# Making disability rights real Whakatūturu ngā tika hauātanga



Second Report of the Independent Monitoring Mechanism of the Convention on the Rights of Persons with Disabilities

Aotearoa | New Zealand July 2012 – December 2013



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Please note, names and details in case studies included in this report may have been changed to protect privacy.

Cover image: Jeffrey Barnett enjoys an encounter with Burma and Andrew Coers (Team Leader, Elephants) at the Auckland Zoo during Blind Week 2012. Photo: NZ Herald/B Phibbs.

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# Introduction

# Manaaki whenua, manaaki tangata, haere whakamua. Care for the land, care for the people, go forward.

Human rights in New Zealand have bicultural origins, a Tangata Whenua whakapapa that sits alongside tauiwi (settler) beliefs about the importance of human dignity and rights. The Treaty of Waitangi was the promise of these two peoples to manaaki, to take the best possible care of each other. It is about us all, in all our diversity.

For Māori, mana tangata (the dignity and rights of people) and mana whenua (the customary rights and connections between people, generations, and land) are intertwined and central to tikanga (culture and practice). This intrinsic value of all people and the importance of freedom, justice and peace are also central to many other cultures and belief systems around the world.

New Zealand has often helped lead the way in promoting these principles and in taking steps to protect the rights and wellbeing of all its citizens. Following the Second World War, New Zealand played an important role in the drafting of the Universal Declaration of Human Rights (UDHR). The declaration recognises the inherent dignity and "equal and inalienable rights of all members of the human family".<sup>1</sup>

New Zealand has adopted many other important international human rights standards including the United Nations Convention on the Rights of Persons with Disabilities (the Disability Convention or the Convention). Many New Zealanders were instrumental in the development and introduction of this Convention. As a country we now have an obligation to ensure that the purpose of the Disability Convention is fully realised. This is necessary so that all citizens with disabilities are able to fully enjoy their human rights and fundamental freedoms on an equal basis with other members of the community.

Developments such as the increasing engagement between Disabled People's Organisations (DPOs) and government agencies are to be applauded. Moves towards the introduction of people driven service models are also encouraging. However, there is still a long way to go and some changes are occurring too slowly. This second report of the Disability Convention Independent Monitoring Mechanism (IMM) details some of the experiences disabled people in New Zealand encounter each day. It highlights barriers that prevent the full realisation of the rights set out in the Disability Convention. The report also recommends steps that need to be taken to better respect, protect and fulfil those rights. The five key overarching issues the IMM has identified during the current reporting period are:

- 1 data
- 2 accessibility
- 3 building a people driven system
- 4 violence and abuse
- 5 education.

The first part to this report also highlights four more specific matters of concern. These include the passing of the New Zealand Public Health and Disability Amendment Act 2013. This legislation means people are no longer able to pursue complaints of unlawful discrimination in relation to the Government's family care policy.

The other three issues are the reliance on substituted decision-making, serious health outcomes for disabled people and their right to family life. The IMM partners trust this report will act as a powerful catalyst for change that will lead to further improvements in the daily lives of people with disabilities.

Paul hm

Paul Gibson Disability Rights Commissioner Human Rights Commission

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Mnnm

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# The Disability Convention and the Independent Monitoring Mechanism

New Zealand signed the Disability Convention on 30 March 2007 and ratified it on 26 September 2008. Its introduction followed decades of work to change attitudes and approaches towards people with disabilities. Instead of considering people with disabilities as "objects" of charity, requiring medical treatment and social protection, disabled people are viewed as "subjects" with rights. This recognises the right of disabled people to make free and informed decisions about their own lives.

The Convention is a human rights instrument with an explicit social development dimension. It reaffirms that all people, living with all types of disabilities, must enjoy the full range of human rights and fundamental freedoms. The Convention describes in practical terms how the rights of disabled people can be achieved.

Six months after New Zealand signed the Disability Convention, the United Nations General Assembly adopted the Declaration on the Rights of Indigenous Peoples (UNDRIP). New Zealand expressed its support for UNDRIP in April 2010. While the declaration itself is not binding, many of the provisions reflect obligations set out in ratified conventions or covenants. The Disability Convention shares some common underlying human rights principles with both the Treaty of Waitangi and UNDRIP. These include the importance of partnership, autonomy, close consultation and full and effective participation.

Article 33 of the Disability Convention requires an independent mechanism to be established to promote, protect and monitor implementation of the Convention. The partnership approach underpinning the Disability Convention is reflected in the structure of New Zealand's IMM. It comprises the Human Rights Commission (the Commission), the Ombudsman and the New Zealand Convention Coalition Monitoring Group (the Convention Coalition).

The Commission and the Ombudsman are established by statute and have roles and responsibilities in relation to discrimination, human rights, access to information and public accountability. The Convention Coalition comprises eight DPOs and provides an important voice for disabled people. The DPOs who make up the coalition are:

- 1 Blind Citizens New Zealand
- 2 Balance New Zealand
- 3 Deaf Aotearoa New Zealand

- 4 Deafblind (NZ) Incorporated
- 5 Disabled Persons Assembly (New Zealand) Inc
- 6 Ngā Hau e Whā
- 7 Ngāti Kāpo o Aotearoa Inc
- 8 People First New Zealand Inc.

This arrangement reflects Article 4(3) of the Disability Convention. This provides that all decision-making processes relating to disabled people shall actively involve them through their representative organisations.

The IMM's first report *Making Disability Rights Real* covered the five years to 30 June 2012, with emphasis on the final year. It is available in accessible formats and can be downloaded from:

www.hrc.co.nz/makingdisabilityrightsreal.

This second report covers the period from 1 July 2012 to 31 December 2013.

### The approach

In its first report published in December 2012, the IMM focused on developing a baseline picture of the state of disabled people's rights in New Zealand. The report contained seven key recommendations, pulling together the main priorities from a full list of 44 recommendations. It recommended that the Ministerial Committee on Disability Issues should ensure that action on those recommendations was completed by the end of 2014. This second report assesses what progress has been made since June 2012. The introductory sections highlight and discuss some key issues identified by the IMM during the reporting period, including its priority recommendations.

The remainder of the report provides a detailed analysis of compliance against specific provisions of the Disability Convention.

As recognised in the first report, monitoring the Disability Convention presents some unique challenges. These include the breadth of issues covered by the Convention and the lack of disability data and research in important areas. In addition, environmental and attitudinal barriers hinder disabled people's full participation in society on an equal basis with others. Collectively these factors can make the effective measurement and assessment of progress difficult.

The IMM intends to continue working with government agencies to provide guidance, increase knowledge and to assist in the realisation of rights. The IMM will also speak out independently when issues relating to the Disability Convention arise.

# Key issues

A full list of IMM recommendations for the 2012/2013 period is set out later in this report. As noted earlier, the IMM has identified five broad areas that require particular attention in order to promote greater realisation of the rights set out in the Disability Convention. While promising progress has been achieved in some of these areas during this latest reporting period, much more work is still required. These five key areas are:

- 1 data
- 2 accessibility
- 3 building a people driven system
- 4 violence and abuse
- 5 education.

### Data

The dearth of statistics and information relating to disabled people in New Zealand was noted in the first IMM report.<sup>2</sup> There is a continued absence of quality data based on consistent definitions across a range of indicators. This makes it difficult to obtain an accurate view of many issues that have an impact on the lives of disabled people. It also hinders the measurement of progress and the recognition of improvements that have been made. Statistics New Zealand expects to release the 2013 Disability Survey results in mid-2014. These should provide further valuable information about the experiences of disabled people, their needs and the barriers they encounter. However, ongoing work is required in this area to ensure that robust, timely and useful data are regularly collected across a range of sectors. This data can then be used to make practical changes that will improve the daily experiences of people with disabilities.

# Accessibility

Accessibility is one of the fundamental principles on which the Disability Convention is based. It encompasses the right to access the physical environment, transportation, information and communication, and services. It is important that these multiple components of accessibility are recognised because they are essential for disabled people to live independent and full lives.

The IMM is concerned that the legal requirement to take reasonable steps to accommodate the rights of disabled people in a variety of situations and settings is not well understood.

The Disability Access Review was announced on 20 October 2013. It will

be undertaken jointly by the Ministry of Business, Innovation and Employment and the Office of Disability Issues. The review will consider whether the current building regulatory system meets the needs of people with disabilities. This is an important step towards improving the physical accessibility of buildings.

However, the IMM is concerned that proposals in the Building (Earthquake-prone Buildings) Amendment Bill may undermine current accessibility requirements when upgrading buildings. This proposed legislation will provide councils with the ability to grant exemptions for earthquakeprone buildings in some circumstances.

# Building a people driven system

Building a people driven system is essential to ensuring that disabled people live with dignity. Although this is a broad concept, it is particularly important when decisions are made regarding access to disability assistance and support services.

All supports and services must be provided in a manner that promotes individual autonomy and choice for disabled people to the greatest extent possible. People driven means: "I direct what happens to me". Service provision should not be driven by the needs of multiple agencies but by disabled people themselves and their families.

The implementation of a comprehensive people driven model must remain a priority for the Government. The IMM recognises that there has been progress in this area since the last report and that building a people driven system can take time. Significant changes cannot occur overnight. However, the IMM remains concerned that the roll-out of policies and practice is too slow. Many current projects do not include representatives from DPOs; neither do they have disabled people or their family members in leadership roles.

## Violence and abuse

Violence, neglect and abuse directed at disabled people are ongoing concerns. They can occur in people's homes, places of work and education, and in residential settings. Abuse of this kind can be hard to detect and disabled persons are particularly at risk of ongoing and sustained abuse over extended periods of time. Abuse can take many different forms, including emotional, psychological, physical or sexual abuse. Financial abuse is also an emerging issue of concern, particularly for older disabled people. The IMM uses the term "abuse" to cover all the types of abuse referred to above, as well as instances of neglect.

There is increasing awareness of the prevalence of violence and abuse within society generally. However, the specific forms of abuse disabled people face require particular attention. These include where people may have limited ability to verbalise or communicate what is happening to them, or where they may be reliant on the abuser for day-to-day support and assistance. Further work is required to prevent abuse against disabled people in all environments. If abuse does occur, there need to be systems in place to detect it quickly and to respond effectively and in a manner appropriate to the needs of the disabled person concerned.

## Education

The IMM supports initiatives that have been taken to make schools more inclusive. Since the last monitoring report, the Education Review Office (ERO) has undertaken a number of evaluations and surveys. These indicate that good progress has been made towards schools and early childhood centres becoming more inclusive. However, the IMM shares ERO's concern about the way schools report on their inclusiveness. This reporting focuses predominantly on activities and strategies and much less on the outcomes that are achieved for disabled students. Some concerns have also been raised with the IMM about the methodology used in the ERO's surveys.<sup>3</sup>

Exclusion, isolation and bullying remain significant issues for children and youth. Education-related complaints continue to make up a large proportion of disability complaints to the Human Rights Commission. It is essential more work is done to ensure that disabled children are able to fully realise their education rights, and that this occurs in partnership with DPOs. The IMM remains concerned that there is a gap between the legal right to education and the ability to ensure that this right is realised at a practical level for individual students. There is still no enforceable right to inclusive education in New Zealand.

## Other matters of concern

In addition to the key general issues that have been identified, there are a number of other specific matters of concern that have arisen during the last reporting period. These are discussed more fully later in the report and are summarised briefly below.

# Reliance on substituted decision-making

Respect for individual autonomy, including the freedom to make one's own choices, is one of the underpinning principles in the Disability Convention. In those limited circumstances where a disabled person cannot make an independent decision, a supported decision-making process should be used. This contrasts with substituted decision-making where decisions made by others are imposed on disabled people. Further work is required to ensure that the right to equal recognition before the law (Article 12) is realised for all disabled people and in all circumstances, and that practical supports are provided in order to achieve this.

# Removal of remedies for unlawful discrimination in relation to family caregivers

The introduction of the New Zealand Public Health and Disability Amendment Act 2013 effectively removed any potential domestic legal remedy for unlawful discrimination relating to the Government's family care policy. The IMM urges the Government to repeal this legislation and to properly acknowledge the right of disabled people to choose a family member to be their caregiver. In addition, these arrangements need to be funded on the same basis as those provided by people who are not family members. Without such flexibility, disabled people risk being denied the most appropriate form of care.

### Serious health outcomes

There has been clear evidence, for a long period of time, that there are significant disparities in health outcomes and life expectancy between disabled people and non-disabled people. These are particularly striking for people with learning/intellectual disabilities. The IMM urges the Government to give immediate attention to this important issue.

### Right to family life

Sections of the Children, Young Persons and Their Families Act 1989 undermine disabled children's right to a family life and discriminate against them because of their disability. The IMM recommends that these provisions be repealed so that children with a disability have the same rights as other children when an out of home care arrangement is being considered.

# Key recommendations

The key recommendations from the IMM for the current period largely replicate those from 2011/2012. This reflects the importance of these key issues and the fact that ongoing work is required in these areas, even though some progress has been made. The IMM recommends:

- A That the Government continue to jointly develop the Disability Action Plan with disabled persons organisations, disabled people, children and their families, and commit to its full implementation.
- B That Statistics New Zealand, in partnership with DPOs, lead a programme of work to ensure that key outcome and prevalence data are collected in a way that makes it possible to compare outcomes for disabled and non-disabled people. This work should include a common definition of disability and involve consultation with key stakeholders, government and international agencies.
- C That the Government integrate accessibility and universal design across all its work by:
  - 1 improving access to the built environment including through the review of NZS 4121:2001

- 2 improving access to transportation services for disabled people, including development of national accessibility design standards for all aspects of public land transport
- 3 providing accessible communications services, including websites, throughout all government agencies.
- D That the Department of Corrections and Ministry of Health work together, in consultation with the IMM, to ensure:
  - the requirements of prisoners
     with disabilities are reasonably
     accommodated and
  - 2 best practice in the detention and treatment of people with an intellectual/learning disability or a mental illness.
- E That the Government:
  - 1 establish an enforceable right to inclusive education
  - 2 implement a whole of school antibullying programme to ensure that schools are safe and nurturing places for disabled students
  - 3 establish initiatives that promote the value of difference and affirm the identity of disabled students.

- F That the Government develop a range of initiatives to ensure that:
  - disabled people have the same protection from domestic and other forms of violence as non-disabled people, and
  - 2 agencies identify and appropriately respond to abuse, neglect and violence directed at disabled people.
- G That the Government urgently address the specific matters of concern identified by the IMM in the introductory section of this report, by:
  - 1 repealing the New Zealand Public Health and Disability Amendment Act 2013, particularly those sections which remove remedies for unlawful discrimination in relation to complaints by caregivers who are family members and limit when family members can be paid
  - 2 reviewing relevant laws, in particular mental health legislation, to ensure that the principles of supported decision-making are appropriately reflected and applied in accordance with Article 12 of the Disability Convention
  - 3 addressing significant disparities in health outcomes between disabled people and non-disabled people, particularly for people with an intellectual or learning disability

- 4 amending the Children, Young Persons and Their Families Act to ensure that disabled children have the same rights as other children when an out of home care arrangement is being considered, and have legal representation and protection when decisions are being made in relation to these matters.
- H That the Government provide the IMM with a progress report, as at the end of 2014, on implementing the recommendations of the IMM's 2011/2012 report.

# Monitoring programme for the next period

The next 12 months will be a crucial period for monitoring compliance with the Disability Convention, including progress against the IMM's recommendations. The release of the 2013 Disability Survey data from mid-2014 onwards will provide much needed information that should assist better monitoring and assessment.

Implementation of the Disability Convention will be in the spotlight during September 2014. This is when the New Zealand Government's first periodic report is due to be considered by the United Nations Committee on the Rights of Persons with Disabilities.

Key priorities that the IMM intends to monitor over the next reporting period are:

- opportunities for disabled people's voices to impact on policy decisions about their lives
- 2 supported decision-making
- 3 issues relating to vulnerable children with disabilities, particularly those at risk of being parted from their families
- reporting the experiences of Māori and
   Pacific disabled people
- 5 preventing violence, abuse and neglect within residential services, homes and public places

- 6 considering the compounding challenges experienced by people with disabilities as they age
- 7 accessibility of information, including Government web standards
- 8 guidance provided by the Disability Convention in relation to bio-ethical issues such as pre-natal testing
- 9 support for people with experience of mental illness in prisons and other places of detention.

# Article 3 General principles

The Disability Convention's general principles are:

- 1 respect for inherent dignity and individual autonomy including the freedom to make one's own choices, and independence of persons
- 2 non-discrimination
- 3 full and effective participation and inclusion in society
- 4 respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
- 5 equality of opportunity
- 6 accessibility
- 7 equality between men and women and
- 8 respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

These principles underpin the Convention and are fundamental to the IMM's monitoring of compliance against the obligations set out in the Convention.

# Article 4 General obligations

Article 4(1) of the Disability Convention requires that governments:

ensure and promote the full realisation of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability.

Most New Zealand legislation is compliant with the Disability Convention and noncompliance primarily occurs at the policy and practice level. However, as noted elsewhere in this report, the IMM has significant concerns that the following acts undermine disabled people's rights:

- a the New Zealand Public Health and Disability Amendment Act 2013
- b sections of the Children, Young
   Persons and Their Families Act 1989,
   and
- c proposed changes to the Building Act 2004.

#### Engagement

Article 4(3) of the Disability Convention provides that all decision-making processes relating to people with disabilities shall actively involve disabled people, including children, through their representative organisations. Key Recommendation 1 from the 2011/2012 report reflected the low level of engagement between the Government and DPOs and called for significant improvement.

During 2013, the Office for Disability Issues (ODI) initiated high level engagement between eight DPOs and government agencies. The first meeting between the IMM and the Chief Executives' Group on Disability Issues occurred in July 2013. The Chief Executives' Group is chaired by the chief executive of the Ministry of Social Development. It includes members from the Ministries of Health; Education; Justice; Transport; and Business, Innovation and Employment (MBIE) as well as chief executives from Foreign Affairs and Trade; ACC; and Housing New Zealand Corporation. The role of the Chief Executives' Group on Disability Issues is to lead the implementation by government agencies of the Disability Action Plan.

The Government and the DPOs subsequently reached agreement on a plan of work to discuss the Government's Disability Action Plan. There has been discussion around capacity and capability issues facing DPOs in order to sustain their future existence. Improved capacity and capability would enable them to maintain

effective connections with disabled people and contribute effectively to this new way of working. It was recognised that the early involvement of DPOs in key stages of policy design, implementation and outcome monitoring is essential for the joint initiative. This is equally true with specific initiatives or projects undertaken by government agencies.

In August 2013, the Chief Executives' Group agreed to five principles to underpin government agencies' engagement with DPOs. These were designed to ensure consistency with Article 4(3) of the Disability Convention:

- 1 Government will engage with DPOs as representatives of disabled people
- 2 We involve the right people, at the right time, in the right work
- 3 We value the contribution of each party and make it easy to engage
- 4 We will be open, honest, transparent and creative in our engagement with each other
- 5 We jointly learn about how to engage with each other.

The proposed work programme agreed between the Chief Executives' Group on Disability Issues and the DPOs in 2013 included the following:

a ODI will fund DPOs to work together with government agencies for 18 days over the next 12 months

- b DPOs and government agencies will work together to update the Disability Action Plan (with a 3–5 year focus)
- c Processes will be jointly developed for seeking DPO representatives when establishing new community consultation groups
- d A project will be undertaken to build understanding of the current capacity and capability of DPOs and to identify quick wins to streamline processes
- Government agencies will consider
   how they can work together to reduce
   compliance costs for DPOs making
   funding applications and to pool funding
   relating to capability building of DPOs
- f DPOs and government agencies will meet monthly to review progress.

In September 2013, the Ministerial Committee on Disability Issues affirmed the engagement process. It endorsed the agreement for Government to work with the DPOs to develop the Disability Action Plan for ministers to discuss at their meeting in December. The Minister for Disability Issues commented very favourably on this in the October 2013 issue of the Newsletter of the Office for Disability Issues.<sup>4</sup> There is now a shared understanding that DPOs should be involved in decisions that affect disabled people at the beginning of the process. This is more effective than the Government only seeking their valuable input and expert advice at the end.



Robyn Carter is campaigning to get more public broadcasting on TV fitted with captions for Deaf people. Photo: NZ Herald/R Robinson.

At the deadline for this report, in early 2014, the process of government agencies and DPOs working together to update the Disability Action Plan was well underway.

The IMM applauds the Government for its developing engagement with DPOs. It is very encouraging to see that both the Chief Executives' Group on Disability Issues and the Ministerial Committee on Disability Issues are supporting this work. Both groups are exhibiting a readiness to embrace the idea of partnership. This also demonstrates a significant level of commitment and openness from DPOs to new ways of working in line with Article 4(3) of the Convention.

### **Recommendation 1**

That the Government continue to jointly develop the Disability Action Plan with DPOs (including disabled people, children and their families) and commit to its full implementation.

# Article 5 Equality and non-discrimination

Article 5 of the Disability Convention requires governments to:

- recognise that everyone is equal before the law
- 2 prohibit all forms of discrimination on the basis of disability and ensure effective protection against disability discrimination
- 3 take all appropriate steps to ensure reasonable accommodation is provided for disabled people
- 4 recognise that measures to create equality for disabled people are not discrimination.

