn't always been easy. The transition from a small primary school to a large high school has put the stress levels up, but knowing the special education system helps. I am on the Special Education Parent Reference group. The problems Thomas has faced have been bullying, students and teachers looking at the "label first not the person" and focusing on what he can't do rather than what his abilities are.
>
> Thomas does work experience at the Bait N Tackle shop. This is such a positive experience; he is out there in the community working with people. His tasks are packing bait, counting hooks, writing price tags, talking to the customers and he loves it, even if we have to put up with the smelly bait plastered down his clothes.
>
> Kathryn, *Life is for Living*, to be published at www.odi.govt.nz

## *Activity and opportunities*

The Child, Youth and Family Service reports:

- the development of a booklet explaining process and guidelines to help with the support of children with high and complex needs. Information is also regularly updated at the www.hcn.govt.nz website
- a project to analyse the policy and legislative frameworks across Child, Youth and Family Service, and health and education frameworks in regards to disabled children
- completion of an action plan between Child, Youth and Family Service and the Capital and Coast District Health Board to improve the needs of their clients with mental health issues
- their executive committee participated in a workshop focused on improving services to disabled children and their families.

The National Library of New Zealand reports that disabled students can access the library's print disabilities section via the children's and young adult collection and services to schools and special needs units.

The Ministry of Youth Development sponsored two disabled young people and their supporters to attend a conference in Christchurch that explored opportunities for young people and their families.

## Objective 14: Promote participation of disabled women in order to improve their quality of life

> I found out later that my family were told I would not live to 20; that I would never marry and never have children. Well, in 1963 I got married and later had a child. I was a mum to one child of my own and to three step-children and now I'm a grand-mum! I was a mum on crutches. When my son was a baby I had it all worked out. I had a modified old-fashioned dinner wagon and when I needed to move him around I put him on that and pushed him from bed to kitchen etc. My wonderful husband died in 1989. My son has never seen me as disabled, and now at age 40 he still sees me as just Mum.
>
> As I have got older my bone problems have got worse. I have osteoarthritis in most of my joints. Years of using crutches have damaged my shoulders. Unfortunately a car accident in 1993 put me back in a leg plaster for another eight months. I now have home care; a great lady comes in every morning to help me with a shower. She does my housework and washing. I do feel the home carers are so underpaid for what they offer. I cook my meals, but the weekend without assistance is a bit of struggle. I have my scooter, and both a manual and an electric wheelchair.
>
> I really value my independence. Since 1990 a big thing in my life is my once or twice a year visit to the Queen Elizabeth Hospital (now called QE Health) in Rotorua. The combined physiotherapy and occupational therapy plus the mineral baths etc have been the major things in keeping me mobile. Being mobile means being independent – it's my way of staying active in the community and not being forced into a rest home situation that I'm not ready for yet…
>
> Jean, *Life is for Living*, to be published at www.odi.govt.nz

### *Latest trends and data*

The 2002 report to the United Nations on New Zealand's progress on implementing the Convention on the Elimination of all Forms of Discrimination against Women (CEDAW) noted a concern within the disability sector that the management of the sexual behaviour and reproductive health of women with intellectual impairment has been over-medicalised and over-managed. This compromises the rights of the women concerned.

The United Nations committee that considered New Zealand's report on CEDAW in July 2003 recommended that action be taken to ensure disabled women do not suffer discrimination, in particular in the areas of employment and access to health care and loans. The committee also suggested New Zealand pay attention to ensuring married disabled women are able to be economically independent.

Women, including disabled women, have traditionally been the primary caregivers of family members. As a result, they have been the most likely to bear the costs of providing care, which can include isolation from the wider community, a weakened economic position and little time for themselves. This can create double disadvantage for disabled women.

According to the 2001 Disability Survey women comprise nearly 70% of approximately 25,900 disabled adults who live in residential facilities. This is because women live longer than men, and older people account for the majority of disabled people in residential facilities.

