ARTICLE 33

Convention Coalition
Monitoring Group

Disability Rights in Aotearoa New Zealand 2012

A report on the Human Rights of Disabled People in Aotearoa New Zealand

Disability Rights Promotion International

He mihi

Karanga karanga karanga ra nau mai ki te ata hapara e kawea mai te rangi hou me maumahara tonu ki a raatou ma e moe nei i te moenga roa, moe mai moe mai moe mai ra.

Ka rere tonu ra nga kupu whakamihi ki teenaa ki teenaa ki teenaa o taatou ngaa ringa raupaa e tautoko kaha nei ki teenei kaupapa whakahirahira.

Ma te whakaaro ko te korero, ma te korero ko te waananga, ma te waanga ka tau mai te matauranga hei oranga ma tatou katoa.

Noo reira tena kautou tena kautou tena tatou katoa!

Disability Rights in Aotearoa New Zealand 2012

A systemic monitoring report on the human rights of disabled people in Aotearoa New Zealand

This report is an analysis of six key areas initially identified by the 2010 monitoring of the individual experiences of disabled people in Aotearoa New Zealand, following the ratification of the United Nations Convention on the Rights of Persons with Disabilities in 2008.

This project was funded by the New Zealand Government through the Ministry of Social Development and administered by the Convention Coalition, a collaboration of NZ Disabled Peoples’ Organisations. One of the members, Disabled Persons Assembly (New Zealand) Incorporated, acted as administrative fund-holder on behalf of the other Disabled Peoples’ Organisations.

Disclaimer

Any opinions expressed in this report are those of the research participants and authors, and do not necessarily represent the views of the Convention Coalition.

Dedication

In preparing this report, we remember all those disabled people who were segregated, and often mistreated, in institutions and all those who continue to struggle to achieve ‘an ordinary life’. This report is dedicated to the diversity of disabled New Zealanders and the humanity we all share.

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PREFACE

On 30 March 2007, New Zealand signed the United Nations Convention on the Rights of Persons with Disabilities (herein known as “The Convention”).This was ratified on 26 September 2008. The Optional Protocol has not yet been ratified.

A significant aspect of The Convention is the monitoring process. New Zealand Disabled Peoples’ Organisations formed a governance level steering group, called the Convention Coalition, to undertake this process.

The Convention Coalition is a group of national Disabled Peoples’ Organisations governed by disabled people (as defined in Article 33 of The Convention). The Convention Coalition comprises:

- Association of Blind Citizens of New Zealand (ABCNZ)
- Balance New Zealand
- Deaf Aotearoa
- Deafblind (NZ) Incorporated
- Disabled Persons Assembly (New Zealand) Incorporated
- Ngā Hau e Whā
- Ngāti Kāpo o Aotearoa Inc
- People First New Zealand Inc —Nga Tangata Tuatahi.

In April 2012, the Project Coordinator, Pam MacNeill, and Assistant Coordinator, Nathan Bond, (the project team) met with the Convention Coalition to discuss various options for the monitoring project. After careful consideration of the timeframe and resources available to undertake systemic monitoring of the status of disabled New Zealanders in 2012, following Disability Rights Promotion International guidelines, the Convention Coalition agreed to confine the project to six key areas which had initially been highlighted during the monitoring of individual experiences in 2010.

These areas are:

1. Social inclusion

2. Health
3. Employment
4. Access to disability related services and supports
5. Barriers to making complaints
6. Lack of disability awareness.

The project team brought together a small group of disabled professionals to monitor the policies, programmes and laws relating to the six key areas. A summary of systemic monitoring is contained in chapter three. The Disability Rights Promotion International: Law, Policy & Program Monitoring Annex is also provided with this report.

In addition to the systemic monitoring process it was agreed that the project team would organize a range of consultation meetings and other methods to: enable a cross-section of disabled New Zealanders to participate in the project and share their experiences of the six key areas. Not all consultation methods were necessarily accessible to all project participants, however the variety of consultation methods employed ensured there was at least one way for disabled people to participate.

Consultations took place in May and June 2012, and consisted of:

- fora for disabled people, held in Wellington, Christchurch and Auckland
- a fono for disabled pasefika, held in Lower Hutt
- a hui for disabled Māori, held in Christchurch
- an open call for submissions
- an online survey.