# Human Rights Commission's discrimination data

Under the Human Rights Act 1993 (HRA) the Commission has a number of statutory functions relating to advocating and promoting respect for human rights. These functions include a responsibility to provide a disputes resolution service in relation to complaints about discrimination made under the Act. The Commission records approaches in three categories:

- enquiries: seeking information, advice or guidance
- 2 **complaints:** seeking intervention in a particular matter
- 3 **registering concern:** expressing an opinion about a matter.

|         |           |            | Number<br>registering | Total of all disability |
|---------|-----------|------------|-----------------------|-------------------------|
| Year    | Enquiries | Complaints | concern               | matters                 |
| 2008–09 | 96        | 497        | 28                    | 621                     |
| 2009–10 | 220       | 884        | 75                    | 1179                    |
| 2010–11 | 231       | 548        | 42                    | 821                     |
| 2011–12 | 194       | 628        | 49                    | 871                     |
| 2012–13 | 176       | 599        | 55                    | 830                     |

### Table 1: All new disability matters by year

In the five years since the New Zealand Government ratified the Disability Convention, there have been between 497 and 884 complaints each year of unlawful discrimination on the ground of disability.

Complaints can be about:

- discrimination by the Government or those performing a public function (Part 1A of the HRA)
- 2 discrimination by the private sector in areas covered by the HRA (Part 2 of the HRA) and/or
- 3 human rights issues other than discrimination (section 5 of the HRA).

Some complaints fall into more than one of these categories. Therefore the total number of Part 1A, Part 2 and section 5 complaints in any year (as recorded in Table 2) is always greater than the number of complaints recorded in Table 1.

# Table 2: Disability complaints by HRA provision

| Year    | Part 1A | Part 2 | Section 5 |
|---------|---------|--------|-----------|
| 2008–9  | 140     | 267    | 159       |
| 2009–10 | 134     | 246    | 562       |
| 2010–11 | 160     | 235    | 246       |
| 2011–12 | 184     | 293    | 208       |
| 2012–13 | 165     | 204    | 267       |

# Table 3: Part 1A and 2 disability complaints by area

| Area                            | Average of<br>3 previous<br>years | 2011–<br>2012 | 2012–<br>2013 |
|---------------------------------|-----------------------------------|---------------|---------------|
| Govt activity*                  | 191                               | 244           | 181           |
| Employment                      | 90                                | 121           | 69            |
| Goods and services              | 56                                | 58            | 56            |
| Pre-employment                  | 34                                | 37            | 27            |
| Land, housing,<br>accommodation | 14                                | 14            | 26            |
| Places, vehicles and facilities | 19                                | 12            | 16            |
| Professional associations       | 1                                 | 0             | 2             |
| Advertisements                  | 2                                 | 1             | 0             |

\* The number of complaints related to "government activity" is higher than the number of Part 1A complaints in Table 2. This is because some education complaints fall under both Part 1A and Part 2 of the Human Rights Act.

In 2011/2012 and 2012/2013 the majority of disability complaints (83 and 73 per cent respectively) were in three main areas: government activity (including education), employment or pre-employment. Each of these is analysed in more depth below.

#### Government activity

In each of the last two years, a third of all complaints about government activity were education complaints. Thirty five of these related to school-aged children, and 13 were about tertiary students. Education complaints and enquiries are analysed in more depth in the next section.

The remainder of complaints were spread across eleven other government agencies or related to comments by politicians. Work and Income was the only government agency that received at least 10 per cent of all such complaints in both years. In 2012/2013 this involved 19 complaints, primarily about entitlement to assistance or a change to the level of support a disabled person received. In 2012/2013 there were 10 similar complaints about support from the Accident Compensation Corporation (ACC). The next most common type of complaint was about the Ministry of Health's funding for caregivers.

### Education

Education complaints and enquiries continue to be largely in the same categories and in the same proportions as in 2011/2012. A total of 88 complaints or enquiries were received in the 2012/2013 year. The following selection gives a good indication of the sort of complaints and enquiries the Commission continues to receive.

#### Lack of reasonable accommodation

These disability complaints or enquiries related to:

 children with autism and learning disabilities not learning well at school because they were not getting the support they need

- 2 a tertiary provider not supplying a microphone in lecture theatres to reasonably accommodate a student who is hard of hearing
- 3 a school not accommodating a child's disability saying "We have 30 in a class, if you want us to keep an eye on his diabetes, why don't you move him to a special school?"
- a school excluding a student and not reasonably accommodating his oppositional defiance disorder, attention deficit disorder and dyspraxia
- 5 a woman who complained that a teacher said her son was lazy, when her son has a disability that affects his ability to take instruction
- 6 a boy being discriminated against because of his disability as he was not getting any support for his education needs
- 7 teachers at a special school not assisting with toileting a child with disabilities
- 8 a school not reasonably accommodating a boy's disabilities and teaching staff saying they cannot cope with his needs.

#### Lack of full participation

These disability complaints or enquiries related to:

- 1 a child not being permitted to go on a school trip due to his epilepsy
- 2 a boy being told he is not able to go on camp with his class even after his parents organised a caregiver for the duration of the time away
- 3 several children with disabilities being put in a separate group during a school camping trip.

#### Enrolment declined or conditions applied

This matter related to a tertiary provider not enrolling a woman because she experiences mental illness.

#### **Different conditions**

This matter related to concerns that a school was apparently crediting extra NCEA points to students who played a sport for the school, excluding children who do not play in a school sports team because of a disability.

#### Funding issues

These disability complaints or enquiries related to:

- a boy not being at school for several months due to lack of funding to support his intellectual disability
- 2 a special education unit closing early each day, due to a lack of funding

3 a mother being told for two years that her child did not qualify to receive extra help but, after a change of schools, being offered funded assistance immediately.

# Employment (including pre-employment)

During the 2012/2013 year employment discrimination complaints and enquiries continued in a similar pattern to previous years. A total of 141 employment complaints or enquiries were received during the year. The following selection gives a good indication of the sort of complaints and enquiries the Commission continues to receive.

#### Lack of reasonable accommodation

In employment, the concept of reasonable accommodation has two main elements. The first is making the necessary adjustments in order to make employment available to the disabled person. The second is not imposing an unreasonable burden on the employer. In the following examples people considered that sufficient steps had not been taken to reasonably accommodate their disability. Their complaints or enquiries related to:

- an employer failing to provide reasonable accommodation to an employee who was hard of hearing
- 2 a new manager refusing to accommodate a female employee's arthritis when assigning duties.

A previous manager was willing to consider her disability but the new manager considered it was unfair to treat people differently

- an employer refusing to allow an employee to bring a guide dog to work
- 4 an employer not accommodating an employee's learning disability while increasing the complexity of her work
- 5 a woman being declined a promotion due to time taken off work in order to have medical investigations for her long-term illness.

#### Disclosure, privacy issues

These disability complaints or enquiries related to:

- a woman being disciplined after informing her employer of her medical conditions (even though these did not affect her ability to perform her work)
- an employment agency disclosing disability information to a prospective employer without permission
- 3 a man being rejected for a driving job because his ACC records showed he had a back injury some years ago, from which he has since recovered
- 4 employers turning a woman down for jobs if she mentioned having depression
- 5 prospective employees routinely being asked to sign authority forms requesting

disclosure of all personal information relating to their history as recorded by ACC and/or GPs.

#### Termination of employment

These disability complaints or enquiries related to:

- being unfairly dismissed due to having a recurring illness
- 2 a man losing his job as he did not disclose his mental health issues
- 3 a man being dismissed for taking time off work to get some medication for his disability.

#### Work conditions

These disability complaints or enquiries related to:

- a man's subsequent employment problems after failing a drug test (as the test detected medication he had taken because of his disability)
- 2 being disciplined for not bending, kneeling or using the stairs after a recent flare-up of rheumatoid arthritis
- 3 an employer monitoring use of the toilet despite knowing an employee has a medical condition that makes her need to go to the toilet more often than others
- 4 misuse of the minimum wage exemption process

- 5 concerns that many people who deliver pamphlets for a job have disabilities and are underpaid, undervalued and not treated well by their employer
- 6 an employment agency not considering a woman for any work as she does not have a driver licence, yet this employee is unable to drive because of a vision impairment
- 7 being refused a job because of having an epileptic seizure during an unpaid work trial.

# Key issues

In 2012/2013, disability complaints continued to be one of the two main areas of discrimination complaints to the Commission. There remains a clear and immediate need for guidelines to be developed and education to be conducted to ensure duty bearers are aware of their obligations and equipped to carry them out.

## **Recommendation 2**

That the Ministry of Justice and the Office for Disability Issues jointly develop guidance on the requirements and application of reasonable accommodation and the associated provisions of the Human Rights Act and New Zealand Bill of Rights Act, in consultation with DPOs and the IMM.

# Article 6 Women with disabilities

Disabled women and girls often face multiple forms of discrimination. Governments should take all reasonable measures to ensure disabled women can enjoy their full human rights.

Complaints of discrimination to the Commission indicate approximately the same number of males and females make complaints on the basis of disability. In the four years before the 2011/2012 report, there were19 complaints where both disability and sex were cited as the grounds of discrimination. In the period 1 July 2012 to 31 December 2013 there were five complaints of this nature.

#### **United Nations guidance**

As noted in the 2011/2012 report, in July 2012 the United Nations Committee on the Elimination of Discrimination against Women expressed its concern about the situation of disadvantaged groups of women, including disabled women. After the Committee's examination of New Zealand's implementation of the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), the Committee made its concluding observations and recommendations. It recommended that the Government provide data and information in its next report about disabled women, including on their access to education, employment and health-care services.<sup>5</sup>

### **Key issues**

The IMM is concerned that government sponsored research on key aspects of women's lives does not often include disabled women as a distinct group. For example, otherwise excellent recent research on the hidden abuse of disabled people does not analyse the separate experiences of disabled men and women.<sup>6</sup>

The most reliable source of data that compares the experiences of disabled men and women with non-disabled men and women is the Disability Survey. The results of the 2013 survey are due to begin being released in mid-2014.

The Families Commission has established a Social Policy Evaluation and Research Unit to provide high quality independent monitoring and evaluation on how effective initiatives are in addressing key issues across the social sector. The unit will commission research, set standards and specify best practice and maintain a data base of research being undertaken in the social sector. It is important that research and evaluation carried out in future includes the experiences of disabled men and women.

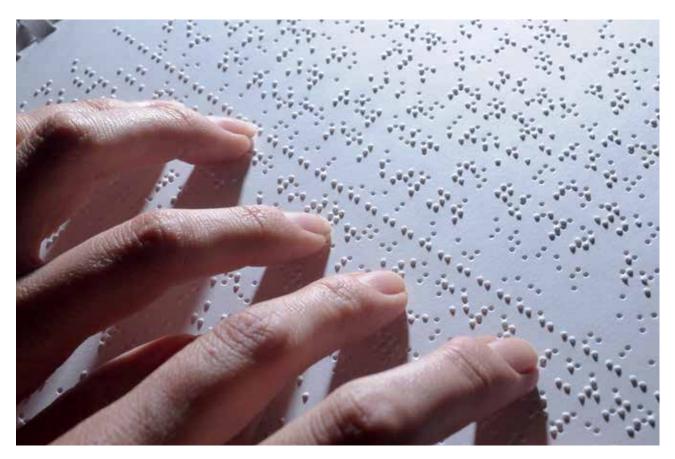


Photo: Blind Foundation.

#### **Recommendations 3 and 4**

#### **Recommendation 3**

That Statistics New Zealand make it a high priority to:

- 1 produce a report from the Disability Survey 2013 comparing the human rights outcomes of disabled women and men with non-disabled women and men
- 2 where possible, make data tables available from the 2013 Disability Survey so that data users are able to compare the human rights outcomes of disabled men and women with non-disabled men and women.

#### **Recommendation 4**

That the Families Commission and DPOs jointly develop standards and best practices for ensuring that research and evaluation in the social sector includes the experiences of disabled women and men.

# Article 7 Children with disabilities

The Disability Convention requires governments to:

- Do everything necessary to ensure disabled children enjoy their human rights on the same basis as non-disabled children
- 2 Ensure decisions about disabled children are in their best interests
- 3 Ensure disabled children are supported to express their views and these are listened to and taken seriously.

### Experiences of young people

As part of its contract with the Government, in December 2013 the Convention Coalition interviewed young disabled people about how they experience their rights in everyday life. Twenty seven young people between 16 and 25 years of age were interviewed using a tool developed by Disability Rights Promotion International. Their experiences were discussed in the *Youth Monitoring Report* (2013).

Several of those interviewed reported very positive experiences involving the use of technology, support from family and friends and treatment by medical practitioners. They also reported positively about access to advice and information from disability and other service providers and access to a diverse range of recreational pursuits. Removal of attitudinal and physical barriers to participation was welcomed by many interviewees. Examples included accessible venues, disability-aware airport and cabin crew, and teacher aides who are discreet and sensitive to young people's need to fit in and not feel different to their contemporaries.

However several participants cited negative experiences in these areas including:

- isolation from family, both selfimposed and imposed by family members
- 2 educational mainstreaming not equating with social mainstreaming and leading to a lack of friends
- 3 medical practitioners not listening to their needs
- 4 lack of communication from disability and other service providers
- 5 aircraft cabin crew behaving rudely
- 6 teacher aides causing disruption and preventing disabled students interacting with teachers and classmates.

#### The report concluded:

"For people aged sixteen to twenty-five years, an ordinary life includes: being part of a peer group; developing independence from family; developing romantic attachments; and preparing for and taking on employment. This study highlights the lack of opportunity common to many disabled youth, to undertake these life tasks. In several cases they are hampered by:

- 1 a lack of accessible and age appropriate housing, meaning they frequently have to remain with family for longer than they otherwise might, and/or accept housing options that are less than conducive to developing independence
- 2 isolation and exclusion within the school system, often caused by the very supports designed to promote their academic achievement, and
- 3 intimidation and bullying at school and beyond, a further illustration of the lack of acceptance and inclusion by society."<sup>7</sup>

### Data on children with disabilities

The 2006 Disability Survey identified that 14 per cent of disabled people were children aged under 15. An estimated 90,000 children, 10 per cent of all children under 15, had a disability. Almost half of these (46%) had what the Disability Survey defined as "special education needs".<sup>8</sup> Chronic conditions or health problems and psychiatric or psychological disabilities were the next most common disability types.

#### Māori children with disabilities

In 2006, there were an estimated 28,200 disabled Māori children under the age of 15. Fourteen per cent of Māori children experienced disabilities compared to 9 per cent of non-Māori children. This is reflected in disabled Māori children having higher rates of many disabilities than non-Māori children.<sup>9</sup> The 2006 Disability Survey identified other differences between the experiences of Māori and non-Māori children (under the age of 15) including:

- 1 An estimated 2500 disabled Māori children (9%) had an unmet need for special equipment or technology related to their disability (compared to 5% of non-Māori children). A similar difference was found in unmet need for help with disabilityrelated transport costs.
- 2 Only 16 per cent of disabled Māori children lived in households with total annual incomes over \$70,000, compared with 32 per cent of disabled non-Māori children. (For children without disabilities the equivalent rates were 27% for Māori and 42% for non-Māori).

While the proportions of Māori and non-Māori children receiving special education support were similar (23% and 25%), only 16 per cent of disabled Māori children had an individual education plan compared to 23% of non-Māori children with disabilities.

In 2011, the Ministry of Health published *Te Ohonga Ake: The Health of Māori Children and Young People with Chronic Conditions and Disabilities in New Zealand*.<sup>10</sup> A significant concern expressed in the report is the incompatible and incomplete data that limits the ability to accurately assess the needs of these mokopuna and their whānau. As noted by Dr Papaarangi Reid in the foreword to the report:

> It is not that chronic conditions and disabilities among young Māori are rare, sadly no. The issue is that our data systems have not been organised to give voice to mokopuna with these conditions through the routine collection and reporting of meaningful indicators with quality data.

#### Pacific children with disabilities

In 2006, an estimated 6100 Pacific children (8.1% of those aged 0–14 years) had a disability. The 2006 Disability Survey estimated 2500 Pacific children (40% of those with a disability) had special education needs, while 2400 (39%) had a chronic condition or health problems. More detailed analysis of the 2001 Household Disability Survey found that Pacific children reported higher rates of deafness and asthma, while non-Pacific children reported higher rates for all other disability types.<sup>11</sup>

A 2011 report prepared for the Ministry of Health, *The Health of Pacific Children and Young People with Chronic Conditions and Disabilities in New Zealand* also identified higher rates of intellectual disabilities. In a foreword to the report, Dr Teuila Percival collated available evidence about additional pressures faced by Pacific youth with disabilities and their families, including:

- Pacific children with disabilities face
   social exclusion, poorer health and
   educational outcomes and poverty.
   Two thirds of Pacific people with
   disabilities live in the lowest socio economic neighbourhoods.
- b There is some evidence that Pacific families are less likely to receive the child disability allowance than non-Pacific families.

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Parents of disabled Pacific children are less likely to attend IEP (individual education programme) meetings at schools. Their children are less likely to attend health clinic appointments than other New Zealand children with disabilities, resulting in fewer receiving appropriate diagnoses and treatment.<sup>12</sup> Recommendations under Article 31 highlight the need for data that enables outcomes to be compared between disabled and non-disabled people. These include addressing the lack of disaggregated data about disabled children generally and Māori and Pacific children specifically. Further qualitative and quantitative research could play a valuable role in building understanding about whether the relatively low proportion of Pacific children with disabilities is due partly to under-reporting, invisibility or stigma.

Administrative data collected by government agencies about disabled children is frequently inconsistent. This is because there is greater variability of disability definitions among agencies in relation to children than to adults. There is a need for better shared understanding of disability in children. Agreement is also needed to collect data that can be more easily compared to create a comprehensive picture of the experiences of disabled children and youth. Changes to the 2013 Disability Survey are expected to improve the quality and relevance of data that is collected. But it is important that further work be undertaken to support continued improvement in this area.

### **Key issues**

There are a number of current projects contributing to reform of the disability support system (see the commentary later in this report in relation to Article 19). It is critical that these initiatives are available for disabled children as early as possible. A disabled child's immediate needs should be met. Families also require support so they can stay connected with extended family and the wider community, including community-based service providers. The family should also have access to other families who have been through similar situations.

Article 23(1)(c) clearly states that disabled people, including children, have the same right to maintain their fertility as others. Media coverage has highlighted the lack of legal safeguards in place regarding decisions about medical procedures that affect the fertility of young women under the age of 18. In Australia, a court order is required before sterilisation procedures are carried out. In New Zealand, there is no equivalent legal protection. This leaves young disabled women potentially vulnerable to decisions being made by others, for reasons other than medical necessity. This raises concerns about whether there are sufficient safeguards to protect their rights and to enable supported decision-making. If this is not the case, current laws and practice need to be reviewed.

International research shows disabled children are three to four times more likely than others to be neglected or physically or sexually abused. The rates are higher for children with intellectual/learning disabilities. The current care and protection system does not provide disabled children with the same rights as others, and proposed changes do not address this. For more detail and recommendations see the commentary accompanying Article 23.

### **Recommendation 5**

That routine collection and reporting of meaningful indicators and data about the experiences of children with disabilities continue to be improved, in partnership with DPOs.

# Article 8 Awareness-raising

The Disability Convention requires that governments take immediate steps to:

- raise awareness in society to encourage respect of disabled people
- 2 combat prejudice and abuse
- 3 raise awareness of the value of the contribution disabled people make to society.

### Broadcasting Standards Authority and Advertising Standards Authority complaints

The Broadcasting Standards Authority (BSA) makes decisions about complaints from members of the public who believe a television or radio programme has breached broadcasting standards. The IMM's 2011/2012 report noted there had been seven complaints since 2009 that involved some element of disability discrimination. This included a case which was upheld against Paul Henry for making derogatory remarks about singer Susan Boyle.

In 2012/2013, there were six new disabilityrelated complaints. The majority related to use of phrases of a derogatory nature, for example descriptions of callers as "nutters" or "nut bars" during talkback radio shows or television broadcasts. There was one complaint regarding a television news report about a new pre-natal test for Down Syndrome. The complainant felt that the report discriminated against people with Down Syndrome and was unbalanced in its coverage. None of these 2012/2013 complaints were upheld by the BSA.

The Advertising Standards Authority (ASA) is an industry body established to self-regulate advertising in New Zealand. The ASA receives complaints from the public about advertisements in any media. Complaints are heard by the Advertising Standards Complaints Board and appeals can be made to the Advertising Standards Complaints Appeal Board. If a complaint is upheld, the advertiser, agency and media are asked to withdraw the advertisement.

The ASA receives 700–800 complaints a year. The IMM's 2011/2012 report noted that since 2004, only four complaints were received by the ASA relating to disability discrimination. In 2013 there were two additional disability complaints, including one where the ASA ruled an image on a company's Facebook page had to be removed because it was likely to cause serious offence.<sup>13</sup>

#### **Think Differently**

The *Think Differently* campaign aims to change social attitudes and behaviours that limit opportunities for disabled people.<sup>14</sup> The initial funding of \$3 million over three years ended on 30 June 2013. In the May 2013 budget, \$6 million in additional funding was allocated so the campaign could continue for the next two years with increased resource. The programme consists of:

- 1 a national communications strategy
- 2 national partnerships
- 3 community action projects funded through the Making a Difference Fund (MAD)
- 4 research and evaluation.

The national DPOs were involved in some strategy sessions run by MSD when *Think Differently* began. There is also a DPO representative on the independent selection panel for the Making a Difference Fund.<sup>15</sup> However, DPOs have stressed that a partnership approach requires their active involvement and leadership in key decisions about the *Think Differently* campaign on an ongoing basis. This should also involve including families in projects that relate to disabled children.

There have now been four MAD funding rounds. Projects supported to date have included developing disabled Pacific people as leaders, accessibility initiatives in Christchurch, employment transitions and reducing barriers to legal services. Other projects are the Auckland community circus, inclusive practices in rural schools, accessible marae, and positive employer attitudes to disabled people.

An evaluation of the projects in the first two rounds of MAD funding focussed on establishing good practice from overseas experience. Many funding recipients have observed attitude changes at various levels of the community, although the evidence of this was generally anecdotal. An initial evaluation of round three of MAD funding has concentrated on recipient views of the impact their initiative has had on the community.