### *Activity and opportunities*

The Ministry of Women's Affairs tries to incorporate consideration of disabled women across all areas of their policy work. Current examples include:

- Family violence. Inter-agency work undertaken in this area has raised a concern that women with mental health issues who suffer partner violence are denied access to most women's refuges. This is a matter of great concern and a response is being explored.
- Sexual and reproductive health. The Ministry of Women's Affairs is involved in a review of sexuality education for secondary school level students. One component of this review will assess whether the needs of groups such as Māori, Pacific and disabled women are being adequately met through current sexuality education.
- The Ministry of Justice has led work on designing the next New Zealand National Survey of Crime Victims. As part of this the Ministry of Women's Affairs is discussing with the Ministry of Justice the inclusion of information on the level of victimisation experienced by people who have impairments.
- The Ministry of Women's Affairs has a nominations service that records information about disabled women on their database. This service could contribute to disabled women's participation in leadership and decision making on statutory boards and committees.

## Objective 15: Value families, whānau and people providing ongoing support

> It's tough. If I get the flu, and especially if Sam is sick too, there is no going to bed for me. Sometimes I get very tired. There is no available respite care for Sam available in this city. Apart from me, Rose (14) is Sam's principal carer. I have total trust in her and she can do all that is required to care for Sam. This means I can go to an appointment and leave him with her. It's sad that even when she is older she can't ever be paid as a carer because she lives in the house. Soon she will want a part-time job, and I can't pay her for her care of Sam.
>
> Fiona at 17 is beginning to explore her independence and has a part-time job. Some of her money she uses to buy the things other families provide, like clothing and make-up and money for outings. Luckily our teenage daughters are not the demanding type. They and their friends come to the house a lot; we always have kids staying over. The girls are brilliant; they kind of understand there is no space in our family for teenage tantrums. I do make sure they get to do their own things and not resent their Dad and Sam's disabilities. Whenever Darren can look after Sam I use my time with the girls. However, we are a day-by-day family. We can't plan a day ahead. We wake up and see how everyone's health is and then adapt accordingly.
>
> Sarah and her great family, *Life is for Living*, to be published at www.odi.govt.nz

### Indicator 21: Percentage of family caregivers who report that their needs for respite care or carer support is met.

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 is 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 provisions is available to assist, there is growing awareness that more support is needed.

> We do worry about Alma's future if Harold and I are not there to look after her. She has always been with family and we would never consider putting her where she will not be happy. We are aware that some time, hopefully well into her future, we will have to make some hard decisions.
>
> Alma, *Life is for Living*, to be published at www.odi.govt.nz

## Latest trends and data

The 2001 Disability Survey found that disabled people relied heavily on their spouse, daughter, son or mother to get help for everyday activities. Nearly one-fifth of parents or caregivers of disabled children reported needing respite care or carer support in the previous 12 months, and nearly half said they had been unable to get this respite care. A comparison with the Disability Survey done in 1996 found the unmet need for respite care had not changed substantially.

Consultation with family caregivers by the Office for Disability Issues has found that 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 also key issues.

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 little support available specifically for young carers.

## Activity and opportunities

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.

> About 14 years ago we decided there needed to be some sort of support group for families like us and this was the beginning of the Northland Down Syndrome Support group…
>
> As a group we share our ups and our downs as we care for disabled family members, our frustrations with service providers, our breakthroughs with and successes with service providers. It's a place where you can both laugh and cry about our situations and so some of the stress is vented. We take good care of each other and, for most of us amongst the group we find special friends. I've a great mate that I first met through the group and we talk every day. Through our newsletters and our meetings we communicate information. Sometimes it's very hard to find out what we are entitled to, or how to get access to services or carers that will work for us, so we share information…
>
> We network with other organisations and work to hold events and social events so our members from throughout the far north can take part.
>
> Kathryn, *Life is for Living*, to be published at www.odi.govt.nz

The Ministry of Women's Affairs is undertaking work to enhance the choices available to parents and other carers in relation to labour market participation. One workstream is considering issues for people with caring responsibilities other than parenting (such as elder care or care of people who have impairments), by parents who are themselves disabled, and parents of disabled children.

### Intensive flexible family support project

CCS led this project with funding from the Ministry of Social Development. It emerged following concerns that supporting for families with a disabled child only occurred when the family were nearing or already in crisis. The project emphasised community development, family strengths and child rights. Central to the project was a commitment to increasing interagency understanding, co-ordination and practice.

The project generated an early support framework, which sets out how families might be supported, and how this service could be designed, funded and outcomes measured. CCS, together with the members of the project group, supports and endorses this framework.

It is hoped the project will lead to the development of a service in keeping with the early support framework and a commitment to ensure disabled children have the best possible chance of the ordinary experiences of family, play, community, education and friendships that are key to all children's lives.

ACC provisions allow disabled people to engage immediate family members as paid caregivers, 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. The tribunal ordered IHC 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 and further complaints to the Human Rights Commission, the government asked the Office for Disability Issues to lead a review of payments to, and support of, family caregivers of disabled people. The Office is progressing this work in two ways: analysing the current policy that makes family members ineligible for paid employment as caregivers and developing a range of options for assisting family caregivers.

Initial consultation and scoping work for the review 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?

Government's objectives for family caregiving of disabled people, and of responsibilities in meeting related costs, were outlined at the Caring for the Carers Summit in March 2005.

## Progress for New Zealanders with an intellectual disability

In September 2003, *To have an Ordinary Life*, a seminal research report on the lives of adults with an intellectual disability, was released by the National Advisory Committee on Health and Disability. It sparked a great deal of concern, and commitment to address longstanding and sometimes disturbing problems that New Zealanders with an intellectual disability experience. It is important to maintain this momentum and make the most of the "window of opportunity" created by the research.

This year government agencies were asked to provide information in their progress reports and implementation plans, where relevant, about work related to recommendations in the Ordinary Life report.

I have lived in lots of different IHC homes. I really like this one. We are surrounded by good neighbours. In the summer we all get together for a neighbourhood cricket match and a barbecue. In this house I have my own room and my own TV. I don't need any support to look after myself. Bev and Heather do the cooking but we have turns to help. We each have a week on at doing the ironing. Bev and Heather help me manage my money.

I go to the Trentham races and meet up with my cousins. I put some bets on but I have a limit and I do all right. I went over to the Melbourne Cup with Heather.

Elena, *Life is for Living*, to be published at www.odi.govt.nz

Some progress is evident, for example:

- The disability allowance is no longer paid to vocational service providers, allowing individuals better access to income support and autonomy.
- People First has a representative on the newly established Disability Advisory Council, which advises the Office for Disability Issues.

- Social Services Select Committee have reported back on the Disabled Persons Employment Promotion (Repeal and Related Matters) Bill.
- The development of a number of services for ex-Kimberley Centre residents, including an innovative programme called "Explore". This specialist service includes health and social service professionals from a wide range of disciplines working together to provide a one-person interface with clients. They educate each other, local providers and families, and work collaboratively to promote the best "whole-of-life" outcomes for their clients. Work has also begun with local primary health care organisations to improve the provision of health care. This is also discussed in chapter four.
- Self advocates have been involved in the many aspects of the development and ongoing review of the programmes developed for ex-Kimberley residents. This includes inclusion on the interview panels when selecting providers.
- A major evaluation of the lives of Kimberley residents pre- and post-de-institutionalisation is planned. Reviews of the various new initiatives should provide useful evidence for wider service development.
- The Ministry of Health undertook an "Enhancement Project" which aimed to encourage and support people in residential care and their providers to focus on individual needs, rather than taking a group approach to service delivery. In the project's first phase 659 assessments were undertaken. In the second phase a training programme was developed. Currently work is in the Auckland and Northern region but if successful it may be taken out further.
- The recommendations made in the "Ordinary Life" report regarding policy and purchasing frameworks were considered in the Quality and Safety project described in chapter three.
- The Ministry of Health reports that many of the recommendations in the "Ordinary Life" report related to Pacific people with intellectual disabilities will be addressed through activity under way to implement the Pacific Health and Disability Action Plan. This plan was launched in 2002; programmes are now gaining traction, in particular in relation to the newly developed Auckland Pacific Disability Plan.
- The Office for Disability Issues has begun work considering personal advocacy and communication services for people with an intellectual disability. In the 2004–2005 year this included a literature review and consultation.

There is evidence from various conferences and discussions that many service providers are interested in developing ways to change their service delivery to address the concerns outlined in the "Ordinary Life" report. However, there are concerns expressed by the sector that the government activity to date is not enough to support these developments or make a real difference for this seriously deprived group of New Zealanders.

While many pre-existing programmes have been modified to take account of the research findings, not often are specific or new resources allocated to ensure the required changes or development occurs. In particular, more work is needed to deal with inappropriate prescribing practices, poor dental outcomes and to improve the rules and systems related to services so they can better support ordinary lives and move away from a custodial model of service provision.