#### Media

In June 2013, the Convention Coalition published a report analysing the portrayal of disabled people by the New Zealand media.<sup>16</sup> Almost all of the 55 people who responded to its online survey recalled a disability-related media story that made them feel uncomfortable. On a positive note, more than half could recall examples of outstanding journalism.

The report found that while most media stories used a charitable, heroic/superhuman or medical framework, a significant minority involved rights-based coverage. There were significant gaps in conveying the voices of disabled people, particularly those who are Māori, or are from Pacific or other ethnic minorities.

Media representatives interviewed had rarely consulted with DPOs or disabled people on disability-related stories. Typically they had very little information about being disability aware and responsive, beyond some general language guidelines.

The report made several recommendations including the need for:

- 1 disability responsiveness and rights awareness training for media staff
- 2 clear policies on reporting disability issues and more inclusive portrayal of disabled people that do not focus on impairment
- accessible and responsive mediacomplaints mechanisms
- 4 training and employment of disabled people for frontline presenting and other media roles, including through scholarships and NZ On Air funding for disability programming
- 5 greater consultation and dialogue with disabled people, including through formal advisory panels or working groups and their appointment to statutory bodies involved in broadcasting funding or regulation
- 6 fundraising campaigns for disability service providers that are led by disabled people and that avoid publicity based on charitable, heroic/ superhuman or medical models and

 a more extensive study into media attitudes about disabled people.

#### Nominations service

The Office for Disability Issues has a nominations service that recommends disabled people for appointment to government boards and committees. There are currently about 100 people on the database. Appointments are made by Cabinet, based on the recommendations of the Appointment and Honours Committee. In the last IMM report it was noted that ODI is not informed of the decisions, so does not know how many appointments have been made as a result of the service.

No evaluation of the service had been carried out. So the IMM recommended that the Ministry of Social Development conduct a survey of all those on the database. The aim would be to find out how many had been successful in being appointed to boards and what boards they were serving on. At the time of preparing this second IMM report, the Office for Disability Issues' nomination service had been on hold for over a year and decisions regarding the functions of the service were still to be made.

# Article 9 Accessibility

Accessibility is essential for disabled people to live independently and participate fully and equally in society. It is one of the principles on which the Disability Convention is based (Article 3(f)).

Accessibility rights are broader than access to the physical or built environment. They also encompass access to transportation, information and communication, and to services.

Access to the physical environment and public transport is a precondition for freedom of movement. Access to information and communication is necessary for freedom of opinion and expression (as discussed under Article 21). Whenever goods, products and services are provided to the public they must be accessible to everyone.<sup>17</sup>

The Disability Convention requires the Government to take appropriate measures towards ensuring all facilities and services provided to the public are accessible to disabled people on the same basis as others. The Government should take appropriate steps towards:

 developing and monitoring minimum access standards and guidelines for public services and facilities

- 2 ensuring the private sector makes its services to members of the public accessible
- 3 providing accessibility training
- 4 ensuring signs in public buildings are in Easy Read and Braille
- 5 ensuring assistance, including New
   Zealand Sign Language (NZSL)
   interpreters, is available to support
   access to buildings and facilities
- 6 promoting accessible information and access to information and communication technology
- 7 promoting inclusive design for new information and communication technologies.

#### **Buildings**

Two pieces of legislation apply to the accessibility of public facilities. They are the Human Rights Act 1993 (HRA) and the Building Act 2004, including the accompanying regulations containing the New Zealand Building Code (the Code). More details about these legislative requirements were provided in the IMM's 2011/2012 report.

Briefly, section 119 of the Building Act provides that New Zealand Standard

4121:2001 Design for Access and Mobility will demonstrate compliance with the Code. This standard covers design for access and use of buildings by disabled people. Compliance documents are not mandatory. So a designer can choose to use NZS 4121:2001 to obtain a building consent or put forward their own design that complies with the requirements.

In 2012, the Canterbury Earthquake Royal Commission (Royal Commission) made significant proposals on a nationwide approach to strengthening earthquake prone-buildings. These included removing the existing requirement that buildings requiring strengthening must be made accessible to disabled people to a standard "as nearly as reasonably practical" to the Code's standard for new buildings. The Royal Commission concluded that the requirement would impede earthquake strengthening work.

From December 2012 until March 2013, the Ministry of Business, Innovation and Employment carried out a public consultation on a number of proposals largely in line with what the Royal Commission had recommended.<sup>18</sup> A significant number of submitters (47 per cent) agreed that the cost of compliance with the access and fire requirements was a barrier to carrying out earthquake strengthening work.<sup>19</sup> The subsequent Cabinet minute indicated that Cabinet had agreed to amend the Building Act to enable territorial authorities to issue building consents for earthquake strengthening works on earthquake-prone buildings without triggering requirements for other upgrades. It also indicated that regulatory powers might be included in the Act specifying criteria for territorial authorities to apply when making decisions about whether or not to require other upgrades.<sup>20</sup>

Provisions of this nature have since been included in the Building (Earthquakeprone Buildings) Amendment Bill. The IMM is concerned about these legislative proposals. They may mean that opportunities to ensure better access for disabled people to the built environment would be lost when upgrade work is being carried out. The existing legislation already permits territorial authorities to exempt alterations from Building Code requirements in relation to means of escape from fire and provisions of access and facilities for disabled people. The grounds for these exemptions are that the requirements would be overly burdensome for the building owners. The proposed amendments introduce a further basis for exemption. This approach reinforces the perception that the rights of disabled people are of low priority.

The Earthquake Disability Leadership Group (EDLG) was established with funding from the Ministry of Social Development to advocate for the rights of disabled people during the recovery after the Canterbury earthquakes. The EDLG is led by disabled people. It includes disabled people and their organisations, family and whānau, representatives of service providers, and key people and organisations with an interest in disabled people's rights. A key focus for the group has been making the rebuilt Christchurch the most accessible city in the world. Since its inception the EDLG has been instrumental in facilitating a number of key initiatives:

- Coordinating, with the Barrier Free New Zealand Trust (Barrier Free), the updating of guidelines for using the NZS:4121:2001 to achieve quality accessibility<sup>21</sup>
- 2 Working with the Canterbury District Health Board to produce short video clips that illustrate the accessibility issues confronting disabled people in the rebuild
- 3 Developing a plan, or outcomes framework, with the health board to ensure all aspects of accessibility are covered in the rebuild
- Working with the Central City Development Unit (CCDU) to ensure that the cornerstone or anchor projects within CCDU's control achieve design options that meet people's needs. The CCDU has contracted with Barrier Free to provide accessibility advice and audits on the first anchor project, the Avon River Precinct/Te Papa Ōtākaro.

The EDLG has been particularly successful in ensuring that disabled people have an effective and united voice in the rebuilding of Christchurch. Nonetheless, accessibility issues continue to be an issue both in Christchurch and across the country. A December 2013 report by the Human Rights Commission noted that a number of two or three level buildings have been constructed without lifts or the capacity to include them at a later date. Also, a number of new and repaired buildings do not comply with minimum accessibility standards.<sup>22</sup>

# Progress on the disability access review

Early in December 2013, the Ministers for Building and Construction and for Disability Issues jointly announced the terms of reference and timeframes for a review into building access for disabled people. The review will consider how New Zealand Standard 4121:2001 aligns with the Building Code and how the Code more generally meets the needs of disabled people. It will include asking how well people understand the regulations. It will look at how well the provisions work together, particularly New Zealand Standard 4121:2001 and the relevant Acceptable Solutions under the Building Code. The Minister for Disability Issues noted reports from disabled people that buildings are still being built that are not accessible. These limit their opportunities for education, employment, and their ability to contribute to, and participate in, the community.<sup>24</sup>

#### Case study: Effects of the rebuild

Matua B has a dual sensory loss. He is a very proud and independent man who has been undertaking a Māori studies course over the last three years at a tertiary institute in Christchurch. Before the earthquakes Matua B had received support from various organisations including the Blind Foundation and the tertiary institute. This enabled him to access his study, travel safely and independently to the tertiary institute, and access local facilities. Catching a bus on a multiple bus route when he is unable to identify the appropriate bus in peak times presented too many difficulties. So Matua B preferred to walk the long distances to study and services.

Following each earthquake and significant aftershocks, Matua B has had to move house. He has had to become oriented to his new environment and new routes, and deal with the continually changing footpaths and infrastructure. This has not been easy with the uneven surfaces, liquefaction, changing traffic controls, blockages to footpaths because of repairs, and vehicles parked over footpaths. Matua B had a significant fall because of the uneven surface which resulted in hospitalisation. It has been difficult for him to get suitable rental accommodation that meets his needs. Due to his vision loss, Matua B needs to be close to study, services and facilities so he can travel independently. His original home is in the red zone area,<sup>23</sup> the second required significant structural repair and he had to find board while waiting for his current property.

Matua B has had to learn two routes to his study as either can be blocked for repairs without warning and he requires signalised crossings for the busy roads. For many people, the earthquakes have highlighted the need for having accessible communication systems in place. But using a standard cell phone is not an option for Matua B. His dual sensory loss means that he requires a voice programme that he is able to hear. These are additional costs of his impairment.

Matua B will be able to continue with his daily routes more confidently and safely once the streetscapes have been repaired and if they are prioritised for pedestrian travel.

Recommendations from the review into building access for disabled people are due in the middle of 2014. The review is being carried out by the Ministry of Business, Innovation and Employment and the Office for Disability Issues. It is assisted by an Access Reference Group, including representatives from Blind Citizens NZ, Barrier Free New Zealand Trust, CCS Disability Action, Blind Foundation, and the Hearing Association of New Zealand, among others.

The IMM welcomes this review which is consistent with one of the key recommendations of its first 2011/2012 report.

# **Recommendation 6**

That the review of NZS 4121:2001, announced by the Ministers for Building and Construction and for Disability Issues, also consider whether the standard should be made mandatory and cover residential housing.

#### Accessible buses

There was a comprehensive review of this issue in the IMM's first report. The IMM has decided to report in detail again when significant developments occur. There are ongoing concerns about inconsistencies across the country in developing and adopting electronic ticketing schemes, providing online timetable and other information, and ensuring every bus stop is accessible. The IMM has concluded that its previous recommendation remains the best way to ensure that all public transport users, including disabled passengers, receive an accessible service.

It is worth noting that the United Nations Committee on the Rights of Persons with Disabilities has recognised the value of introducing regulations to govern the implementation of accessible public transport. This point was made in the Committee's concluding observations in 2013 when Australia presented its initial report on progress implementing the Disability Convention.<sup>25</sup>

# **Recommendation 7**

That the Ministry of Transport develop national accessibility design standards for all aspects of public land transport.

# <mark>Article 10</mark> Right to life

The Disability Convention requires governments to reaffirm that every human being has the inherent right to life. Governments shall take all necessary measures to ensure disabled people effectively enjoy this right on an equal basis with others.

The right not to be deprived of life is included in the New Zealand Bill of Rights Act.

Issues such as euthanasia, pre-natal testing, termination of pregnancy, access to medical care and assisted suicide are often discussed in the context of the right to life.

These matters can inspire strong passions which may polarise people within the community. This can make it difficult for a disability perspective to be recognised or heard. However, bioethical and legal issues like these can be of particular significance for disabled people. In many cases, the potential impact of changes can be far greater for members of the disabled community than for other population groups.

The voices of disabled people, their families and DPOs need to be at the forefront of national debates in relation to these matters.

# **Recommendation 8**

That high priority be given to the perspectives of DPOs, disabled people, and their families in relation to policy development on the right to life and bioethical issues which have a high impact on disabled people and/or public perceptions about disability.

# Article 11 Situations of risk and humanitarian emergencies

Disabled people are often among the most vulnerable in situations of risk and humanitarian emergencies. Poorly designed public facilities and services that make disabled people's lives difficult are often exacerbated by emergencies.

The Disability Convention requires that countries take all necessary measures to ensure the protection and safety of disabled people in situations of risk. This includes situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.

## Canterbury earthquakes

The IMM's first report in 2011/2012 focused extensively on steps taken to identify and address inadequacies in readiness and response to disabled people in the immediate aftermath of the Canterbury earthquakes. In 2013, the Ministry of Civil Defence produced two new resources in consultation with DPOs. One of these was guidance for the Civil Defence and Emergency Management sector on including people with disabilities. The other was a factsheet on recognising disability assist dogs in emergencies.<sup>26</sup>

As the Article 9 section of this year's report shows, much of the attention has

been focused on the rebuilding so that Christchurch is a fully accessible city. In December 2013, the Human Rights Commission published a detailed report *Monitoring Human Rights in the Canterbury Earthquake Recovery*. It included a recommendation that:

> government agency officials involved in any emergency response are appropriately and adequately prepared and trained to be familiar with a range of ways of communicating with vulnerable communities, including but not limited to Te Reo Māori, New Zealand Sign Language, the Video Relay service and interpreting services for community languages.

#### Earthquake-related complaints

The Ombudsman continues to receive a significant number of complaints relating to the Canterbury earthquakes, mainly in relation to the Earthquake Commission (EQC).

Many of the complaints received about the EQC have concerned delay and communication issues. Complainants wish to receive information about the progress of their EQC claims, and are frustrated with

the delays in having their claims settled. For disabled people, these two issues combine to add to the difficulties they face in the wake of the earthquakes.

EQC has developed a programme for prioritising repairs for vulnerable claimants. But the adequacy of this programme for addressing the needs of disabled claimants is dependent on:

- 1 appropriate criteria for inclusion
- 2 effective processes for identifying those who meet the criteria, and
- 3 high standards of service delivery to prioritised claimants.

Concerns have been raised in various forums about each of these three areas, as well as the pace at which EQC has moved to implement the programme. There are also questions about whether EQC has engaged sufficiently with disabled people's organisations and other community groups. The aim of this would be to ensure that the rights of disabled people in the residential rebuild are afforded sufficient recognition and protection. The monitoring mechanism will discuss these matters with EQC in the coming reporting year to determine whether further improvements need to be made.

In the 2011/2012 report, the IMM recommended that the Earthquake Commission initiate a review of the three month time limit set out in law for lodging an EQC claim. For a number of years, the Ombudsman has noted with concern the strict three month time limit. This affected a complainant with limited vision. She did not become aware of the damage to her house following an earthquake until more than three months after that event. The Ombudsman has previously recommended that the legislation be amended to extend the time limit for lodging a claim, and to allow for claims to be accepted out of time in exceptional circumstances. It has been suggested that EQC should be able to allow for exceptional circumstances in this respect. However, EQC is currently prevented by legislation from doing so.

# **Recommendation 9**

That the Government expedite a review of the three month time limit set out in legislation for lodging a claim with the Earthquake Commission.

# Articles 12 and 13 Equal recognition before the law, and Access to justice

These articles are considered together as they ensure disabled people have the same legal rights as others in the community.

The Disability Convention states:

- disabled people have the right to make their own decisions in all areas of life on the same basis as other people
- 2 governments should provide access to support that might be needed by disabled people in making their own decisions
- 3 if decisions are made about a person's capacity to understand, there must be safeguards against abuse
- 4 disabled people have the same rights to go to court, take other people to court, act as witnesses and take part in what happens in court as anyone else
- 5 disabled people must be given support to do this which, for example, may include the provision of sign language
- 6 there should be training for courts, police and prison staff to support this right.

#### Supported decision-making

United Nations committees with responsibility for overseeing the implementation of covenants and conventions provide guidance to states about how to interpret and implement the provisions of a human rights treaty. One way they do this is by issuing general comments related to the interpretation of a specific article.

The United Nations Committee on the Rights of Persons with Disabilities has recently issued its first two draft general comments including one on Article 12. The Committee states that the full implementation of equal recognition before the law will require a paradigm shift. This will require supported, rather than substituted, decision-making in circumstances where a person cannot make independent decisions without support. In the Committee's view none of the countries that have reported so far have grasped the full extent of this requirement.

Legal capacity is most often denied because of:

- 1 a diagnosis (the status approach)
- 2 considered negative consequences (the outcomes approach)



The Hon. Tariana Turia. Photo: C. Macdiarmid.

3 a person's decision-making skills being seen to be deficient (the functional approach).

Denial of legal capacity for any of these reasons is considered to be inconsistent with the provisions of the Disability Convention. Legal capacity may be restricted for legitimate reasons, but these restrictions must not be based either directly or indirectly on a person's disability. A common approach in the countries that have reported so far is to promote supported decision-making while retaining some forms of substituted decision-making.

There are three pieces of New Zealand legislation most relevant to the application of Article 12. They are the Protection of Personal and Property Rights Act 1988, the Mental Health (Compulsory Assessment and Treatment) Act 1992, and the Intellectual Disability Compulsory Care and Rehabilitation Act 2003. All these statutes contain provisions that support the ability of people with disabilities to make their own decisions to the greatest extent possible. However, it is not clear whether these pieces of legislation are fully compliant with the Committee on the Rights of Persons with Disabilities draft general comment on Article 12.

Nor is it clear whether the provisions are applied in practice in a manner consistent with supported decision-making principles. The current legal frameworks for mental health treatment need to be reviewed in light of Article 12 and the guidance issued by the Committee.

# New Zealand Sign Language in court proceedings

The New Zealand Sign Language Act 2006 refers to proceedings before any court or tribunal.<sup>27</sup> If a person's first or preferred language is New Zealand Sign Language, an interpreter must be provided. It covers situations where the person is a member of the court, a party or witness, or is counsel to a party.

The 2012 report of the IMM highlighted concerns about inconsistent access to interpreters in some courts because of lack of access to qualified interpreters. In September 2013, the Human Rights Commission released *A New Era in the Right to Sign*, a comprehensive report into New Zealand Sign Language. One of the objectives of the report was the promotion and maintenance of NZSL as an official language of New Zealand. The recommendations made in this regard should increase the availability and accessibility of NZSL interpreters in the medium to longer term.

# Recommendations 10 and 11

#### Recommendation 10

That the Law Commission undertake a review of the Mental Health (Compulsory Assessment and Treatment) Act, with a particular focus on compliance with articles 12 and 13 of the Disability Convention.

#### **Recommendation 11**

That research be undertaken by the Office for Disability Issues to determine whether the provisions of the Protection of Personal and Property Rights Act that relate to supported decision-making are well understood and applied by welfare guardians and property managers appointed under the Act.

# Article 14 Liberty and security of the person

The Disability Convention requires governments to ensure disabled people are not unlawfully or arbitrarily deprived of their liberty, and that any disabled people who are deprived of their liberty are provided with reasonable accommodation.<sup>28</sup>

As discussed in the 2011/2012 report, the Ombudsman investigated prison health services in 2012. The report examined the treatment provided by the Department of Corrections (Corrections) to prisoners with disabilities.<sup>29</sup> A number of suggestions were made, together with 31 recommendations for improvement. Particular matters noted by the Ombudsman included issues relating to prisoners with physical disabilities, mental health care, and aged and frail prisoners. Corrections is continuing to work through the recommendations and has advised that all of these are in progress or have been completed.

## Prisoners with physical disabilities

Prisoners with physical disabilities face significant barriers in prison. Some prisons have designated cells and other facilities for disabled prisoners. However, many prison buildings and amenities are not generally accessible to disabled prisoners. Prison doorways are narrow, and there is a lack of ramped access to visitors' areas. There is a lack of handrails, special furniture and equipment, and access to staff in control rooms is difficult. Assistance and facilities for prisoners with sensory impairments are limited.

Corrections advises that all new building work is required to comply with the New Zealand Building Code, and in new buildings it provides features to facilitate access. These include wider car parks, signage, ramps, corridors and doors of minimum width, lower height counters in visitor reception areas, and toilet facilities for people with disabilities.

Corrections also advises that the progressive upgrade of facilities, the closure of aged prisons and modernisation efforts will result in significant gains in this area. For example, it notes that there are plans to extend bed numbers at the High Dependency Unit at Rimutaka Prison (which opened in 2012) from 20 to 30 beds by the end of 2014.

#### Mental health care for prisoners

Many prisoners have complex mental health care requirements, including those linked to substance abuse. The delivery of mental health care for prisoners is made more difficult by the constraints of a prison environment and the transfer of prisoners causing disruptions in continuity of care.

#### Case example: Round room at Mt Eden Corrections Facility

Some prisoners considered to be at risk of harm to themselves may be required to wear anti-rip clothing and are then placed in the "round room" which is a bare cell (see photo). The round room also contains a mattress and an anti-rip blanket (which were being cleaned at the time this photo was taken). The purpose of placing someone in these conditions is to prevent incidents of suicide or self-harm.

Corrections acknowledges that the environment in a round room is not pleasant. However, the design of the cell minimises risk to life. Corrections believes that round rooms are necessary for the short-term placement of prisoners who are at significant risk of suicide. Corrections also notes such cells are not intended for ongoing use. Multidisciplinary

When compared to the general community, prisoners have significantly higher levels of mental health conditions. It is estimated that almost a third of the prison population experience mild to moderate mental health conditions.<sup>30</sup>

The Ombudsman's 2012 investigation of prisoner health services suggested there are deficiencies regarding the care of mentally unwell prisoners. Significant unmet needs in prison were reported in terms of common mental health conditions including depression, anxiety, emotional distress and adjustment problems.



Round room at Mt Eden Corrections Facility.

teams made up of custodial staff, health services staff, forensic staff and psychologists work closely to manage these prisoners and progress them into the at-risk unit or general accommodation. Corrections is currently reviewing the use of round rooms.

The Ombudsman is currently monitoring a project where Corrections and the Ministry of Health are working together to improve mental health care in prisons. This is an area that has been of concern for some time. To be resolved it needs real co-ordination and commitment by both agencies. The Ombudsman will report independently on the project, and decide whether any further action is required in due course.