The changes required will take time to get right, however, and momentum appears to be building rather than waning. And, if some of the small scale innovative service developments prove as effective as currently hoped, it may be possible to roll these out on a wider scale.

The Office for Disability Issues will keep activity in this area on the agenda for progress reporting around the Disability Strategy. It will also be possible in future to measure progress in terms of outcomes. In April 2005, the Ministry of Health published *Living with Intellectual Disability in New Zealand*, outlining key findings on intellectual disability from the 2001 Disability Survey. This report, along with information from the Enhancement project and the Ordinary Life report, provides the most comprehensive picture of the status of intellectually disabled New Zealanders we have ever had. It will be an effective baseline against which to measure progress.

# Appendix: Table of Indicators

| | Indicator | Baseline data sources | Trends and future data sources |
|---|---|---|---|
| 1 | Level of public understanding and knowledge about disabled people and disability issues. | Like Minds project evaluations.<br>Disabled people indicate attitude barriers in consultations and stories. | Significant improvements in attitudes towards people with experience of mental illness have been measured between 1997 and 2005.<br>Possible survey of public knowledge and attitudes to disabled people. |
| 2 | Level of knowledge and understanding of the rights of disabled people amongst key decision makers, legal practitioners, advocacy agencies and disabled people and their families. | Descriptive information from a 2004 Human Rights Commission consultation on the status of human rights.<br>Experience of disabled people and the Office for Disability Issues. | Noted increase in visibility as a result of various activities including the Disability Strategy, Human Rights Status Report and United Nations negotiations on a convention on the rights of disabled people.<br>Possible survey of key individual's knowledge of the rights of disabled people. |
| 3 | Number of disabled people in governance or management roles in the public sector. | The Human Resource Capability Survey collected by the State Services Commission.<br>Career Progression and Development Survey, 2000 and 2005 (yet to be released). | There is evidence to suggest the historic Human Resource Capability Survey data may not be reliable. There are plans to improve it.<br>In June 2000, it showed that 9% of public service managers reported having a disability.<br>It also showed the proportion of disabled public servants declined from 11% in 1998 to 7% in 2002. |
| 4 | Number of disabled people appointed to government boards or bodies. | Not yet available but will start to become available as part of the Nominations Service being set up by the Office for Disability Issues. | |

| | Indicator | Baseline data sources | Trends and future data sources |
|---|---|---|---|
| 5 | Proportion of government websites that are accessible to disabled people. | Survey of websites (in June - July 2005) owned by government agencies or agencies funded by government and E-government data. | Access to websites is improving. In a sample of 149 government websites in July 2005 approximately 8% were found to be excellent, and more than 38% provided access to critical information.<br>A repeat survey is planned. |
| 6 | Extent of quantitative and qualitative research about disabled people carried out by government and used to inform policy development. | Stocktake of disability information in 2005.<br>Evidence noted by the Office for Disability Issues on use of disability information. | Significant increase in the occasions post census Disability Survey data is evaluated and documented in government publications.<br>An increase in disability-related research is indicated for the future. |
| 7 | Perception of people accessing disability support services of how simple to access, flexible and fair the system is. | Several consultations carried out by various parts of government between 2000 and 2005. | Consistent reporting of same problems over more than the last five years. Some indications of increased problems in specific areas related to handling of budget constraints. |
| 8 | Percentage of disabled children participating in some aspect of mainstream education. | Post-census Disability Surveys 1996 and 2001.<br>Information available from the Let's Talk initiative. | In 2001, about 74% (53,300) of disabled children aged 5–14 attended only mainstream classes; 16% (11,400) attended "mainstream" classes and a special unit. This leaves 10% without mainstream participation.<br>Group Special Education is developing measures for presence, participation, quality learning and achievement. |
| 9 | Percentage of disabled adults participating in formal education. | Post-census Disability Surveys 1996 and 2001. | In 2001, about 55,800 (9%) of disabled adults living in households were enrolled in formal education. |

| | Indicator | Baseline data sources | Trends and future data sources |
|---|---|---|---|
| 10 | Percentage of disabled people with a school or post school qualification. | Post-census Disability Surveys 1996 and 2001. | 27% of disabled adults in households had a post-school qualification compared to 34% of non-disabled people in 2001. |
| 11 | Percentage of working age disabled adults who are employed. | Post-census Disability Surveys 1996 and 2001 and Ministry of Social Development analysis. | In 2001, 58% of disabled people aged 15–64 living in households were employed (full and part-time) compared to 77% of non-disabled people. |
| 12 | Percentage of public housing stock that is accessible to disabled people. | Housing New Zealand Corporation consultation in 2002 and data from their housing stock. | In 2005, 10% of more than 64,000 Housing NZ Corporation properties are currently modified or able to be adapted for physical impairments.<br>Research commissioned by CHRANZ should provide further insight. |
| 13 | Proportion of public buildings, facilities and environments that are accessible. | Not yet available; however, maybe acquired in future via a possible survey of public buildings, in particular state-owned buildings. | |
| 14 | Percentage of the disabled population who are able to undertake independent journeys. | Post-census Disability Surveys 1996 and 2001. | In 2001, 3% of disabled adults and 2% of disabled children had not made any short trips (less than 80 km) in the previous 12 months.<br>Of the disabled adults able to make short trips, 9% (49,500) needed someone to help them. |
| 15 | Percentage of disabled people who report their communication needs have been met. | Post-census Disability Surveys 1996 and 2001. | 21% of adults with an uncorrected hearing impairment reported unmet needs for equipment or services.<br>20% of adults with an uncorrected vision impairment indicated unmet needs for equipment or services. |

| | Indicator | Baseline data sources | Trends and future data sources |
|---|---|---|---|
| **16** | Percentage of disabled people who report their need for health services have been met. | Post-census Disability Surveys 1996 and 2001.<br>Research by the National Advisory Committee on Health and Disability. | In 2001, 15% of disabled adults (94,900) and 17% of disabled children (15,500) indicated there had been a time in the previous 12 months when they had needed to see a health professional, therapist or healer but had not been able to. This was a slight increase in unmet need from the 1996 survey. |
| **17** | Proportion of the disabled population involved in sports and recreation. | Sport and Recreation New Zealand (SPARC) surveys from 1997–2001. | In 2001, 28% of disabled adults were active members of a club or gym compared the 36% of the whole population, 19% took part in at least one organised sport/active leisure competition, compared to 26% of the whole population. |
| **18** | Percentage of disabled Māori who report their need for transport, and special equipment has been met. | Post-census Disability Surveys 1996 and 2001. | In 2001, disabled Māori were more than twice as likely to report an unmet need for transport costs than other disabled people. Nearly 25% of disabled Māori reported an unmet need for some type of health service compared with 14% of non-Māori. 15% of disabled Māori had an unmet need for special equipment compared to 11% of non-Māori. |
| **19** | Percentage of disabled Pacific people who have received a needs assessment. | Post-census Disability Surveys 1996 and 2001. | In 2001, disabled Pacific children were much less likely to have ever received a needs assessment than their non-Pacific counterparts. |

| | Indicator | Baseline data sources | Trends and future data sources |
|---|---|---|---|
| **20** | Number of disabled children in residential care. | The Child Youth and Family Service collect some data.<br>There are plans to collect more comprehensive and reliable data. | In March 2005 there were 194 disabled children recorded as placed in alternative care. Of these 101 were under care and protection agreements or orders and 93 were under section 141 agreements. There is no knowledge of how many in the former category were placed in residential care. Of the latter group 35 were known to be in some form of institutional care. |
| **21** | Percentage of family caregivers who report that their needs for respite care or carer support is met. | Post-census Disability Surveys 1996 and 2001. | In 2001, nearly 20% of parents or caregivers of disabled children reported needing respite care or carer support in the previous 12 months, and nearly half said they had been unable to get this respite care. A comparison between the Disability Surveys found the unmet need for respite care did not change between 1996 and 2001. |

# Information sources

Arts Access Aotearoa (2005) *Creative Spaces and Art Programmes Survey*

Committee on the Elimination of Discrimination Against Women (2003) *Draft Report on New Zealand's Report on the United Nations Convention on the Elimination of all Forms of Discrimination Against Women*

Committee on the Rights of the Child (2003) *Concluding Observations of the Committee on the Rights of the Child: New Zealand*

Department of Labour (2001) *Pathways to Inclusion, Improving Vocational Services for People with Disabilities*