In the interim, Corrections has advised that with the recent introduction of a mental

health screening tool, every prisoner arriving into custody is now screened and referred for assistance where appropriate. Corrections also advises that mental health in-reach clinician positions have been established in Christchurch Men's Prison and Spring Hill Corrections Facility. At both sites, clinicians work across the facility supporting prisoners who have spent time in at-risk units, or who have primary mental health needs. Education and support is also provided to the staff working with these prisoners on a frequent basis.

# Aged and frail prisoners

The Ombudsman's 2012 investigation of prisoner health services found that hospice care can be provided to prisoners, but it is geared toward terminal illnesses. Prisoners only become eligible if there is a prognosis of about six months or less to live.

Corrections advises that national policies are in place for the care of prisoners with age-related conditions. Updates are given through the Department's frontline communication, which provides a weekly update to all frontline custodial and health staff. In addition, Corrections notes that health centre managers regularly conduct training relating to new or changed policies with staff working in health units.

Some prison units visited by the Ombudsman cater for frail and aged prisoners well. However, there is concern about the overall ability of Corrections to provide care for prisoners who in the outside world would be in a rest home, hospital or hospice. While Corrections has advised it has scheduled an aged care strategy as part of its work plan for the 2013/2014 cycle, we consider that aged and frail prisoners remain vulnerable.

# **Recommendation 12**

That the Department of Corrections take steps to identify any gaps in the current care and facilities provided for prisoners with disabilities.

#### Case study: Prisoner on medical oversight

In December 2012, the Ombudsman noted a prisoner on medical oversight had been in the Management Unit at Rimutaka Prison for over three months. He was placed in the unit following a recommendation by the visiting forensic psychiatrist.

While the prisoner had a management plan, there was a lack of multidisciplinary involvement and no forward planning to help him progress out of his current situation. The quality of documentation was inconsistent and did not reflect good levels of care or meaningful engagement with the prisoner. The plan was disciplinefocused with no health input. He was not allowed to mix with other prisoners and was receiving less than his minimum entitlements; one of those being at least one hour of fresh air daily. The Ombudsman also saw no evidence to suggest the prisoner was having any daytime therapeutic support services within the unit.

After the Ombudsman's visit this prisoner was transferred to another facility which better addressed his re-integrative needs.

#### Case study: High Dependency Unit at Rimutaka Prison

Corrections opened a 20-bed High Dependency Unit (HDU) at Rimutaka Prison in December 2012. This much needed facility is a first for New Zealand prisons and will hopefully address some of the growing concerns relating to the aging prison population.

The HDU is a refurbished unit in a selfcontained compound on the Rimutaka Prison site. Prisoners are accommodated in 20 single cells, each containing a shower, toilet and hospital-type bed. An accessible shower room is installed in the unit, along with a health office with medication administration facilities, and a treatment room.

Corrections advises that the HDU is managed by a principal corrections officer and a custodial team. Health services staff are also based at the unit, with a dedicated registered nurse providing clinical leadership, supported by health care assistants.

# Article 15 Freedom from torture or cruel, inhuman or degrading treatment or punishment

The Disability Convention requires governments to take all effective measures to prevent disabled people from being subjected to torture or cruel, inhuman or degrading treatment or punishment.

Discussion of practices within private sector aged care facilities is not included within this part of the report. The Ombudsman is designated as a National Preventive Mechanism under the Crimes of Torture Act in respect of "health and disability places of detention". It is currently considering whether this encompasses private sector aged care facilities in which people have been detained. These include 132 aged care facilities with dementia units, which the Ombudsman is not currently resourced to inspect.

# Intellectual Disability (Compulsory Care and Rehabilitation) Act

As reported in the IMM's 2011/2012 report, there is an apparent lack of appropriate facilities in some areas of the country for people with an intellectual disability. These are people requiring residential or intensive support and care who have not committed a criminal offence. The Intellectual Disability (Compulsory Care and Rehabilitation) Act was not intended to cover individuals who have not been convicted of a criminal offence, because detention would be a breach of their human rights. Where a person with an intellectual disability has been diagnosed with a mental illness they may be committed to an inpatient facility under the Mental Health (Compulsory Assessment and Treatment) Act. However, the Ombudsman has become aware of a lack of provision in some cases for those whose support needs relate primarily to intellectual disability.

The Ministry of Health advises that it has a high and complex intellectual disability framework. This provides a range of services to both care recipients with an intellectual disability and civil clients who are deemed to have high and complex needs. These people present significant risk to themselves or others. Intensive supports such as residential placement, behaviour support, life skills, day activity programmes, and sexual offender treatment programmes may be included.

It is pleasing to note that one individual identified by the Ombudsman as being in an inappropriate detention facility has now been moved to a residential community home. No further cases have since come to light during the Ombudsman's visits

to places of detention. However, the Ombudsman will continue to monitor the situation as it remains concerning that there are no dedicated facilities in some areas.

We are advised the Ministry's new model for supporting disabled people includes a demonstration project entitled *Choices in Community Living*. This involves working with people with intellectual disabilities to enhance their choices in where and how they live in the community. The Ministry also notes that when an individual is being transferred from hospital-level care back into the community, a "least restrictive option" policy is applied. This incorporates a "proactive multi-disciplinary team approach".

#### Mental Health (Compulsory Assessment and Treatment) Act

The Office of the Director of Mental Health's annual report provides the following data in relation to application of the Mental Health (Compulsory Assessment and Treatment) Act in 2012:<sup>31</sup> ... 4838 applications for a compulsory treatment order or extension to a compulsory treatment order were dealt with in the Family Court. Of these applications, 4328 were granted ... 2428 resulted in compulsory community treatment orders and 1687 in compulsory inpatient treatment orders...

A slightly higher number of applications were made for compulsory treatment orders in 2012 than in 2011 (4838 compared with 4801). However in 2012, an average of 77 people per month were detained under a compulsory community treatment order, compared with an average of 85 in 2011. On average, 13 people per month were under a compulsory inpatient treatment order in 2012, compared with 19 in 2011.

Data relating to the length of time people are detained under a compulsory treatment order is not available.

#### Case example: Helensburgh Cottage

In March 2013, the Ombudsman visited Helensburgh Cottage at Wakari Hospital, a relatively new intellectual disability facility. The cottage is a step down facility for clients/care recipients with an intellectual disability and has four beds. Generally, clients move to the less restrictive environment and continue the gradual reintegration process back into the community. One of the current clients was previously in a secure unit when the Ombudsman visited in 2008. It was encouraging to see the client in such a contrasting environment and their general improvement since the last visit.

## Seclusion and restraint

The Office of the Director of Mental Health's annual report provides the following data in relation to seclusion in 2012:<sup>32</sup>

> Between 1 January and 31 December 2012 ...1101 patients ... experienced at least one seclusion event. Sixty-six per cent of secluded patients were male and 34 per cent were female ... A total of 60 young people were secluded in the country's specialist facilities for children and young people ...

... Māori are more likely to be secluded than people from other ethnic groups ... [and] in 2012 of the 882 people (aged 20 to 64) secluded in adult services, 32 per cent were Māori.

Historically, the human rights of patients have been affected by controlling practices. It has, therefore, been pleasing to see a general improvement in the philosophy of care used in most mental health facilities visited by the Ombudsman over the last three years.

However, in 2012/2013 the Ombudsman identified two forensic units where controlling practices were still in place and a blanket policy was applied of locking patients in their bedrooms overnight under outdated "night safety" procedures. These were the Totara Unit in the Mason Clinic (Waitemata DHB) and Purehurehu Unit at Te Korowai-Whariki forensic mental health service (Capital and Coast DHB). The Ombudsman considers the practice of locking someone in their bedroom (at any time of the day or night) should be considered a period of seclusion and reported as such. However, no such reporting was taking place. Both units have now taken steps to remove blanket night safety procedures.

The Director of Mental Health noted that annual seclusion rates have dropped yearly since a reduction policy was introduced in 2009. However, four district health boards (Nelson Marlborough, Hutt Valley, Southern and Northland) were identified as using seclusion more often than the rest of the country in 2012. The Director of Mental Health advised that he was confident things were heading in the right direction. However, the Ministry of Health will undertake discussions with the aforementioned DHBs concerning their use of seclusion.

The Ministry of Health has also advised that it is reviewing its seclusion guidelines. It is hoped that this review will clarify the interaction of the Mental Health (Compulsory Assessment and Treatment) Act 1992, and the New Zealand Bill of Rights Act 1990. Seclusion guidelines need to more effectively protect the rights and safety of patients in secure mental health units.

#### Case example: Patient held in seclusion on semi-permanent basis

In September 2011, the Ombudsman discovered a patient in Tawhirimatea Unit, Korowai-Whariki forensic mental health service who was being held in seclusion on a semi-permanent basis. The Ombudsman recommended that "a more appropriate facility needs to be sourced for the client". Capital and Coast DHB (CCDHB) had been seeking to resolve the situation. However, a follow-up visit in June 2012 found the patient in the same situation and a repeat recommendation was made.

The Ombudsman then began to look into the overall treatment and management of the patient by the DHB. The particular focus of the investigation was on the extensive use of seclusion and the failure to arrange a more appropriate placement. In early August 2013, the Director of Area Mental Health Services at CCDHB confirmed that funding had been secured for a targeted service for this patient in the community. The Ombudsman is actively following up with CCDHB concerning this patient's future placement.

#### Case example: Rising to the Challenge

Rising to the Challenge: The Mental Health and Addiction Service Development Plan 2012/2017 (Rising to the Challenge) was agreed to by Cabinet in November 2012. It sets the direction for improvements to mental health and addiction services to 2017.

The Ministry of Health advises that *Rising to the Challenge* recognises that disabilities and long-term physical health conditions can have a significant impact on mental health and wellbeing, and vice versa.

*Rising to the Challenge* contains 100 key actions to improve services and outcomes for clients. A high level goal of *Rising to the Challenge* is to improve the interface between mental health and addiction services and disability support services.

# Privacy and dignity

The Ombudsman noted concerns in the 2012/2013 year that bathroom and toilet doors in the Totara Unit in the Mason Clinic (Waitemata DHB) are not lockable from the inside. This does not adequately maintain the dignity and privacy of patients. Many mental health facilities visited have internal doors that can be overridden by staff, should they need to gain access in an emergency. We have been advised that the Ministry of Health intends to have a wide discussion on privacy and dignity issues and the "appropriate balance between protecting rights and managing risk in such situations".

#### Electroconvulsive therapy

The Office of the Director of Mental Health's annual report provides the following data in relation to electroconvulsive therapy (ECT) in 2012:<sup>33</sup>

A total of 265 people received ECT during the year ending 31 December 2012. The total number of treatments administered over this period was 2670, with the mean number of treatments per person being 10.08.

The number of people receiving ECT treatment was 6 per 100,000 in 2012, compared with 6.5 in 2011. Moreover, fewer patients received ECT treatment nationwide in 2012 than in 2011. (That is, 265 patients in 2012 compared with 286 in 2011.) However, the total number of ECT treatments not able to be consented to increased from 495 treatments in 2011 to 690 treatments in 2012.

Of the 265 people who received ECT treatment in 2012, 172 (65 per cent) were women, 79 (30 per cent) were men, and for the remaining 10 (5 per cent) the gender was unknown. The main reason for the gender difference is that more women present to mental health services with depressive disorders. This ratio is similar to that reported in other countries.

# Article 16 Freedom from exploitation, violence and abuse

Governments must take all appropriate measures to protect disabled people from all kinds of exploitation. This encompasses violence and abuse including that which is related to a disabled person's age or gender. The Government must take a range of preventative measures such as help, support and education. Disability services must be independently monitored and rehabilitation provided for victims.

At times, abuse and violence towards disabled people can be invisible due to lack of data and limited research, including about disability-specific manifestations of abuse. Most responses to these issues continue to be instigated by disabled people and allied organisations. These include the national Disability Coalition against Violence, the Auckland Domestic Violence and Disability Group, People First's PIP project to address bullying and harassment, and the Disability Clothesline. These groups continue to have difficulty securing sustainable resourcing.

Work continues on ensuring government funded domestic and anti-violence programmes in New Zealand are able to cater for the needs of disabled people. People who experience impairment and disability want and deserve to live safely in their communities. They need sustainable services to support their wellbeing and to prevent abuse. A few of the recent developments are highlighted in the following paragraphs.

In February 2013, the Disability Coalition Against Violence (DCAV) produced a report for the Ministry of Social Development's Taskforce for Action on Violence within Families. The report concluded that services need to be accessible to people with disabilities. This requires not only accessible facilities and information, but also attention to the particular support needs of this population. The report made recommendations for professional development of service staff. These included work around violence prevention policy and practice and making information available in a range of communication formats including material about healthy relationships and strategies for keeping safe.34

In November 2012, the Green Party New Zealand launched the *Everyone Needs the Right Help* campaign highlighting the need for better access to specialist services for survivors of rape and sexual abuse. This campaign included a specific focus on disabled people. In August 2013,

following a request by the Green Party, the Social Services Select Committee agreed to conduct an inquiry into the funding of specialist sexual violence social services.<sup>35</sup> The closing date for written submissions was 10 October 2013, with the Committee due to hear oral submissions in April and May 2014.

During New Zealand Sign Language Week a series of campaign messages in New Zealand Sign Language were launched to the Deaf community. These were part of the *It's not OK* anti-violence campaign and included *It's OK to Help*, *It's OK to Ask for Help* and *Keeping Children Safe*.<sup>36</sup>

Instances of violence, abuse and neglect of disabled people, including those in State-funded care, continue to come to light. This is despite the recommendations from the Social Services Select Committee inquiry in 2008 which highlighted ways to address this issue. During the last reporting period, the Ministry of Health engaged a panel of independent experts to review and report on certification of Ministry of Health disability support services residential facilities. The review was undertaken by Beverly Grammer, Karen Van Eden and former Consumer Institute CEO David Russell. The resulting report, Putting People First – A Review of Disability Support Services Performance and Quality Management Processes for Purchased Provider Services was released in November 2013.<sup>37</sup> It included a list of "early warning markers" and a number of wide-ranging

recommendations intended to improve the quality and safety of residential facilities. These were clustered under four headings:

- supporting providers to offer high quality care and supports that place disabled people at the centre of their service
- 2 giving disabled people a voice the ability to speak out when unsafe, including the support to do this if they are unable to do so on their own
- 3 ensuring the processes that capture complaints, incidents, and issues, do so in a way that keeps disabled people safe, and resolves the complaint or issue
- improving the effectiveness of performance management systems, so no providers and no disabled people fall off the radar.

Many similar issues have been reported from aged care residences, dementia units and mental health care facilities. However, they are outside the scope of the *Putting People First* report.

Overseas research shows that children with disabilities were 3.8 times more likely to be neglected or physically abused, and 3.1 times more likely to be sexually abused, compared to children without disabilities.<sup>38</sup> In New Zealand, the website of the National Collective of Independent Women's Refuges includes some specific

information for disabled women.<sup>39</sup> At the 2011 launch of *Domestic Violence and Disabled People*, the Minister of Women's Affairs noted that "international research shows that women with disabilities are much more likely to suffer from domestic violence than other women".<sup>40</sup>

Domestic Violence and Disabled People was developed by the Auckland Domestic Violence and Disability Group in collaboration with the Disability Coalition Against Violence and other agencies.<sup>41</sup> It lists factors that may make it particularly difficult for a disabled person to tell others about abuse, including:

- 1 fear of losing a caregiver
- 2 fear of being institutionalised

- 3 communication barriers
- 4 being unable to access support in mainstream ways
- 5 social isolation, and
- 6 lack of access to transport.

A 2013 exploratory study focused on violence against disabled people in Tairawhiti. This highlighted the hidden nature of much abuse directed against disabled people within the community. In addition to the physical, emotional and sexual abuse experienced by non-disabled people, "locked in" and "silencing" violence is often specifically directed at disabled people. The report noted that it was reasonable to interpret the Domestic

#### Case example: Parklands

Up to 19 intellectually disabled people lived at Parklands, a farm in the Waikato district contracted to provide residential disability services. Between 2004 and 2012, numerous audits and evaluations of the Parklands facility were undertaken by Disability Support Services. Significant shortcomings were identified in all but one of the audits. In 2012, two temporary managers were appointed and they provided a report to the Ministry on 26 September 2012. The Ministry of Health subsequently terminated the contract with Parklands and found new homes for all residents.

Reviewers appointed by the Ministry of Health concluded that although the language used by the temporary managers in their September 2012 report was different, the sentiment expressed was consistent with the original audit undertaken in 2004, some nine years previously. The reviewers concluded:

In plain English, residents at Parklands were not given the stimulus or support they could expect or deserved. Over the years nothing much had changed.<sup>44</sup>

Violence Act 1995 as generally excluding people in employer/employee relationships, such as care workers, from the definition of a domestic relationship. The author continued:<sup>42</sup>

> As such, it is not clear whether the Act adequately protects disabled people experiencing abuse in homecare/live-in support situations. There appears to be an uncertainty about the legal protection available to disabled people experiencing such abuse, and particularly emotional and psychological abuse.

To date, there has only been limited acknowledgement of historic abuse and violence against disabled people that occurred in social welfare homes and institutions for people with learning disability or mental illness. Part of ensuring the safety and wellbeing of disabled people today and tomorrow is to ensure that these mistakes are made visible and that lessons are learned.<sup>43</sup>

# **Recommendation 13**

That the Government develop a range of initiatives to ensure that:

 disabled people have the same protection from domestic and other forms of violence as non-disabled people, and

- 2 agencies identify and appropriately respond to abuse and violence directed at disabled people, including by:
  - a ensuring all government-funded
     domestic and anti-violence
     programmes include material about
     disabled people
  - b investigating whether legislative reform is required to extend the range of protections and support available
  - c considering ways to increase awareness of abuse experienced by disabled people and mechanisms to address it. This would include extending the *It's Not OK* campaign to residential facilities and providing sustainable funding for DPOs working in this area, and
  - d training staff within police, courts, service providers and DPOs about the protection and support needs of disabled people.

# Article 19 Living independently and being included in the community

The right to live independently and be included in the community is a right many non-disabled people take for granted. Parallel rights for disabled people are not included in any other international human rights treaties.

The Disability Convention recognises that:

- 1 disabled people have an equal right to live in and take part in the community
- 2 disabled people have the right to the same choice and control as nondisabled people
- 3 governments should ensure disabled people have the right to choose where they live and who they live with; have access to support services to prevent isolation and support inclusion; and can access the same community services as everyone else.

# Supporting Disabled People and Enabling Good Lives

The IMM continues to support the principles behind new initiatives under the Ministry of Health's New Model for Supporting Disabled People and the cross-government Enabling Good Lives framework. Enabling Good Lives is being jointly led by the Ministries of Social Development, Health and Education. There is a growing momentum that needs to be supported. It is important to work in ways that enable disabled people and their organisations to be involved in key decisions about developing new services. However, the current rate of progress means it will be many years before the service changes currently being trialled are available to all disabled people as a realistic option.

The Bay of Plenty demonstration of the *New Model* has made significant progress since the last report. An evaluation of the programme during the 2012 calendar year showed that 27 people and their families had worked with local area coordinators during the year and achieved some real changes in their lives. These included doing courses, working part-time, attending a gym, developing a home-based business, solving transport needs, and organising a support group for disabled people.

The approach of working with both a national reference group and a local working group appears to be an effective mechanism to involve disabled people in developing the programme and responding to service design issues as they arise. The slower than expected pace in uptake is an issue that will need to be addressed if the model's full potential is to be realised.<sup>45</sup> As at August 2013 a total of fifty-nine people had asked to work with a local area coordinator.<sup>46</sup>

An Enabling Good Lives demonstration project has been established in Christchurch. The project will initially work with approximately 40–50 students who have high and very high needs and who began to transition from school in November 2013. The project will use funding and services from the Ministries of Health, Education and Social Development to enable disabled people to receive more person-centred support in their local community. This means they would have more choice and control over the support they receive. The project replicates the system of advice and accountability established in the New Model demonstration with an Enabling Good Lives advisory group in Christchurch and a national Enabling Good Lives leadership group. The demonstration will allow information to be gathered on how the Enabling Good Lives approach works best in practice.47

## **Residential services**

In 2008 the Social Services Select Committee investigated issues in residential services. Its report, *Inquiry into the Quality of Care and Service Provision for People with Disabilities*, found disabled people living in residential services do not have the same housing options available to other people. This included limited choice over who they live with.<sup>48</sup> The IMM's 2011/2012 report discussed the Hamilton and Auckland Choice in Community Living (CiCL) project. This supports disabled people, who might otherwise need residential services, to plan for the lives they want. Options include living in a home they rent, lease or own. It aims to provide disabled people with greater choice and control about where they live, who they live with and how they are supported. A total of eight organisations are contracted as providers in the Auckland and/or Waikato regions. Progress is solid with 36 people being supported through CiCL as at 24 December 2013. Approximately 150 people will take part in the project over three years to October 2014. The project will then be evaluated before a decision is made on future implementation.

The IMM is concerned that the slow pace of change is reflected in the number of young people still living in aged residential facilities. The 2006 Disability Survey identified over 600 people with a disability living in rest homes. Between 2008, when the Select Committee reported, and 2011 the total number of young people in aged residential facilities increased from 684 to 738. The IMM is aware of some promising initiatives. Nonetheless the IMM is concerned at the slow rate of change and that some of the proposed solutions may in fact be replacing one form of institutional living with another. This is an issue that the IMM will investigate further in the coming year.

#### Parents as caregivers

The Court of Appeal decision in Ministry of Health v Peter Atkinson in 2012 confirmed the decisions made by the High Court and the Human Rights Review Tribunal. These were that the Ministry of Health's blanket policy of not paying parents and resident family members to provide home and community supports to disabled people was discriminatory on the basis of family status.<sup>49</sup> The Ministry of Health did not appeal the decision to the Supreme Court and undertook a degree of limited consultation on options for responding to the Court's findings. The New Zealand Public Health and Disability Amendment Act 2013, was subsequently passed under urgency in May 2013 as part of legislation related to the 2013 budget process. This amendment sets out the Crown's authority to establish family care policies.<sup>50</sup> A clearly stated purpose of the amendment was to keep support services provided by families within financially sustainable limits.

The Funded Family Care policy came into effect on 1 October 2013 with funding of \$92 million over the next four years. The policy has a number of significant constraints. It is only available to disabled people 18 years and over to pay for personal care and household management supports. Only a parent or other resident family member can be employed and not the person's spouse, civil union or de facto partner. The funding is only available if the person has high or very high support needs, including situations where they are not able to remain at home unless they can employ a family carer.<sup>51</sup>

The Act prevents any complaint being made to the Human Rights Commission or to any court in specific circumstances. These are if the complaint is wholly or partly based on an assertion that an individual's right to be free from discrimination on the basis of marital status, disability, age or family status has been breached by the provisions of this amendment. It also prevents complaints that any family care policy (or any act or omission carried out as a result of a family care policy) is discriminatory.

The IMM is concerned at a number of aspects of this legislative change. The main concern is it contradicts and undermines the Government's reported policies reflected in the current Disability Action Plan and the principles outlined in *Enabling Good Lives*.

The IMM is also concerned that the legislation curtails avenues for redress in relation to complaints about family care policies and related activities. The law was also passed under urgency without the usual opportunity for public input. The IMM is further concerned that the Act was passed despite a report from the Attorney-General that it was inconsistent with the rights and freedoms contained in the New Zealand Bill of Rights Act. This includes the right to be free from discrimination.

In the IMM's view, the passing of the Act directly contravenes the antidiscrimination provisions of the Disability Convention (Article 5). It also contravenes the undertaking that the Government will "closely consult with and actively involve" disabled people through their representative organisations, in all issues concerning them (Article 4 (3)). Rather than fixing a previous inequality, the IMM is concerned that the Act regularises a further inequality for disabled people and their families. The IMM acknowledges that the Government undertook some degree of consultation with disabled people on options for responding to the court's decision. However, the policy that has now been introduced does not adequately nor appropriately address the core concerns that led to the original court proceedings. Nor does it properly give effect to the rights of disabled people.

In August 2013, at a forum at Parliament, the Disabled Person's Assembly (DPA) launched a petition to repeal the New Zealand Public Health and Disability Amendment Act 2013. DPA emphasised that disabled people want the right to choose who works alongside them – whether it is family members or other people. Law Professor Andrew Geddis of Otago University stated that the removal of the right to take future complaints to the Human Rights Commission amounted to bullying by the Government.<sup>52</sup>

# Inclusion within cultural communities

For many disabled people, the best option to make their rights real and to enable a good life is through employing a family member. This may require a supported decision-making process.

For cultural reasons, Māori and Pacific disabled people are more likely to choose support from within the whānau, aiga or family. This comes with a financial cost to the family. For Māori, living in the community involves all aspects of Te Whare Tapa Whā – physical, mental, spiritual and whānau health. Therefore whanaungatanga and whānau ora are integral to supporting disabled Māori. Current resourcing structures and systems do not provide Māori and Pacific people the level of rangatiratanga or choice to which they aspire.

A November 2012 report from the ChangeMakers Refugee Forum sets out challenges faced by Wellington's refugeebackground communities in accessing disability support services.<sup>53</sup> It states that there is a lack of inter-agency coordination across refugee, health and disability agencies. This means disabled people from these communities have faced protracted isolation and their right to live independently has been undermined. Ad hoc provision of disability services has left disabled people reliant on family members to fill in the gaps. Language and cultural barriers mean refugee-background people with disabilities may not feel confident sharing important information with the Needs Assessment and Service Coordination (NASC) system. This compounds the usual challenges disabled people and families face when trying to gain choice and control, in order to make their rights real, in a system still focused on needs and services.

## Recommendations 14 and 15

#### **Recommendation 14**

That the Government review all disability support systems to ensure that they reflect the whole of life, strengths-based approach recommended by the Social Services Select Committee Inquiry and incorporated into *Enabling Good Lives*.

#### **Recommendation 15**

That the Government urgently reconsider the New Zealand Public Health and Disability Amendment Act 2013 and repeal those sections that limit further legal action and limit the circumstances in which family members can be paid and the categories of family members that can be paid.

## Universal design and housing

The IMM's 2011/2012 report described the impact the aging population is likely to have on the need for an accessible housing stock. It referred to research indicating that building lifetime design features into a new house is likely to add little or no additional cost. There would be economic efficiency gains if all new houses incorporated universal design features.

Lifetime Design Ltd (LDL) has developed the Lifemark Design Standards to assess whether a dwelling meets universal design principles. While many of the requirements are based on NZS 4121:2001 Design for Access and Mobility, this is the only existing New Zealand guideline developed specifically for housing.<sup>54</sup>

A 2012 report showed that New Zealand's housing stock does not function adequately for people with impairments. It also tends to be costly to adapt and is a significant contributor to the process by which a person's impairment is transformed into a disability.55 Citing both local and overseas evidence, the report argues that converting houses on an "as needed" basis and providing "special" housing has not provided for the needs of older and disabled residents. This is because the approach has largely failed to meet the demand or to respond to the issues on a strategic basis. The report recommended that a combination of regulation, policy and economic measures be adopted. This is similar to the approach that has been taken to make the housing stock more energy efficient.

Government housing policy reforms have placed a clear emphasis on affordable housing, particularly in Auckland and Christchurch. The IMM is concerned that the opportunity to also provide for

accessible housing, as part of these reforms, has not been taken up as fully as it could be.

There have been significant changes to the way social housing is provided. Making income-related rent available to approved social housing providers and their tenants will mean affordable housing is available to more households. Arguably, having the Ministry of Social Development responsible for assessing people's need for social housing will potentially provide a more broad and comprehensive assessment of need. At present, potential providers of social housing have to meet a pre-qualification process in order to be eligible for social housing fund grants.

The IMM recommends that all prequalification applicants undertake to provide accessible housing using the Lifemark Design Standards or an alternative certification process with at least as robust standards. The same requirement would apply to all new and renovated Housing New Zealand Corporation units. The Commission understands that access issues are taken into account in both these processes but are not mandatory requirements.

The IMM strongly supports the Christchurch City Council's adoption of Lifemark Design Standards to apply to all of its new and renovated social housing units. In the May 2013 budget the Government committed a further \$1.5 million in operating funds over three years to further support Lifetime Design Ltd to increase the number of houses built to universal design standards.

# **Recommendation 16**

That all applicants for pre-qualification for Social Housing Fund grants be required to undertake to provide accessible housing using the Lifemark Design Standards (or an alternative certification process with at least as robust standards).

# Article 20 Personal mobility

The Disability Convention states governments should do everything possible to ensure disabled people can get around as independently as possible, including by:

- ensuring people can travel where they want to at a price they can afford
- 2 ensuring people have access to quality, affordable mobility aids
- 3 providing mobility training to disabled people and staff working with them
- 4 encouraging manufacturers of mobility aids and technologies to consider all aspects of mobility for disabled people.

The IMM has decided to only report in detail when significant developments have taken place since the last report. There continue to be inconsistencies in laws and policies that refer to guide dogs, companion dogs or disability dogs. There is also some tension between the Dog Control Act and protections from unlawful discrimination under the Human Rights Act. All these impact on the rights of access for disabled people with service animals. The IMM's concerns are outlined in its 2011/2012 report and these issues remain a problem.



Photo: Blind Foundation.

# Article 21 Freedom of expression and opinion, and access to information

Limited access to information in accessible and appropriate formats is a major barrier to the full realisation of disabled people's rights.

The Disability Convention states governments should take steps to ensure disabled people can express their views freely and access information on an equal basis to everyone else, including:

- providing disabled people with information in accessible formats and technologies at no extra cost
- 2 ensuring people can use sign language, Braille and other types of communication when they are dealing with public services or the State
- encouraging private sector providers to provide accessible information, including accessible websites
- 4 encouraging mass media and internet providers to make their services accessible
- 5 recognising and promoting the use of sign language.

# Modern information and communication technologies

The internet and modern information and communication technologies have the potential to revolutionise the lives of disabled people. But this potential will only be realised if best practice design is consistently followed. The Government's *Better Public Services* initiative has set goals for the public sector to achieve over the next five years. One of these states that New Zealanders can complete their transactions with the Government easily in a digital environment.<sup>56</sup>

As reported in 2011/2012, the Government has established the Government web standards, based on the widely accepted international Web Content Accessibility Guidelines developed by the World Wide Web Consortium. It is mandatory for all public sector departments, the New Zealand Police, the New Zealand Defence Force, the Parliamentary Counsel Office and the New Zealand Security Intelligence Service to be compliant with the standards.<sup>57</sup> A self-assessment in 2011 indicated "no government website fully conforms to the Government Web Standards".58 The Department of Internal Affairs is investigating ways to help agencies meet the standards.

The wider state sector (excluding State owned enterprises and Crown owned companies) is encouraged to use the guidelines. Local government has also been invited to adopt the standards.

A working group comprising disabled people and government web practitioners was established in late 2012. This group works to support the implementation of the web standards by government agencies and to improve the accessibility of government websites.

Updated Government web standards were issued in July 2013, following consultation with disabled people and disabled people's organisations. The IMM worked with the Department of Internal Affairs to support the launch of these standards.<sup>59</sup>

# Recommendations 17 and 18

#### **Recommendation 17**

That all government agencies ensure their own and government funded initiatives, for which they are responsible, comply with the Government web standards for accessibility and other accessible information and communication requirements.

#### **Recommendation 18**

That the Government web standards become mandatory for all territorial authorities, district health boards, other Crown entities and organisations receiving substantial government funding.

#### Access to information

As reported in 2011/2012, everyone in New Zealand has the right to request information held by state sector agencies under official information legislation.<sup>60</sup> Individuals can also request personal information about themselves from both state and private sector agencies, under the Privacy Act.

Under the legislation, information may be made available in a number of different formats.<sup>61</sup> Importantly, the Acts require that information must be made available in the way preferred by the person requesting it. This is required unless it would impair efficient administration, be contrary to a legal duty of the agency, or prejudice a protected interest.

The legal requirement to make information available in the way preferred by the requester does not appear to be widely known. In the 2012/2013 year, the Ombudsman received only seven complaints about the form in which information was released.

The Ombudsman continues to receive a small number of complaints about decisions by state sector agencies to release information only in hard copy or electronically in PDF format. These agencies refuse to provide the information in Word or another more accessible electronic or hard copy format. The complaints generally revolve around difficulties in being able to use PDFs or hard copies to easily extract

and analyse information. These issues are particularly important for people with vision impairments.

Cases in this area need to be considered on their own merits. However, when a person has a valid reason for seeking information in a particular format, it would seem reasonable for agencies to provide information in that format. Significant technical or administrative difficulties should be the only grounds for refusing such requests.

# **Recommendation 19**

That all state sector agencies develop internal guidelines for communication with disabled people, including making information available in accessible formats.

## New Zealand Sign Language

In 2013, the Commission completed its inquiry into New Zealand Sign Language (NZSL).<sup>62</sup> New Zealand Sign Language was made an official language of the country in 2006. Despite this, the Commission continued to receive enquiries and complaints. These show that deaf people and other users of NZSL have significant barriers to accessing education, employment, government services and public information.

In addition to the rights under Article 2, the right to education includes the obligation for governments to facilitate the learning of sign language and promote the linguistic identity of the Deaf community. Governments should ensure that education is delivered in the most appropriate language and that teachers are educated in sign language.

The terms of reference for the inquiry were informed by the deaf community's priorities and focused on:

- 1 the right to education for deaf people and other NZSL users
- 2 the right to freedom of expression and opinion including the right to receive and impart information using NZSL interpreter services
- 3 the promotion and maintenance of NZSL as an official language of New Zealand.

The findings of the inquiry included:

- 1 the right to education, including early childhood education, is a high priority because of deaf people's persistent under-achievement in the education system
- 2 most deaf children are born into hearing families with no prior experience of childhood deafness. It is crucial that children born deaf or who become deaf before their speech is well established develop NZSL skills early in life
- 3 NZSL education resources and supports need to be more consistently available including opportunities for face-to-face learning

- 4 education in NZSL and Deaf culture is minimal for education staff who work with deaf students
- 5 equity funding for deaf students is often not sufficient to access the full range of tertiary education opportunities
- 6 crucial rights to public services are often compromised by a lack of interpreter services
- 7 there is no monitoring of the quality or cost of NZSL interpreter services within or across government agencies including district health boards
- 8 funding for NZSL interpreter services is inconsistent
- 9 work support funds for deaf people are often insufficient to support normal work-related education and career development, and
- 10 there are no interpreter standards outside court settings.

The report made 15 recommendations addressing these issues. Since the report was published, the Ministry of Education has established a sector advisory group to improve access to NZSL in schools and early childhood services. The group will build on work already undertaken to improve the work of the two Deaf Education Centres and rationalise resources available to deaf students. The Ministry aims to offer NZSL as a National Certificate of Educational Achievement (NCEA) subject from 2015. It also aims to improve deaf students' achievements at levels 1, 2 and 3 of the NCEA to the same proportions as hearing students.<sup>63</sup>

The Ministry of Social Development established a temporary expert advisory group to work with government agencies on what could be done, in the longer term, to promote and maintain NZSL. It was to meet between September 2013 and March 2014 and identify a work programme and priorities for Ministers to consider.

#### Video Remote Interpreting Service

The Video Remote Interpreting Service (VRI) was launched in October 2013 and is being progressively implemented in some government services. The initial participating government agencies are the Ministries of Social Development, Health, Education and ACC.<sup>64</sup> VRI enables a deaf person to have a virtual meeting with a government employee by connecting to a NZSL interpreter via an internet video connection. However, it is essential that VRI complements rather than replaces face-to-face interpreting, which will often continue to be the most appropriate and accessible service for deaf people.

## Article 23 Respect for home and family

This article covers the right of disabled people to marriage, family, parenting, relationships, fertility and education. Disabled people should have the same rights to adoption and guardianship under the law, taking into account the best interests of the child. Disabled people should have appropriate assistance to help to raise their children if they need it.

Disabled children and disabled parents have the same right to family life as non-disabled people. Children should not be arbitrarily removed from their families because of the child's or parent's disability.

### Family planning services

As the IMM's 2011/2012 report noted, Family Planning's philosophy includes a statement that people have the right to live free from discrimination. Disability is one of the eight prohibited grounds of discrimination specifically mentioned. The website has some information designed for people with learning disabilities. This includes order forms for three free booklets on safer sex and puberty. Family Planning runs courses on non-clinical aspects of disability and about relationships for disabled people, parents and professionals. The youth site contains basic information and an NZSL video.

## Adoption

Section 8 (1)(b) of the Adoption Act gives courts, in certain circumstances, the power to dispense with consent of a birth parent or guardian to adoption. Physical or mental incapacity is a ground for applying for dispensation. Section 8 of the Act appears to be inconsistent with Article 23 of the Disability Convention.

In a recent case on discrimination under the Adoption Act, the Crown argued that the courts have always applied their discretion in a non-discriminatory manner. Disability, however, remains a separate ground for dispensing with consent. This is arguably discriminatory. Consistent with Article 23, disabled people should not be singled out for special treatment as it sends a derogatory message about the ability of disabled people to parent children.

## **Recommendation 20**

That the Ministry of Justice review the Adoption Act, with particular consideration given to whether section 8 complies with the Disability Convention.

# Out of home care arrangements for children

Sections 141, 142, and 144(2) of the Children, Young Persons and Their Families

Act (CYPFA) provide a mechanism allowing disabled children to be placed in the care of an approved organisation. This applies to those children "who are so mentally or physically disabled" that their suitable care can only be provided by such a placement.

Children can be placed in the care of an organisation approved by the Director-General of Health, with the agreement of their parent or guardian, for a period of up to two years. The timeframe can be extended for further periods of up to two years at a time if agreed by a family group conference. The situation was explored in detail in a 2006 report prepared jointly for the Department of Child Youth and Family and the Disability Support Directorate of the Ministry of Health.<sup>65</sup>

The effect of section 141 means that disabled children are not afforded the same rights as other children who are placed in out of home care. The agreed arrangements are not subject to the same degree of regular oversight as other processes for placing children outside their family unit. The provisions do not require priority to be given to family-based or extended family placements in the first instance. Nor do the children concerned have the benefit of an independent court-appointed advocate to represent their interests in any decisionmaking process.

If passed in its current form, the Vulnerable Children's Bill (currently before Parliament) would reduce the maximum period for extended care arrangements under section 141 from two years to one. This would provide children with disabilities with the same regularity of reviews as other children in out of home care arrangements. However, in the IMM's view these proposed changes do not go far enough to ensure that disabled children have the same rights as other children.

Closely related to this issue is the broader need to provide flexible support options for families to assist them to provide care for a disabled child in their own homes. Providing better support services may prevent the need for out of home care options to be considered in many cases. The pressures of providing care with little support can lead to relationships breaking down. The breakdown of family relationships can have a huge longterm impact on disabled children and young people. Appropriate supports need to be available to help prevent this from occurring.

Modern practice, including options of intensive wraparound support, or shared care across families, can help support all children within a family environment. This is no more costly than placement in a residential service. In fact, it is usually cheaper. An important next step would be to document emerging good practice in this area.

All families with disabled children need to be supported as early as possible. Too often, formal supports are not provided until the family has reached a crisis.

#### Whānau Ora

Whānau Ora is an inclusive inter-agency approach to providing health and social services to build the capacity of New Zealand families in need. It empowers whānau as a whole rather than focusing separately on individual family members and their problems. Its aspiration, to return more choice and control to families, aligns with the direction of disability support reform in New Zealand. The IMM and the disability community are looking to learn from its roll out. Whānau Ora is particularly important in the lives of whānau hauā, Māori families with a disabled family member. It is essential that Whānau Ora works for them and has sufficient disability capability available for them to draw on.

## Recommendations 21 and 22

#### **Recommendation 21**

That as part of the Government's work in relation to vulnerable children, sections 141, 142, and 144(2) of the Children, Young Persons and Their Families Act are repealed to ensure that disabled children have the same rights as other children when an out of home placement is being considered.

#### **Recommendation 22**

That the Government further extend NGO-led intensive wraparound support programs for disabled children, in partnership with DPOs.

## Article 24 Education

Without equal access to education, disabled people are disadvantaged in other areas of life, such as employment and overall life satisfaction.

The Disability Convention recognises that:

- governments must ensure the education system is inclusive and supports disabled people to achieve their full potential and participate equally in society
- 2 disabled people should be able to access free, inclusive primary and secondary school education wherever they live
- 3 disabled people must not be excluded from the general education system, at any level, because of their disability
- disabled people have the right to reasonable adjustments and extra support to take part in education
- 5 governments must promote the learning of Braille and sign language and use appropriate forms of communication for disabled learners. This includes promoting the linguistic identity of deaf people and ensuring enough teachers are trained in different communication methods.

New Zealand has ratified both the International Covenant on Economic, Social and Cultural Rights and the United Nations Convention on the Rights of the Child. Both instruments provide for the right to education.

#### Inclusive education

Inclusive education is based on the principle that all children should learn together, wherever possible, regardless of difference. The United Nations Special Rapporteur on the Right to Education has provided advice on minimum standards for inclusive education.<sup>66</sup> Further details are set out in the IMM's 2011/2012 report.

In New Zealand the legal right to education for disabled students is not fully established. It should consistently guarantee disabled students are able to attend their local state school and receive an education aimed at the full realisation of their abilities and talents. While the concept of inclusive education underpins Article 24 of the Disability Convention, the term does not appear in the Education Act 1989.

The Education Act 1989 recognises that:

 every person between the ages of five and nineteen years old has the right to free education at any state school

- 2 people with special education needs, including those with disabilities, have the same rights to enrol and receive education in state schools as those who do not
- 3 the Secretary of Education may direct a person's special education by directing enrolment at a particular state school, class, clinic or service.

As the IMM's 2011/2012 report noted, what this might mean in practice was tested in the High Court and the Court of Appeal in Daniels v Attorney-General.<sup>67</sup> The High Court saw the right as a substantive one. However, the Court of Appeal ruled there was no general right to education enforceable by individual students. Rather, the right to education was met by procedural rights to a regular and systematic education, such as through minimum days and hours of tuition, teacher registration and a national curriculum. Only exceptional cases are likely to fall within this narrowly defined right to education. There is currently a gap between the right to education and the ability and means to enforce it.68

IHC is self-funding legal proceedings against the Ministry of Education, claiming special education policies are discriminatory. This is in response to a high number of complaints and concerns IHC has received. These focus on how disabled children have been treated differently to non-disabled children in matters to do with enrolment, access to the curriculum and participation in school life.<sup>69</sup> IHC has also raised concerns with the IMM about aspects of the methodology used by the Education Review Office and the statistical significance of some of the findings in the ERO's reports referred to below.

The IMM's 2011/2012 report described the Government's 2010/11 review of school's inclusiveness. Since then, ERO has undertaken a number of evaluations and surveys. These show good progress has been made towards schools and early childhood services becoming fully inclusive.