Education Review Office (2003) *The New Zealand Disability Strategy in Schools*

Housing New Zealand Corporation (2002) *New Zealand Housing Strategy Reports from Stakeholders*

Housing New Zealand Corporation (2005) *Building the Future: The New Zealand Housing Strategy*

Human Rights Commission (2004) *Framework for the Future: Equal Employment Opportunities in New Zealand*

Human Rights Commission (2004) *Human Rights in New Zealand Today*

Human Rights Commission (2004) *Inquiry into Accessible Public Land Transport,* a consultation report

Human Rights Commission (2005) *The Accessible Journey: Report of the Inquiry into Accessible Public Land Transport*

Human Rights Commission (2005) *The New Zealand Action Plan for Human Rights*

Johnston, M. 2005. Mentally ill encounter less prejudice, survey reveals. *New Zealand Herald* 27.08.05, URL: www.nzherald.co.nz

Mental Health Commission (2000) *Planning Processes for Providing Supported Accommodation for People with Mental Illness*

Mental Health Commission (2004) *Journeys Towards Equality: Taking Stock of New Zealand's Efforts to Reduce Discrimination Against People with Experience of Mental Illness*

Mental Health Commission (2004) *Our Physical Health Who Cares?* occasional paper No 5

Mental Health Commission (2004) *Report on Progress 2002–2003, Towards Implementing the Blueprint for Mental Health Services in New Zealand*

Mental Health Commission (2005) *Discriminating Times? A Re-survey of New Zealand Print Media Reporting on Mental Health*

Mental Health Commission (2005) *Multi Agency Plan for Addressing Discrimination Against People with Experience of Mental Illness*

Minister for Disability Issues (2001) *New Zealand Disability Strategy*

Minister for Disability Issues (2004) *Progress in Implementing the New Zealand Disability Strategy*

Ministry of Education (2005) *Lets Talk Special Education National Report*

Ministry of Health (2002) *He Korowai Oranga: Setting New Directions for Māori Health*

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

Ministry of Health (2003) *National Plan 2003–2005: Project to Counter Stigma and Discrimination Associated with Mental Illness*

Ministry of Health (2004) *The Health and Independence Report*

Ministry of Health (2005) *Living with Disabilities in New Zealand: An Analysis of the 2001 Post-Census Disability Surveys*

Ministry of Social Development (2005) *Disability and Work Participation in New Zealand: Outcomes Relating to Paid Employment and Benefit Receipt*

Ministry of Social Development (2005) *The Social Report 2005*

Ministry of Women's Affairs (2003) *The Status of Women in New Zealand, 2002, The Fifth Report on New Zealand's Progress on Implementing the United Nations Convention on the Elimination of all Forms of Discrimination Against Women*

Ministry of Youth Affairs (2000) *Children in New Zealand, United Nations Convention on the Rights of the Child, Second Period Report of New Zealand*

Ministry of Youth Affairs (2002) *Youth Development Strategy Aotearoa*

Mintrom M and J True (2004) *Framework for the Future: Equal Employment Opportunities in New Zealand*, Human Rights Commission

National Advisory Committee on Health and Disability (2003) *To Have an "Ordinary" Life: Community Membership for Adults with an Intellectual Disability*

National Advisory Committee on Health and Disability (2004) *To Have an "Ordinary" Life: Background Papers*

Office for Disability Issues (2005) *Life is for Living: 25 New Zealanders Living With Disability Tell Their Stories - 2005*. To be published early 2006 and made available at www.odi.govt.nz

Quinn G and Degener T (2000) *A Survey of International Comparative and Regional Law Reform Human Rights and Disability: The Current Use and Future Potential of UN Human Rights Instruments in the Context of Disability*, New York: United Nations

Shakespeare T, Gillespie-Sells K and Davies D (1996) *The Sexual Politics of Disability: Untold Desires*, London: Cassell

SPARC Aotearoa (2001) *SPARC Facts '97-'01*, www.sparc.org.nz/research-policy/research-/sparc-facts-97-01

State Services Commission (2005) *Review of the State Services Commission's Disability Data Collection in the Public Service*

Transfund NZ (2003) *Total Mobility 2003. The Findings of a Survey of: Users, Support Agencies, Regional Councils, Transport Operators*