A questionnaire was completed by 254 schools in the second half of 2011. The results showed that 88 per cent of schools considered themselves as having mostly inclusive practices, 10 per cent as having some inclusive practices and one per cent (three schools) as having few inclusive practices.<sup>70</sup> Primary schools were more likely than secondary and composite schools to rate themselves as mostly inclusive (90% compared with 79%). These are very similar results to the questionnaire sent to schools in the first part of 2011 and reported in the 2011/2012 report. The latest report found that most school reports to their boards of trustees were limited. They contained "very little information about the achievement of students with high needs, and did not contain sufficient information for boards of trustees to obtain a comprehensive picture of the impact of the school's provision on student learning".<sup>71</sup>

A report released in July 2013 updates the school-level changes made since 2010 to support inclusion for students with high needs in primary schools.<sup>72</sup> The report indicates good progress in schools achieving inclusiveness.

## Table 4: Primary school inclusiveness: students with high needs

| Degree of inclusiveness       | 2010 | 2013 |
|-------------------------------|------|------|
| Mostly inclusive<br>practices | 50%  | 77%  |
| Some inclusive practices      | 30%  | 16%  |
| Few inclusive practices       | 20%  | 7%   |

Schools with mostly inclusive practices shared similar characteristics. Typically there was good coordination between school staff and outside personnel, professional learning and development, and appropriate use of teacher aides in a mainstream context.<sup>73</sup>

The IMM is highly supportive of ERO assessing inclusive school education. However, the IMM shares the ERO's concern about the way schools report on their inclusive practice. Reporting tends to focus on the programmes and strategies adopted and much less on the outcomes the approaches have achieved.

The IMM would like to see a focus, in the next two to three years, on the

achievements of students with low or moderate support needs. It is important that proposed educational performance reviews for partnership schools (kura hourua) specifically monitor outcomes for disabled students. Disabled Māori students also need access to te ao Māori through kōhanga reo, kura kaupapa, and whare wānanga.

A government priority is that every child has the opportunity to participate in early childhood education. The goal is to increase the level and quality of participation for groups with traditionally low participation rates, including disabled students. The ERO has completed a report on the inclusion of disabled students in early childhood services (ECS).74 The report focuses on 268 ECSs reviewed in late 2011. There were 104 services that said they had children with "moderate or severe special needs". Of these, 44 per cent were very inclusive and 49 per cent were mostly inclusive. The seven per cent of services that were less inclusive also demonstrated a poor quality of teaching overall. Most services did not undertake self-review of the impact of their transition practices on the inclusion of disabled students or the outcomes for these children. In this way the practice of these ECS was similar to that in primary schools.75

The report contained the following opinions from Special Education staff and disability action groups:<sup>76</sup>

 Very few children were turned away but where a child was not enrolled

it was often because of lack of support hours, an unsuitable physical environment or where the child-toadult ratio did not allow the child's safety to be guaranteed.

2 Attitudes to inclusiveness were often very dependent on the head teacher or manager and their ability to model good practice. It was common for disabled children to attend on a limited basis usually because of lack of sufficient support hours.

The New Zealand Council for Educational Research has developed a website that supports schools to complete a self-review of their current inclusive practices. This comprehensive, user friendly website also enables schools to develop an action plan to further improve those practices.<sup>77</sup>

Special provisions for disabled students sitting exams are an example of reasonable accommodation that has been available in New Zealand for more than 50 years. In 2012, there was a substantial increase in the number of applications for such special assessment conditions. The Ministry of Education and the New Zealand Qualifications Authority have undertaken a review focusing on equity of access, the effectiveness of the support provided, the capacity and efficiency of systems for managing applications and the impact of assistive technology. The review was informed by a reference group of key stakeholders and experts.



Atsushi Shiraia, member of the Papatoetoe High School's Tongan Group, holding the Te Urunga Award presented by the Human Rights Commission, won at Auckland's Polyfest for the most ability inclusive performance on the Tongan Stage.

It is difficult to see how educational outcomes for disabled students can be improved if they are not being assessed. There is a range of ways in which student learning can be benchmarked, including:

- 1 national standards for primary schools
- 2 achievement at levels 1–3 on the New Zealand Qualifications Framework for secondary school students
- 3 key international studies of literacy and numeracy achievement.

However, currently none of these measures allow a comparison with the learning outcomes of non-disabled students.

#### Ombudsman complaints

Access to funding and support services for disabled students continues to be a common theme among the complaints made to the Ombudsman, in all education sectors.

Complaints often involve differences between the expectations of parents and/ or students, the services an education provider has arranged, and the funding available.

Some complaints arise when a student with a disability has been excluded or expelled from a school due to behavioural issues associated with their disability. There is a question as to whether the current law relating to suspension, exclusion and expulsion provides for sufficient consideration of a student's disability. Other complaints involve dissatisfaction with the level of assistance provided to students with disabilities for assessments and examinations.

### Bullying

All three IMM partners continue to be of the view that bullying at school is a particular issue for students with disabilities. Preventing and responding to bullying in schools requires a consistent response in all schools if students are to be able to learn in a safe and inclusive physical and emotional environment.

In November 2013, a cross-sector group of government agencies, education

sector unions and other interested groups published draft guidelines for schools on preventing and responding to bullying. (These groups included the Human Rights Commission, the Ombudsman and the Office of the Children's Commissioner.) The draft guidelines note that one of the reasons why students may be at greater risk of being bullied is because they "have a disability, special educational needs, or mental health issues".<sup>78</sup> The IMM considers that the final guidelines would benefit from more detailed information about addressing the disability-specific bullying directed at disabled students.

The Ministry of Education's *Positive Behaviour for Learning* (PB4L) initiative represents a major step towards ensuring that New Zealand schools are safe, positive and inclusive places for all students to learn and grow. It is built on the foundation that positive behaviour can be learnt and difficult, disruptive behaviour can be unlearnt. PB4L moves away from seeing individual students as a "problem", and towards proactively changing the environment around them to support positive behaviour. The IMM welcomes such an approach.

Within the PB4L framework, *Wellbeing@ School* provides student and staff surveys and self-review tools in two areas.<sup>79</sup> Its first toolkit helps schools explore the extent to which they are creating a safe and caring climate that deters bullying. Then, in October 2013, *Wellbeing@School* launched

its inclusive practices tools. These enable schools to explore the extent to which they are including all students in all aspects of school life.

Such school-based measurements are important. In addition, there is a need to systematically measure New Zealand's overall performance in addressing school violence and bullying. In 2012 this was recommended by both the United Nations Committee on Economic, Social and Cultural Rights<sup>80</sup> and New Zealand's Law Commission.<sup>81</sup>

The IMM recommends that whole of school approaches to bullying, such as PB4L, pay increasing attention to the experiences of disabled students. This should include:

- measuring the types and extent of bullying experienced by disabled students, and
- 2 documenting the steps taken to ensure schools are safe and affirming of disabled students.

## Key issues

The IMM supports the initiatives taken to make schools more inclusive. However, four issues are of particular concern. There is the need for:

- 1 an enforceable and specific right to education
- 2 learning outcomes and achievement information about disabled students

- 3 a comprehensive transition plan to take New Zealand from a mixed segregatedinclusive education system to a fully inclusive education system, and
- 4 targeted measures to address bullying of disabled students.

The establishment of an enforceable right to education should include a review of sections 8–10 of the Education Act 1989. This review should also consider whether the Ministry of Education should be provided with statutory powers of direction in cases where a disabled student is being prevented from enrolling in, or attending, school.

## Recommendations 23, 24 and 25

#### **Recommendation 23**

That the Government establish an enforceable right to inclusive education.

#### **Recommendation 24**

That the Ministry of Education implement whole of school anti-bullying programmes that ensure that schools are safe and nurturing places for disabled students.

#### **Recommendation 25**

That the Ministry of Education establish initiatives that promote the value of difference and affirm the identity of disabled students.

## <mark>Article 25</mark> Health

The Disability Convention states disabled people have the right to enjoy the highest attainable standard of health. They have the right to the same range, quality and standard of free and affordable health care as everyone else, including sexual health and fertility services. To achieve these rights governments should ensure:

- 1 healthcare professionals are trained to provide disabled people with the same quality of care as others, on the basis of free and informed consent
- 2 health services and treatment are available for a person's specific impairment; and services should ensure impairments and health conditions are identified early and that people get early support, and
- 3 health and life insurance policies do not discriminate against disabled people and are fair and reasonable.

#### Health outcomes

The 2011/2012 IMM report highlighted concerns about health outcomes for disabled people. There were particularly significant disparities in life expectancy between people with an intellectual/ learning disability and their peers. The IMM report included information from the Ministry of Health's 2012 report Health Indicators for New Zealanders with Intellectual Disabilities. The Ministry's report showed that, as at 2011, life expectancy of males with intellectual/ learning disability was 18 years less than other New Zealand males.<sup>82</sup> For females with learning disability, it was 23 years less than other New Zealand females. These disparities are not new. In 2003, the National Health Committee had found that the health status of people with learning disabilities was worse than that of the average population across many indicators, including life expectancy.<sup>83</sup>

Special Olympics New Zealand's Athlete Health Overview was released in November 2013. It provided information about the visual, audiological, dental and podiatric health and mobility of more than 2000 individuals with intellectual/learning disability.<sup>84</sup> This report indicated that nine out of ten athletes failed one of the eye screening tests and one in five athletes presented with an internal eye problem at the 2009 Summer Games. In addition, two out of three athletes had poor oral health. Serious undetected and untreated ear conditions were also identified. The report referred to available data about the health status of people with an intellectual/learning disability. It noted that there had been no comprehensive

or systemic response to the health needs of New Zealand children and adults with intellectual/learning disabilities.<sup>85</sup>

This issue was highlighted in the Commission's submission to the United Nations Human Rights Council as part of the 2013/2014 Universal Periodic Review (UPR) process.<sup>86</sup> The Commission noted that the New Zealand Government, in its first UPR report in 2009, had advised the Human Rights Council that there was a work plan in place to respond to the health disparities of people with intellectual disabilities. However there had been minimal evidence since then of a commitment to address this systemic abuse of the health of people with learning/intellectual disabilities.<sup>87</sup> In its separate submission, the IMM reiterated these concerns, noting that although some district health boards have plans in place, overall there had been minimal progress.<sup>88</sup>

In 2011/2012 the IMM reported that the Ministry of Health was finalising a review of effective health programmes for people with intellectual/learning disability that would be published in late 2012. In December 2013 the Ministry released a literature review and a set of five indepth case studies on successful health interventions and tools for people with an intellectual learning disability.<sup>89</sup> The IMM reiterates the need for a comprehensive plan to respond to the health needs of people with an intellectual/learning disability.

#### Health and Disability Commissioner

The Health and Disability Commissioner (HDC) received 248 complaints about disability services between 1 July 2012 and 31 December 2013. The HDC's 2012/2013 annual report provides further analysis of the disability related complaints received by the HDC and the HDC advocacy service over that period.

The Code of Health and Disability Services Consumers' Rights (the Code) sets out ten rights for disability services consumers. Under the Health and Disability Commissioner Act 1994, the HDC is charged with promoting and protecting the rights of disability service users.

The principal role of the Deputy Health and Disability Commissioner (Disability) is to assist the Commissioner to achieve the functions prescribed in the Act. These include the effective leadership of HDC's disability initiatives. The HDC also has a Consumer Advisory Group (CAG) that includes four disabled people. The CAG provides representative consumer advice to the HDC on strategic and operational health and disability issues.

Advocates from the Nationwide Health & Disability Consumer Advocacy Service visit all disability residential homes each year to raise awareness of HDC's role and the services it provides. During their visits the advocates talk to disabled people about their rights and how to make complaints.

The advocates provide disabled people with informational brochures in a range of accessible formats and languages. HDC advocates also educate providers on their duties and responsibilities to respect disability services consumers' rights.

The HDC's annual work programme includes specific initiatives focusing on the disability sector, as outlined below.

The HDC hosts an annual national disability conference. Approximately four hundred people attend this conference including disabled people, and representatives from DPOs, disability service providers and various affiliated government agencies. The 2013 year conference was titled "Another Complaint, Another Improvement – Towards Better Disability Services". It encouraged both consumers and providers to view complaints as a tool for quality improvement.

The HDC also delivers regional consumer seminars and develops educational resources to increase disabled peoples' awareness of their rights and to improve their experience of health and disability services.

The HDC has developed, and is currently supporting the implementation of the "health passport" in district health boards across the country. The health passport contains information about how a disabled person wants others to communicate with and support them. It is designed to assist nursing, medical and support staff to understand the care, communication and support needs of a person with a disability. The objective of the health passport is to improve the experience for disabled people utilising health and disability services.

#### **Key issues**

The IMM believes the health status of people with intellectual/learning disability requires urgent attention. It is unacceptable that a group in New Zealand with such poor health outcomes has not received remedial attention despite the length of time since these concerns were first identified.

## **Recommendation 26**

That the Ministry of Health work with people with intellectual/learning disabilities and their organisations to establish a comprehensive health monitoring and improvement programme.

## Article 26 Habilitation and rehabilitation

The Disability Convention requires governments to take effective and appropriate measures to enable disabled people to attain and maintain:

- 1 maximum independence
- 2 full physical, mental, social and vocational ability
- 3 full inclusion and participation in all aspects of life.

The Government must organise, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services.

The Ministry of Health funds disability support services for people with intellectual, physical and/or sensory disabilities, who are generally under 65 years of age. District health boards fund long-term support services for people with long-term mental health needs, people with disabling chronic health conditions and older people with disabilities.

The Ministry of Health funds a wide range of supports for people over 65 years of age. These include housing modifications, equipment, hearing aids and support services for people who are blind or have a vision impairment and people who are deaf or have a hearing loss. For people who have suffered a personal injury, ACC provides cover and entitlements, including physical, social and vocational rehabilitation.

In its 2011/2012 report, the IMM recommended that:

- 1 the Ministry of Health consider statutory recognition of the entitlement to home modification assistance as an element of disability support services
- 2 ACC review the vocational rehabilitation/independence assessment process, particularly in light of the employment opportunities that are realistically available in the current economic climate
- 3 ACC review current requirements for the regular provision of medical certificates and attendance at specialist assessment by persons with long-term injuries
- 4 the Ministry of Business, Innovation and Employment consider updating the level of reimbursement for ACC review costs set out in regulation.

There is an ongoing need to monitor progress in these areas.

#### Case example: Surcharge for audiology equipment

The Ombudsman investigated a complaint about the requirement by the Whanganui District Health Board (the Board) to pay a surcharge for audiology equipment. On being fitted for the equipment, the complainant was required to pay a 10% surcharge.

The Ombudsman formed the opinion that it was unreasonable for the Board to impose a flat surcharge of 10% on audiology equipment, regardless of the actual costs involved in supplying and fitting that equipment. Overall, the Ombudsman considered it would be more appropriate for the Board to charge a rate that reflected the actual cost to consumers on a *pro rata* basis.

The Board accepted the Ombudsman's opinion, and agreed to undertake a costing exercise to ensure that fitting charges related to the cost of the actual service provided.

#### Unmet needs

Many disabled people report their disability-related needs are not being met. The IMM's 2011/2012 report documented unmet need in relation to care, transport and travel, and employment. This was based on data from the 2006 Census and Disability Survey.

The postponement of the 2011 Census and Disability Survey until 2013, because of the Canterbury earthquakes, means there is no updated data available to measure progress against these indicators. Those statistics will begin to be released from mid-2014 onwards. A comprehensive assessment of changes between 2006 and 2013 will therefore be included in the IMM's next report.

## Article 27 Work and employment

The Disability Convention provides that disabled people have the right to earn a living through work that they freely choose and in workplaces that are accessible and inclusive. Governments should promote this right to work by:

- ensuring disabled people are protected against discrimination in employment and have access to reasonable accommodation
- 2 ensuring disabled people enjoy fair working conditions, the same union rights as others and protection against harassment
- 3 employing disabled people in the public sector
- 4 promoting career opportunities for disabled people, including through access to training opportunities
- 5 promoting self-employment and employment in the private sector
- 6 supporting disabled people to stay in and get back into work.

### United Nations guidance

In May 2012, the United Nations Committee on Economic, Social and Cultural Rights recommended that the New Zealand Government:

- introduce incentives and other special measures to promote the employment of persons with disabilities and
- 2 explicitly regard denial of reasonable accommodation as a form of discrimination.<sup>90</sup>

#### Equal employment opportunities

Equal employment opportunities are covered in the Local Government Act, the State Sector Act and the Crown Entities Act. The State Sector Act defines equal employment opportunity programmes. They are programmes aimed specifically at identifying and eliminating all aspects of policies, procedures and other institutional barriers that cause or perpetuate inequality.<sup>91</sup>

As noted in the IMM's 2011/2012 report, the 2006 Disability Survey showed that disabled people were significantly more likely to be unemployed than their nondisabled counterparts. They were also less likely to be employed.

An analysis of the three disability surveys to date indicates the employment status of disabled people has hardly improved in the decade from 1996 to 2006. In all surveys over that period, disabled people aged 15-64 were more than twice as likely as non-disabled people to not be in the labour force. They were considerably less likely to be employed.<sup>92</sup>

Other regular employment surveys such as the quarterly Household Labour Force Survey and the Income Survey do not provide data on outcomes for disabled people. Such data is increasingly important in order to monitor the impact of recent welfare reforms.

Disabled Persons Assembly NZ and Workbridge established the Disability Employment Forum (DEF). This brings together disabled people, DPOs, service providers and employers to find solutions to enable more disabled people to find and keep satisfying work. The DEF unanimously agrees there is an urgent need for a long term, whole of government strategy to provide disabled people with pathways to employment. It is working with the Employers Disability Group and the Ministry of Social Development to establish a long term action plan on employment.

The DEF has also been involved in number of other initiatives:

- a survey on improving existing employment services to both providers and users of services
- 2 a report commissioned by the Ministry of Business, Innovation and Employment on work experience and internships and
- 3 the development of a portal website for employers.

Its recent focus has been on building employer confidence.

# Employees with disabilities in the public service

Information about the employment of disabled people has not been published in the State Services Commission's annual Human Resource Capability Survey since 2002.

A report on disabled people in the public service, *Enabling Ability*, was produced in 2008 and relied on the Statistics New Zealand 2006 Disability Survey to estimate the percentage of public service employees with disabilities.<sup>93</sup> The report said, "10.4% of the public service proxy workforce has a disability, compared with 11.2% of the total employed labour force."

In 2013, the Human Rights Commission, as part of a broader equal employment opportunity questionnaire, asked all government departments whether they collected disability data. Those that did were asked how they collected this data and how many people with disabilities were employed in their departments. Of the 29 departments, 25 collected disability data.

The questionnaire asked people to selfidentify, as they do with gender and ethnicity. Guidance was provided which used the World Health Organisation's and Statistics New Zealand's definition of disability. Of the 25 departments collecting disability data, 12 provided employees with a facility for updating that information. Twenty four departments provided information about the number of employees identifying as having a disability, covering 88 per cent of all public sector employees.

The rate of employment of people with disabilities based on that return rate is 3.7% of the public service workforce. The range is from 10% to 0%. In eight of the departments that collected disability data, no staff said they had a disability.

Information about representation of disabled people on their senior management team was returned by 25 departments, covering 96% of the total public service. The percentage of people with disabilities on senior management teams (Tier 1–3) was 2.4% across the public service. The range was 11.5%–0%.

The IMM would expect a greater proportion of disabled people in some occupations and industries, such as disability support services. This recognises that firsthand experience of and knowledge about disability is a specific competency for these jobs.

## **Recommendation 27**

That the Chief Executives' Group on Disability Issues, in conjunction with DPOs:

 promote initiatives to increase the employment of people with disabilities in the public service, and 2 further develop mechanisms and resources to ensure that reasonable accommodations for the employment of disabled people are understood and implemented in the public service.

#### Minimum wage exemptions

Article 27 comprehensively sets out disabled people's right to equal employment opportunities and conditions of work. Disabled people have the same access to work-related legal safeguards as all other workers. These include trade union rights, holidays, health and safety, and protection against harassment and unfair dismissal. Wage rates, including minimum wage rates, make no distinctions between disabled and non-disabled people. A labour inspector can only issue a minimum wage exemption permit (MWEP) if an employee has a disability which significantly prevents them from earning the minimum wage.

Specifically, the Minimum Wage Exemption Act enables a labour inspector to issue a minimum wage exemption permit to a worker if the inspector is satisfied that:

- 1 the worker is significantly and demonstrably limited by a disability in carrying out the requirements of his or her work
- 2 any reasonable accommodations that could have been made to facilitate carrying out the requirements of the work have been considered by the employer and the worker, and

3 it is reasonable and appropriate to grant the permit.

Various wage assessment tools are accepted for the purpose of exemptions. Before accepting a minimum wage assessment tool, Labour Inspectors have to consider it against set criteria. For example, an assessment tool should be balanced and look at both productivity and individual competencies. It should be transparent and clearly show how the assessment is linked to wage rates and how the wage rate is calculated. Disability advocates have raised concerns that the tools used do not appear to be consistent.<sup>94</sup> The IMM understands that the effectiveness of the minimum wage exemption process has yet to be reviewed.

# Table 5: Minimum wage exemption permits issued: 2007–2013

| Financial year | Number of<br>permits issued |
|----------------|-----------------------------|
| 2007–08        | 1188                        |
| 2008–09        | 1344                        |
| 2009–10        | 1200                        |
| 2010–11        | 1300                        |
| 2011–12        | 1052                        |
| 2012–13        | 1039                        |

Source: Labour Inspectorate, Labour & Commercial Environment Group, Ministry of Business, Innovation & Employment (MBIE)

There has not been a review of the MWEP system as recommended in the IMM's

2011/2012 report. Operational changes have been undertaken by the Labour Inspectorate of the Ministry of Business, Innovation and Employment. These include increasing the length of time that permits may be issued for (up to two years) and being able to renew permits without a meeting of all the parties. The IMM is concerned that, as a result of these changes, the Labour Inspectorate will have increased responsibility and power over a group of disabled people who have very limited employment opportunities and rely on others for advocacy support.

While the number of individuals on MWEPs is decreasing it is not clear why this is happening. It is also unclear whether the trend represents an improvement in the employment circumstances of those previously on MWEPs. For both these reasons the IMM continues to recommend a review be undertaken, in the 2014 calendar year, of the purpose and operation of the minimum wage exemption permits. The aim of this review would be to ensure that MWEPs are the most effective way to protect and realise disabled peoples' employment rights.

## **Recommendation 28**

That the Ministry of Business, Innovation and Employment, working with the Disability Employment Forum, conduct a full review of the minimum wage exemption permits system by 31 December 2014, to ensure it reflects the best approach to employment rights for disabled people.

## Article 28 Adequate standard of living and social protection

The Disability Convention recognises that disabled people have the right to an adequate standard of living for themselves and their families, including adequate food, clothing and housing. This encompasses the rights to access:

- 1 social protection and poverty reduction programmes
- appropriate and affordable services, devices and other assistance for disability-related needs
- 3 disability-related expenses for those living in poverty
- 4 public housing programmes, and
- 5 retirement benefits and programmes.

#### Freedom from poverty

The 2006 Disability Survey found that disabled people are more likely than nondisabled people to have a low annual personal or household income. They also live in the more deprived areas of New Zealand. This data has been broken down to show rates for Māori and non-Māori. In all cases the rates for Māori disabled people were significantly higher than for non-Māori. For example, 42 per cent of disabled Māori lived in the most deprived areas (NZ Deprivation Index deciles 9–10), compared to 17 per cent of non-Māori people with disabilities.<sup>95</sup> Eighteen per cent of children with a disability lived in families with an income of less than \$30,000 per year.<sup>96</sup>

A 2004 research report identified that a quarter of people who received the domestic purposes benefit had a child with a disability.<sup>97</sup> The 2006 Disability Survey found that 28 per cent of disabled children lived in one parent homes, rising to 31 per cent for children with high support needs.<sup>98</sup> Data analysed in a 2008 report commissioned by the Children's Commissioner and Barnados confirmed that children with disabilities appeared to be significantly over-represented in beneficiary families. It concluded that it was vital to set measurable national targets for reducing and eventually eradicating child poverty. There is also a strong case for specific goals to address the levels of child poverty experienced by disabled children. 99

In 2012 the Children's Commissioner established an expert advisory group on solutions to child poverty (EAG). The group's working paper on child poverty and disability critiqued the dearth of national information about the extent to which disabled children and families experience financial and material hardship. <sup>100</sup> The EAG's final report noted that the Disability Survey does not include data on children with disabilities who live in poverty. Nor does it include children who live in low-income households where a parent has a disability. It recommended that the Government should commission research to clarify:

- how many children are living with a disability or are being cared for by a parent with a disability
- 2 how many of those children are living in poverty, and
- 3 what the effects are on these children.<sup>101</sup>

The EAG also recommended establishing of a comprehensive framework for measuring child poverty and setting targeted reductions. The EAG proposed that this include both income-related measurements and targets and child poverty related indicators. These include health, education, social inclusion, disability and quality of life measures.<sup>102</sup> The EAG called for submissions on its proposal. CCS Disability Action welcomed the importance of focusing on outcomes for disabled children.<sup>103</sup> However it strongly recommended against an indicator based on disability, especially if it was "based on measures such as disability prevalence and congenital anomalies at birth". Instead it recommended that other indicators should be disaggregated to identify outcomes for disabled children.

CCS Disability Action highlighted the interconnections between financial pressures and other rights. Specifically it noted that 29 per cent of families who responded to its 2011 *Families' Choices* research said that searching for a suitable school for their disabled child had caused financial strain.<sup>104</sup>

#### The right to social security

In addition to Article 28 of the Convention, the right to social security is set out in other United Nations instruments that New Zealand has ratified. This is most notably in Articles 9 and 10 of the International Covenant on Economic. Social and Cultural Rights (ICESCR). Social security, and its interface with the tax system, redistributes resources. It enables people to have an adequate standard of living so they can participate in their communities and attain other rights. These include the rights to equality, education, work, housing and the highest attainable standard of health. Article 28 is also closely related to social inclusion and the right to live independently and be included in the community (Article 19).

Countries are required to progressively realise the right to social security by taking measures "to the maximum extent of their available resources". Guidance from the United Nations Committee on Economic Social and Cultural Rights has highlighted the importance of non-discrimination, particularly for groups such as disabled people, women and children.<sup>105</sup> Accessibility is one of the key elements of the right to social security and means that eligibility criteria must be reasonable, proportionate and transparent. In 2013, DPOs and the Commission raised their concerns that replacing the Invalid's Benefit with the new Supported Living Payment could be particularly confusing for people with a learning disability. This was because an existing service provided to disabled people through the Ministry of Health already used the name "Supported Living Payment".

The Commission made a submission in November 2012 on the Social Security (Benefit Categories and Work Focus) Amendment Bill. In it the Commission critiqued the introduction of work availability and pre-benefit obligations (and corresponding sanctions) on disabled people. The Commission recommended that these changes should not be introduced unless several conditions were met. These were that appropriate work opportunities exist, disabled people's general living arrangements would not be significantly compromised and their right to reasonable accommodation had been protected.<sup>106</sup>

DPOs and some beneficiary advocacy services fear what may happen to disabled people who are moved from the Supported Living Payment onto Jobseeker Support (previously called the Unemployment Benefit). They are concerned disabled people could have a lower level of income with limited opportunities or assistance to move into decent work.<sup>107</sup> Another accessibility issue is the apparently low take-up of the Child Disability Allowance (CDA) by families with a disabled child. This allowance is a weekly non-taxable payment of approximately \$45 made to the main carer of a disabled child or young person. It is available for any child under 18 years assessed as needing constant care and attention for at least 12 months because of a serious disability. As at September 2012, this allowance was paid to 36,274 carers covering approximately three per cent of New Zealand children. This is considerably less than the 10 per cent of children estimated as having a disability. The number of new CDA allowances granted has also fallen from 11,027 in 2007/2008 to 6,702 in 20011/2012.108

The EAG noted that this apparently low take-up of the CDA may mean that the eligibility requirements are too limiting. Or some families may simply not be aware of this available payment. In December 2012, it recommended that the government annually calculate and publish information on the take-up of the CDA, given particular concerns about the potential low takeup of this allowance amongst poorer families.<sup>109</sup>

When preparing its next report, the IMM will be asking the Ministry of Social Development to contribute detailed quantitative and qualitative information. This should include analysis about the impact of welfare reforms on disabled people, disabled people's uptake of benefits and their employment outcomes.

#### Housing

Many disabled people experience great difficulty obtaining accessible housing. Housing affordability is a significant issue and is compounded when a disabled person is not able to share costs by living with others. Living alone may be the most appropriate choice for some disabled people, including to accommodate someone's disability or experience of mental illness. However, high housing costs mean that increasingly this is not an affordable option. Mental health housing providers have reported an ongoing increase in homelessness because of rising housing costs.

Feedback to the EAG from the disability sector supported the need for accessible housing based on the specific needs of the child or adult with a disability. This included, for example, that housing accessibility be a quality indicator in the EAG's proposed warrant of fitness for rental housing.

The following discussion about the right to housing focuses on the experiences of disabled people as a result of the Canterbury earthquakes. It pays particular attention to the barriers faced by people with experience of mental illness.

#### Housing issues in Canterbury

The housing pressures resulting from the Canterbury earthquakes impact disproportionately on many disabled people. These include disabled people on low incomes, those who are trying to find accessible housing from a limited housing pool and those who face discrimination when trying to access rental accommodation.

For people experiencing mental illness there is added pressure because the Canterbury earthquakes destroyed most of the boarding houses in the city centre. About 200 single-bed units on the city's eastern fringe were also destroyed. The incoming workforce now uses much of the remaining single-bed dwelling stock.

Comcare Charitable Trust (Comcare) provides housing services for people experiencing mental illness. Since the Canterbury earthquakes, the Trust has reported a 10 per cent rise in the number seeking accommodation because they are "living with another household", "moving around from place to place" or are living in uninhabitable housing.<sup>110</sup> Overall, Comcare has seen an increase in referrals, with about one third of all referrals being for people categorised as "homeless".<sup>111</sup>

The Canterbury District Health Board is the only DHB that directly contracts housing services. This role, and the increased funding it has provided to Comcare, has been welcomed by NGOs and mental

health service users. However people with experience of mental illness still struggle to find accommodation, often due to a shortage of suitable housing. In December 2013 the Human Rights Commission published *Monitoring Human Rights in the Earthquake Recovery*. It included the following summary of the wider impact of housing pressures on people with experience of mental illness.<sup>112</sup>

> Limited affordable social housing has resulted in delayed discharges from mental health hospitals and residential services. People with experience of mental illness who no longer require residential care have remained in hospital because they could not find suitable housing. Although Housing New Zealand prioritises those in inpatient care, the

waiting time has increased from two weeks to four months or more. Some inpatients seeking social housing have been informed of a waiting list of at least a year. As a result of an inadequate supply of affordable housing, people are not able to access the right care at the right time thereby compromising their recovery.<sup>113</sup>

Low supply and high demand for single bed accommodation has seen sharp rises in private sector rents in Canterbury. The accommodation supplement is a weekly payment provided by the government which helps people with their rent, board or the cost of owning a home. It is income and asset tested and not available to people renting a Housing New Zealand property.

#### Case study: Joe's story

Joe smiles. After all he has just had a shower and eaten at the drop-in centre, where lunch was catered at a meeting for people to talk about mental illness and housing issues. For a long time Joe used mental health accommodation services. He was at home, several floors up, when the Christchurch earthquake struck on 22 February 2011. Joe left his home that day, has not been back, and never again wants to venture above the ground floor in any building.

Over the last three years Joe has stayed for short periods with others, but it has not worked out. He cannot afford to rent his own place, and has not been able to find any other ground level accommodation options. Joe carries his backpack close to him. It contains his sleeping bag and a good quality ground mat. It is enough to keep him warm and dry. The Commission concluded that the accommodation supplement level for Christchurch no longer reflects the local housing costs.<sup>114</sup>

The Commission noted the additional housing pressures faced by disabled people and suggested that the disability allowance be used more flexibly to cover housing costs. The Ministry of Social Development considers that the existing accommodation supplement is a better way to address accommodation costs. This is because it, unlike the disability allowance, is designed specifically to address housing needs.

## **Recommendation 29**

That the Ministry of Social Development:

- enable the disability allowance to be used more flexibly, including to cover housing costs and
- 2 consider and report on the appropriateness of increasing the accommodation supplement for Christchurch to be commensurate with Auckland and Wellington.

## Article 29 Participation in political and public life

The right to vote and participate in political and public life is integral to a strong and functioning democracy. The principle of "Nothing about us without us" can only be achieved if disabled people have the same ability to participate in political and public life as other citizens.

The Disability Convention states that disabled people have the same political rights and should be able to enjoy them in the same way as others. Governments must ensure disabled people are able to:

- 1 access polling stations
- 2 access material about elections and polling stations
- 3 vote in secret or with whatever help is needed from another person
- 4 be elected to public office
- 5 form and join disabled people's organisations.

#### Voting

Section 12 of the New Zealand Bill of Rights Act 1990 provides that every New Zealand citizen over the age of 18 years has the right to vote at parliamentary elections, which shall be by secret ballot.

The Electoral Act and associated regulations have various provisions that

assist disabled people to take part in elections. These include providing:

- 1 assistance with completing enrolment
- 2 accessible voting places
- 3 voting facilities in hospitals and similar institutions and
- 4 electoral staff, or allowing a nominated person, to assist voters.

For the last three general elections, the electoral authorities have developed a disability action plan with the involvement of disability organisations. This has resulted in a number of initiatives and resources including voting information in Easy Read and NZSL and captions on television advertisements. There is also information about accessible voting places, information in accessible formats and a plain English guide to voting.

The electoral authorities provide disability awareness training for returning officers and election day staff, table top voting at every voting place, and NZSL interpreters at some polling places. Funding has also been provided for the "Get Ready to Vote" resource for people with an intellectual/ learning disability. For the 2012 review of Mixed Member Proportional (MMP) voting system, information about the review was produced in NZSL and a number of submissions were received in NZSL.

The Electoral Commission conducts a review of each election, including a survey of voters and non-voters with a disability. The last survey was held following the 2011 general election. It showed a high level of awareness and approval of the measures the Electoral Commission has undertaken to make the voting process more accessible.<sup>115</sup>

For the 2014 general election the Electoral Commission will be implementing measures to enable more disabled people to vote in secret. These include telephone dictation voting for voters who are blind, partially sighted or who have a physical disability that means they are unable to mark the ballot paper without assistance.

The Local Government Minister, the Hon. Chris Tremain, announced in September 2013 that a trial of online voting will take place in the 2016 local authority elections.<sup>116</sup>

A working party to consider the feasibility of online voting in local authority elections has been established. The terms of reference for this work include a requirement to look at the opportunities and risks that online voting presents, including issues of access.<sup>117</sup> The working party will provide advice that will form the basis for implementing online voting as a modern, safe, secure, accessible and engaging method for conducting local authority elections. The working party's report was due to be provided to the Associate Minister of Local Government in May 2014 for consideration. It will be used by the Department of Internal Affairs to inform next steps.

#### Political representation

In 2011/2012, the IMM reported on the experiences of Member of Parliament Mojo Mathers and her request for electronic note-taking services. The issue received media exposure and threw a spotlight on accessibility requirements in Parliament. In May 2013 the Government Administration Committee began an inquiry into the accessibility of services to Parliament. The terms of reference included:

- the accessibility of parliament
   buildings, MPs in their out of
   Parliament offices, Parliament's public
   processes and public events
- 2 the accessibility of Parliamentary information and communications including public information such as Parliament's website, notices and pamphlets and the accessibility of Parliament's communications technologies, and
- 3 disabled people being able to stand for election and effectively hold office in Parliament.

The terms of reference drew significantly on the requirements of the Disability Convention.

#### Candidate information

Blind Citizens New Zealand is a member of the Convention Coalition. It reports that in the last local body elections Auckland voters were unable to get even the most basic candidate information in accessible formats. All registered voters received voting packs in the mail that contained both information on candidates and the means to cast their vote but the Vote Auckland website was not accessible.

Clive Lansink, National President of Blind Citizens New Zealand, stated:

> I'm pretty savvy with technology, having worked with computers all my life, but I certainly couldn't make it work. I tried entering my address, I tried searching for my local ward and community board, I even tried viewing all candidates, and nothing useful was returned. Just to compare, I quickly tried the Vote Wellington website and I congratulate them on how brilliantly easy it was to look up all the candidates and read what they had to say about themselves. At least this shows it can be done, and it is very disappointing that ... Auckland has somehow stuffed this up... of course we do miss out on all the billboards and most other publicity that goes on in our community. But we shouldn't miss out on the information that is formally provided by candidates and made available to all voters. This information needs to be clear and

available in a variety of formats so everyone who wants to can get it.<sup>118</sup>

#### **Key issues**

Within its current mandate, the Electoral Commission does a very good job of ensuring all aspects of the national electoral process are accessible to disabled people. The IMM strongly supports the Electoral Commission's initiative to provide telephone dictation voting at the 2014 general election. The recent local authority elections demonstrate there is still a long way to go in providing consistent access to the local government electoral process for disabled people. Some authorities, such as the Wellington City Council, provided election and candidate information on an accessible website. However, other councils had no accessible alternatives to print information.

Broader issues that are beyond the role of the Electoral Commission include needing to increase the visibility of disabled people as candidates and to ensure equitable access to pre-election campaign resources. Disabled people's access to information about local government candidates would be improved if the new Government website standards, which cover central government elections, were also extended to encompass local government.

The IMM awaits with interest the report of the Government Administration Committee's 2013 *Inquiry into the accessibility of services* to Parliament. Submissions closed in July 2013, followed by oral hearings, and the Committee was considering that evidence as the IMM's report was being finalised.<sup>119</sup>

## Recommendations 30, 31, 32 and 33

#### **Recommendation 30**

That the Electoral Commission ensure that the next general election in 2014 is conducted in a way that allows independent and secret voting for all eligible voters.

#### **Recommendation 31**

That the Department of Internal Affairs' working party set up to trial online voting in the 2016 local authority elections adopt accessibility as a key success measure for the trial.

#### **Recommendation 32**

That funding is provided for party political broadcasts and televised debates for the 2014 general election to be available in New Zealand Sign Language and captioned.

#### **Recommendation 33**

That the requirements of all democratically elected members to government boards and public authorities are reasonably accommodated to support them to carry out their duties.

## Article 30 Participation in cultural life, recreation, leisure and sport

Countries are to promote participation in cultural life, recreation, leisure and sport by ensuring provision of television programmes, films, theatre and cultural material in accessible formats. Other requirements include making theatres, museums, cinemas and libraries accessible. Countries must also guarantee that persons with disabilities have the opportunity to develop and utilise their creative potential not only for their own benefit, but also for the enrichment of society. Countries are to ensure the participation of disabled people in mainstream and disability-specific sports.

The Disability Convention states that:

- disabled people have the right to access books, plays, films and television in accessible formats
- 2 disabled people have the right to access libraries, cinemas, theatres, museums and other places of historical or cultural interest
- disabled people have the right to
   develop and use their creative, artistic
   and intellectual potential
- 4 governments should ensure laws protecting the copyright of books and music do not stop disabled people enjoying real access

- 5 disabled people's different cultures and languages must be respected and supported, including deaf people's language and culture
- 6 governments should do everything to support disabled people to take part in mainstream sport and disability specific sport and
- 7 governments should do everything they can to make sure disabled children can take part in play, leisure and sporting activities, in and out of school, on an equal basis as other children.

#### Captioning

There are limited opportunities for blind, visually impaired, Deaf and hearing impaired people to consume television, cinema, DVDs, and the internet in accessible formats.

Between 2007 and 2011, the Commission received 19 complaints and enquiries in relation to captioning issues for deaf and hearing impaired people. These complaints related to captioning on television, DVDs and internet broadcasts and the lack of caption-enabled television in hotels. In the 2012/2013 period, there were three complaints and enquiries relating to lack of captioning on television and DVDs and one complaint about TV sign language not being clear.

The Broadcasting Act established NZ On Air as the independent government funding agency. Its functions include reflecting and developing New Zealand identity and culture through broadcasting, including television, radio and online audio-visual media. One of NZ On Air's functions is to ensure that a range of broadcasts is available to provide for the interests of people with disabilities.<sup>120</sup>

## Key issues

The Captioning Working Group (CWG) is a partnership between Deaf Aotearoa New Zealand, the Hearing Association, and the National Foundation for the Deaf. It has been advocating for full captioning of television and movies since 2011. In November 2013 the Media Access Charitable Trust officially launched *Able*, a stand-alone television captioning and audio description service. *Able* is fully funded by NZ On Air as an independent entity. It has taken over the service originally provided by TVNZ.

To date 19 television channels have some level of captioning. However, a survey of free-to-air television indicated that only 23 per cent of non-repeated programming is captioned.<sup>121</sup> Free-to-air channel Prime has no captioning despite numerous attempts by the CWG to change this situation. TV on Demand services at both TVNZ and TV3 are not captioned. Currently NZ On Air has a budget of \$1.9 million for captioning and audio description services. The Minister of Broadcasting, the Hon Craig Foss, has indicated there are currently no plans to introduce legislation to make captioning mandatory. But NZ On Air has advised the IMM that it is working to increase funding for captioning over time. The amount of money available for captioning and audio description has also doubled over the past decade.

In all, a total of more than 250 hours of captioned programming (including repeats) is now on television every week. Captioning provided by *Able* covers more than 80 per cent of prime time programmes on the four main networks. Sky provides captioning for 14 of its pay television channels, with between 5–75 per cent being captioned. *Able* makes captioning decisions based on viewing patterns and to reflect engagement with the deaf and hearing-impaired communities.

As the IMM's 2011/2012 report noted, the number of people with hearing and sight impairments is likely to increase significantly in New Zealand, given the ageing population. The way people consume broadcasting programmes is also changing rapidly. Accessible services are not necessarily keeping up with people's needs. Programmes screened with captions on television are not available with captions online.

### Case example

In Auckland, THE EDGE events centre introduced the SIGNAL programme for blind people in 2010. It trained six audio describers, provided disability awareness training to the ushers, and hired audio description equipment. A user describes how the process works:<sup>122</sup>

THE EDGE emails out the programme in advance so it can be read with my screen reader. Then before the show, a touch tour and audio describer add the visual detail not in the print programme. And finally, the show begins! The commentary is slotted in between dialogue and any sung words. Describers take care not to talk over sound effects that the director wants us to hear. And at the end, we are told who is coming on stage for the curtain calls so we can clap our favourites – just like everyone else does.

It's a real pleasure for me to be back in the theatre and concert community – all thanks to audio description.

There is a need for a comprehensive approach to the accessibility of broadcasting. This should recognise changing patterns of media consumption including the need for online captions and audio description when viewing programmes on demand.

## Recommendations 34 and 35

#### **Recommendation 34**

That the Ministry of Culture and Heritage develop an industry-wide voluntary code of practice for broadcasting accessibility in consultation with broadcasters and consumers, taking into account international good practice.

#### **Recommendation 35**

That NZ On Air develop a comprehensive policy on the accessibility of programmes that it funds or supports, in cooperation with broadcasters and consumers, to clarify accessibility objectives and targets.

### Live theatre audio description

Audio description is additional narration of television, cinema or live performance. A narrator describes the visual aspects of the production or event to blind or vision impaired audience members during the gaps in dialogue.

Audio description has become available in New Zealand for live theatre. It has not been a uniform introduction, with provision limited to some main centres only. Funding is inconsistent, coming from a variety of sources, with no consensus on who should provide it. There is also no national funding stream.

In 2011/2012 there were 20 audio described theatre performances in Auckland, Wellington and Dunedin. In 2013, Tauranga joined the other centres, with one production.

Arts Access Aotearoa awarded the 2013 Big 'A' award to the Fortune Theatre in Dunedin which has audio described 10 plays since 2011. This award recognises an arts organisation, company, venue or producer that best demonstrates its commitment to developing its audiences by becoming more accessible to the disabled community.

#### Cultural life

Many disabled people report having restricted access to their culture. The many different cultures from all around the world that make up Aotearoa New Zealand society have diverse beliefs. This includes different ways of answering questions such as "Where does disability come from?". Those explanations may attribute disability to events in past lives or in past generations. Disability may come with a sense of shame for the family. At the same time, within most of these same cultures there are stories and beliefs that convey disabled people's strength and inspirational leadership. This means disability can also be viewed as a gift.

Projects are underway and toolkits have been developed to support access to marae, to whakapapa, and participation in all of te ao Māori. Similarly there are projects supporting Pacific disabled people including positive disability awareness through churches and other community networks.

For disabled people from diverse cultural backgrounds, making all the rights across the Disability Convention real is built on foundations of strength-based cultural understandings of disability. It will be critical to develop additional resources to support such conversations within cultural communities and to build understanding amongst those working in the disability system.

#### Sport New Zealand

Under the Sport and Recreation Act, Sport NZ must encourage participation in sport and recreation by disabled people, and recognise the rehabilitative role of participation. As noted in the IMM's 2011/2012 report, Sport NZ invests in the Halberg Disability Sports Foundation, Paralympics New Zealand (for elite sport) and Special Olympics New Zealand. These organisations are funded to deliver opportunities for sport and recreation to disabled people. There are other disability sports organisations that receive limited or no funding.

## Article 31 Statistics and data collection

The Disability Convention requires governments to:

- collect appropriate information, including statistics and research, to formulate and implement policies that give effect to the Convention and
- 2 disaggregate that data in order to identify and address barriers faced by disabled people in exercising those rights.

As highlighted in the 2011/2012 report, the limited data available about disabled people's lives is a significant barrier to assessing progress and outstanding gaps in realisation of their rights.

In May 2012 the United Nations Committee on Economic, Social and Cultural Rights recommended that the New Zealand Government:

> collect data to monitor the enjoyment of economic, social and cultural rights by persons with disabilities and provide information and statistical data in this respect in the next periodic report.<sup>123</sup>

Good quality information across a range of indicators will assist better measurement of outcomes for disabled people. This in turn will help to identify areas where further work is required. The IMM wishes to underscore the following points made in its first report:

> There are many different understandings and definitions of disability across government departments which compound the challenge of building a whole of life evidence-based picture.

Disability is a core part of necessary demographic information, alongside gender, ethnicity and age, and needs to be collected as a matter of course.

The IMM is constrained in fulfilling its function of developing a comprehensive monitoring framework by the lack of information on outcomes for disabled people. It welcomes the long-awaited release of the 2013 Disability Survey in mid-2014. This provides an ideal opportunity for Statistics New Zealand to work closely with disabled people's organisations and the IMM to identify data analysis needs. These include ensuring reports developed from the 2013 Disability Survey are sufficiently comprehensive. The reports need to inform priority areas of work in the Disability Action Plan, the New Zealand Action Plan on Human Rights and the IMM's ongoing monitoring work.

## **Recommendation 36**

That Statistics New Zealand, in partnership with DPOs, lead a programme of work to ensure that key outcome and prevalence data are collected in a way that makes it possible to compare outcomes for disabled and non-disabled people. This work should include a common definition of disability and involve consultation with key stakeholders, government and international agencies.

## Article 32 International cooperation

The Disability Convention recognises that international cooperation is important to support its implementation and promotion. Cooperation should occur between and among countries and in partnership with civil society organisations, particularly disabled peoples' organisations.

Governments should:

- ensure that international development programmes are inclusive of and accessible to disabled people
- 2 facilitate and support capacity building including through sharing information, experiences, training programmes and best practices
- 3 provide, as appropriate, technical and economic assistance.

# Ongoing commitments and representation

As noted in the IMM's 2011/2012 report, since New Zealand ratified the Disability Convention its international presence in this area seems to have declined. Other countries with similar legal systems to New Zealand, including Australia, have ratified the Optional Protocol to the Disability Convention. There is an expectation, from inside New Zealand and abroad, for New Zealand to do this as well.

Other commitments New Zealand has made or recommendations of United Nations treaty bodies should be implemented. As noted under Article 25, this includes a reassurance to the Human Rights Council in 2009 that New Zealand had a work plan to improve the health and wellbeing of people with an intellectual/learning disability. At the time this report was being finalised, the Ministry of Health confirmed its commitment to develop a strategic approach for achieving better physical and mental health outcomes for people with an intellectual disability. This commitment was to be reflected in the Disability Action Plan 2014/15 and had included the involvement of the Chief Medical Officer and Chief Nurse.

## Recommendations 37 and 38

#### **Recommendation 37**

That the Government implement recommendations from the United Nations treaty bodies related to disabled people, including recommendations on employment and an adequate standard of living.

#### **Recommendation 38**

That the Government ratify the Optional Protocol to the Disability Convention.

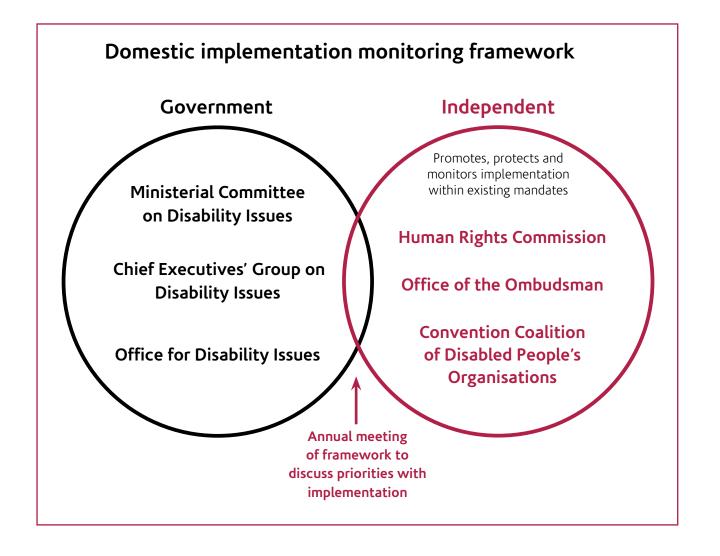
## Article 33 National implementation and monitoring

This article deals with the mechanisms that countries are required to set up in order to effectively implement all of the provisions of the Disability Convention.

The Disability Convention states that governments must:

 establish a focal point within government for matters relating to the implementation of the Convention and consider establishing a coordinating mechanism to facilitate action in different sectors and at different levels

- 2 establish an independent mechanism to advocate for, monitor and report on the implementation of the Convention
- 3 ensure that disabled people and their representative organisations are involved and participate fully in the monitoring process.



The New Zealand Government has established a framework to promote, protect and monitor the implementation of the Disability Convention in line with the Convention requirements.<sup>124</sup> The Convention Coalition is a group of eight disabled peoples organisations set up to provide input from disabled people into the monitoring process. The IMM's monitoring framework is outlined in the introductory sections of this report. In carrying out its work, the IMM works with the Ministerial Committee on Disability Issues,<sup>125</sup> the Chief Executives' Group on Disability Issues<sup>126</sup> and the Office of Disability Issues. The Ministerial Committee sets policy direction and provides visible leadership and accountability across government for implementing the Convention and the **Disability Strategy.** 

The Chief Executives' Group is made up of senior executives from key ministries and government agencies.<sup>126</sup> The group leads the implementation of the Disability Action Plan within government agencies and reports on progress to the Ministerial Committee. The Office for Disability Issues supports the Ministerial Committee and the Chief Executives' Group, promotes and supports the Disability Strategy and the Disability Action Plan and engages with the disability sector.

For the first three years of its existence, the Convention Coalition received year-byyear funding and contract arrangements with the Government. The IMM was of the view that this arrangement did not allow the Convention Coalition to maintain its independence, plan for future work or build capacity and capability amongst its networks.

In the 2013 budget the Government provided for funding of \$275,000 per annum for three years. A three year contract and plan of work has been approved. This will allow the Convention Coalition to develop its programme in the medium term and give real meaning to the phrase "Nothing about us without us". A significant focus of the Coalition's work will be to provide information on how disabled people experience their rights on a day-today basis in significant areas identified by the Coalition.

# Appendix 1 Recommendations

# Key recommendations

#### **Recommendation A**

That the Government continue to jointly develop the Disability Action Plan with DPOs, (including disabled people, children and their families), and commit to its full implementation.

# **Recommendation B**

That Statistics New Zealand, in partnership with DPOs, lead a programme of work to ensure that key outcome and prevalence data are collected in a way that makes it possible to compare outcomes for disabled and non-disabled people. This work should include a common definition of disability and involve consultation with key stakeholders, government and international agencies.

# **Recommendation C**

That the Government integrate accessibility and universal design across all its work by:

- improving access to the built environment including through the review of NZS 4121:2001
- 2 improving access to transportation services for disabled people, including development of national accessibility design standards for all aspects of public land transport

providing accessible communications services, including websites, throughout all government agencies.

# **Recommendation D**

That the Department of Corrections and Ministry of Health work together, in consultation with the IMM, to ensure:

- the requirements of prisoners with disabilities are reasonably accommodated and
- 2 best practice in the detention and treatment of people with an intellectual/learning disability or a mental illness.

# **Recommendation E**

That the Government:

- 1 establish an enforceable right to inclusive education
- 2 implement a whole of school antibullying programme to ensure that schools are safe and nurturing places for disabled students
- 3 establish initiatives that promote the value of difference and affirm the identity of disabled students.

That the Government develop a range of initiatives to ensure that:

- disabled people have the same protection from domestic and other forms of violence as non-disabled people and
- 2 agencies identify and appropriately respond to abuse, negelct and violence directed at disabled people.

# **Recommendation G**

That the Government urgently address the specific matters of concern identified by the IMM in the introductory section of this report, by

- repealing the New Zealand Public Health and Disability Amendment Act 2013, particularly those sections which remove remedies for unlawful discrimination in relation to complaints by caregivers who are family members and limit when family members can be paid
- 2 reviewing relevant laws, in particular mental health legislation, to ensure that the principles of supported decision-making are appropriately reflected and applied in accordance with Article 12 of the Disability Convention
- addressing significant disparities in health outcomes between disabled people and non-disabled people,

particularly for people with an intellectual or learning disability

4 amending the Children, Young Persons and Their Families Act to ensure that disabled children have the same rights as other children when an out of home care arrangement is being considered, and have legal representation and protection when decisions are being made in relation to these matters.

# **Recommendation H**

That the Government provide the IMM with a progress report, as at the end of 2014, on implementing the recommendations of the IMM's 2011/2012 report.

# Recommendations in the body of the report

# **Recommendation 1**

That the Government continue to jointly develop the Disability Action Plan with DPOs (including disabled people, children and their families) and commit to its full implementation.

# **Recommendation 2**

That the Ministry of Justice and the Office for Disability Issues jointly develop guidance on the requirements and application of reasonable accommodation and the associated provisions of the Human Rights Act and New Zealand Bill of Rights Act, in consultation with DPOs and the IMM.

That Statistics New Zealand make it a high priority to:

- produce a report from the Disability
   Survey 2013 comparing the human
   rights outcomes of disabled women
   and men with non-disabled women
   and men
- 2 where possible, make data tables available from the 2013 Disability Survey so that data users are able to compare the human rights outcomes of disabled women and men with non-disabled women and men.

# **Recommendation 4**

That the Families Commission and DPOs jointly develop standards and best practices for ensuring that research and evaluation in the social sector includes the experiences of disabled women and men.

# **Recommendation 5**

That routine collection and reporting of meaningful indicators and data about the experiences of children with disabilities continue to be improved, in partnership with DPOs.

# **Recommendation 6**

That the review of NZS 4121:2001, announced by the Ministers for Building and Construction and for Disability Issues, also consider whether the standard should be made mandatory and cover residential housing.

# **Recommendation 7**

That the Ministry of Transport develop national accessibility design standards for all aspects of public land transport.

#### **Recommendation 8**

That high priority be given to the perspectives of DPOs, disabled people, and their families in relation to policy development on the right to life and bioethical issues which have a high impact on disabled people and/or public perceptions about disability.

# **Recommendation 9**

That the government expedite a review of the three month time limit set out in legislation for lodging a claim with the Earthquake Commission.

# **Recommendation 10**

That the Law Commission undertake a review of the Mental Health (Compulsory Assessment and Treatment) Act, with a particular focus on compliance with articles 12 and 13 of the Disability Convention.

# **Recommendation 11**

That research be undertaken by the Office for Disability Issues to determine whether the provisions of the Protection of Personal and Property Rights Act that relate to supported decision-making are well understood and applied by welfare guardians and property managers appointed under the Act.

That the Department of Corrections take steps to identify any gaps in the current care and facilities provided for prisoners with disabilities.

# **Recommendation 13**

That the Government develop a range of initiatives to ensure that:

- disabled people have the same protection from domestic and other forms of violence as non-disabled people and
- 2 agencies identify and appropriately respond to abuse and violence directed at disabled people, including by:
  - a ensuring all government-funded
     domestic and anti-violence
     programmes include material about
     disabled people
  - b investigating whether legislative reform is required to extend the range of protections and support available
  - c considering ways to increase awareness of abuse experienced by disabled people and mechanisms to address it. This would include extending the *It's Not OK* campaign to residential facilities and providing sustainable funding for DPOs working in this area and

d training staff within police, courts,
service providers and DPOs about
the protection and support needs
of disabled people.

# **Recommendation 14**

That the Government review all disability support systems to ensure that they reflect the whole of life, strengths-based approach recommended by the Social Services Select Committee Inquiry and incorporated into *Enabling Good Lives*.

# **Recommendation 15**

That the Government urgently reconsider the New Zealand Public Health and Disability Amendment Act 2013 and repeal those sections that limit further legal action and limit the circumstances in which family members can be paid and the categories of family members that can be paid.

# **Recommendation 16**

That all applicants for pre-qualification for Social Housing Fund grants be required to undertake to provide accessible housing using the Lifemark Design Standards (or an alternative certification process with at least as robust standards).

# **Recommendation 17**

That all government agencies ensure their own and government funded initiatives, for which they are responsible, comply with the Government web standards for accessibility and other accessible information and communication requirements.

That Government web standards become mandatory for all territorial authorities, district health boards, other Crown entities and organisations receiving substantial government funding.

#### **Recommendation 19**

That all state sector agencies develop internal guidelines for communication with disabled people, including making information available in accessible formats.

# **Recommendation 20**

That the Ministry of Justice review the Adoption Act, with particular consideration given to whether section 8 complies with the Disability Convention.

#### **Recommendation 21**

That as part of the Government's work in relation to vulnerable children, sections 141, 142, and 144(2) of the Children, Young Persons and Their Families Act are repealed to ensure that disabled children have the same rights as other children when an out of home placement is being considered.

# **Recommendation 22**

That the Government further extend NGOled intensive wraparound support programs for disabled children, in partnership with DPOs.

#### **Recommendation 23**

That the Government establish an enforceable right to inclusive education.

# **Recommendation 24**

That the Ministry of Education implement whole of school anti-bullying programmes that ensure that schools are safe and nurturing places for disabled students.

# **Recommendation 25**

That the Ministry of Education establish initiatives that promote the value of difference and affirm the identity of disabled students.

#### **Recommendation 26**

That the Ministry of Health work with people with intellectual/learning disabilities and their organisations to establish a comprehensive health monitoring and improvement programme.

#### **Recommendation 27**

That the Chief Executives' Group on Disability Issues, in conjunction with DPOs:

- promote initiatives to increase the employment of people with disabilities in the public service and
- 2 further develop mechanisms and resources to ensure that reasonable accommodations for the employment of disabled people are understood and implemented in the public service.

# **Recommendation 28**

That the Ministry of Business, Innovation and Employment, working with the Disability Employment Forum, conduct a full review of the minimum wage

exemption permits system by 31 December 2014, to ensure it reflects the best approach to employment rights for disabled people.

#### **Recommendation 29**

That the Ministry of Social Development:

- enable the disability allowance to be used more flexibly, including to cover housing costs and
- 2 consider and report on the appropriateness of increasing the accommodation supplement for Christchurch to be commensurate with Auckland and Wellington.

# **Recommendation 30**

That the Electoral Commission ensure that the next general election in 2014 is conducted in a way that allows independent and secret voting for all eligible voters.

# **Recommendation 31**

That the Department of Internal Affairs' working party set up to trial online voting in the 2016 local authority elections adopt accessibility as a key success measure for the trial.

# **Recommendation 32**

That funding is provided for party political broadcasts and televised debates for the 2014 general election to be available in New Zealand Sign Language and captioned.

# **Recommendation 33**

That the requirements of all democratically elected members to government boards and public authorities are reasonably accommodated to support them to carry out their duties.

# **Recommendation 34**

That the Ministry of Culture and Heritage develop an industry-wide voluntary code of practice for broadcasting accessibility in consultation with broadcasters and consumers, taking into account international good practice.

# **Recommendation 35**

That NZ On Air develop a comprehensive policy on the accessibility of programmes that it funds or supports, in cooperation with broadcasters and consumers, to clarify accessibility objectives and targets.

# **Recommendation 36**

That Statistics New Zealand, in partnership with DPOs, leads a programme of work to ensure that key outcome and prevalence data are collected in a way that makes it possible to compare outcomes for disabled and non-disabled people. This work should include a common definition of disability and involve consultation with key stakeholders, government and international agencies.

That the Government implement recommendations from the United Nations treaty bodies related to disabled people, including recommendations on employment and adequate standard of living.

# **Recommendation 38**

That the Government ratify the Optional Protocol to the Disability Convention.

# Appendix 2 Endnotes

- 1 Preamble to the Universal Declaration of Human Rights.
- 2 Page 9.
- 3 Note the comments under Article 24 of this report indicating that IHC has raised concerns with the IMM about the methodology used by ERO and the statistical significance of some of its findings.
- 4 The October 2013 issue of the Newsletter of the Office for Disability Issues. Accessed 31 May 2014 at: http://www. odi.govt.nz/resources/publications/emailupdate/2013/2013-10-07.html.
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- 7 New Zealand Convention Coalition Monitoring Group (2013) Youth Monitoring Report.
- 8 This includes children who receive special education support because of long-term conditions or health problems, children who have an individual education programme (IEP) or individual programme (IP) because of learning or developmental difficulties, and children with learning difficulties such as dyslexia, attention deficit disorder or attention deficit hyperactivity disorder.
- 9 Statistics New Zealand (2010) Disability and Māori in New Zealand. Wellington: Statistics New Zealand.
- 10 Craig, E. et al. (2012) Te Ohonga Ake: The Health of Māori Children and Young People with Chronic Conditions and Disabilities in

*New Zealand*. A report prepared for the Ministry of Health on behalf of the New Zealand Child and Youth Epidemiology Service.

- 11 Ministry of Health (2004) Living with Disability in New Zealand: A descriptive analysis of results from the 2001 Household Disability Survey and the 2001 Disability Survey of Residential Facilities. Ministry of Health: Wellington.
- 12 Craig, E. et al. (2011) The Health of Pacific Children and Young People with Chronic Conditions and Disabilities in New Zealand, p. 15. A report prepared for the Ministry of Health on behalf of the New Zealand Child and Youth Epidemiology Service, June 2011.
- 13 ASA Complaint Number 13/174.
- 14 See www.thinkdifferently.org.nz Accessed 16 October 2013.
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- 21 Barrier Free New Zealand Trust (May 2013) Barrier Free Built Environments: Guidelines for Quality Accessibility using NZ Standard 4121 and the NZ Building Code.
- 22 Human Rights Commission (2013) Monitoring Human Rights in the Canterbury Earthquake Recovery/Whakaora R, Whenua Waitaha he Aroturuki Tika Tangata, pp. 82-89.
- 23 Residential red zones were declared in areas where there was area-wide damage. Owners were given the opportunity to sell to the Crown so that they had the option of moving out of the worst affected areas.
- 24 New Zealand Government (2 December 2013) *Progress on Disability Access Review*. Joint media release from the Ministers for Building and Construction and for Disability Issues. Accessed 5 February 2014 at: http://www. scoop.co.nz/stories/PA1312/S00008/progresson-disability-access-review.htm.
- 25 Committee on the Rights of Persons with Disabilities (September 2013), *Concluding observations on the initial report of Australia*, adopted by the Committee at its tenth session (2-13 September 2013). CRPD/C/AUS/CO/1.
- 26 Ministry of Civil Defence and Emergency Management (June 2013) Including people with disabilities; Ministry of Civil Defence and Emergency Management (December 2013) Factsheet: Recognising Disability Assist Dogs in Emergencies. Accessed 5 February 2014 at: http://www.civildefence.govt.nz/ memwebsite.nsf/wpg\_URL/For-the-CDEM-Sector-Publications-Index?OpenDocument#i.
- 27 Section 4 and section 7(1) of the New Zealand Sign Language Act 2006.
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- 31 Ministry of Health (2013) 2012 Annual Report, Office of the Director of Mental Health, pp 13-18.
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- 47 Cabinet paper (July 2013) Enabling Good Lives Demonstration in Christchurch. Accessed 10 October 2013 at: http://www.odi.govt.nz/ what-we-do/improving-disability-supports/ enabling-good-lives/cabinet-paper-july-2013-enabling-good-lives-demonstration-inchristchurch.html.
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