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We wish to sincerely thank the following people for their advice, input and hard work on this project:

The members of the Convention Coalition committee.

- Rachel Noble (Chair)
- Kellye Bensley
- Barbara Hart
- Leo McIntyre
- Nigel Ngahiwi
- Graeme Parish
- Mary Schnackenberg
- Wendi Wicks

The systemic monitoring team:

- Chris Ford, Dunedin
- Dr Linda Beck, Christchurch
- Alex Smith, Wellington
- Dr Huhana Hickey, Auckland
- Clive Lansink, Auckland
- Hui facilitator, Gary Williams.
- Fono facilitator, Pati Umaga.

Key informant interviewees:

- Grant Cleland
- Paul Gibson
- Wendi Wicks

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- All those who attended the fora, hui and fono, sent in submissions and completed the online survey.

CHAPTER ONE —OVERVIEW AND KEY FINDINGS

Overview

This project was developed by the Convention Coalition to provide advice and information to the New Zealand Government to enable the formulation and implementation of practical and appropriate disability policy, in partnership with disabled New Zealanders.

The 2010 monitoring report: *Disability Rights in Aotearoa New Zealand*, noted that "Social participation by disabled people in society emerged as by far the biggest single issue ... ." Other major issues identified were negative experiences relating to health. Lack of employment also featured, as did access to disability related services and supports, barriers to making complaints and a general lack of awareness and responsiveness about disability issues. The high cost of living, gender and ethnicity further compounded these issues. Discussions about social participation included tangible issues such as work, transport, communication and lack of money. "... this also includes drivers for true social participation, taken for granted in non-disabled peoples' lives, such as friendships and other social networks and access to the social and cultural world."(*Disability Rights in Aotearoa New Zealand,* 2010).

The six key areas chosen for systemic monitoring and consultation in 2012 have resulted from this earlier study.

A total of 156 people took part in the various consultation mechanisms described in the preface. Contributors represented a cross-section of people with a range of impairments. Quotes from these people are used liberally throughout, in order to give authentic voice to the report.

The remainder of this chapter looks at some of the key findings from consultations and the systemic monitoring of policies, programmes and laws reviewed for the project.

Chapter Two addresses some of the systemic discrimination in New Zealand, from an historical perspective. Issues relating to Deaf people in education, institutionalisation and recent developments, such as the appointment of a disabled Disability Rights Commissioner, are discussed.

Chapter Three is a summary of the systemic monitoring relating to articles 9, 17, 19, 25, 27 and 29.

Chapter four provides an overview of the experiences of disabled New Zealanders, relating to the six areas chosen for consultation.

The final chapter contains appendices relating to the project.

Key findings

The systemic monitoring and consultations undertaken for this report illustrate that discrimination in one area can also adversely affect a person's experience in other areas. Lack of access to transport and disability support services has a direct impact on access to employment. Exclusion from employment has implications for accessing health services and social inclusion. Being unable to access quality health care may in itself be a barrier to making complaints. Taking into account all of these flow-on effects, the whole is often far greater than the sum of the parts.

Major barriers to participation in the life of the community frequently reported by disabled people are bureaucratic structures and policies that hinder interaction and communication. For example, lack of access to Sign Language Interpreters (herein referred to as Interpreters) and information in accessible formats, including plain language, Easy Read, Braille and accessible electronic text. Disabled people reported a noticeable unwillingness on the part of State servants to work with them, preferring instead to filter communications through others. The prevailing attitude is "we know best".

> “*There still seems to be this paternalistic attitude that it’s quite alright to ask non-disabled people about us and about our needs, but it’s not alright!*”

Many people consulted for this report spoke of the lack of disability awareness and responsiveness, on the part of staff of private businesses, utility companies, local bodies and State Services. All agreed that it is critical that disability training of such staff must relate to equity and not merely awareness - furthermore, that this must be delivered by reputable disabled trainers.

> *“No-one would find a man delivering training about and to women acceptable. If you want to know about disability, ask us! It is no more acceptable to filter knowledge through non-disabled people than it is to ask Pakeha about the cultural needs of Māori.*”

There is some evidence that the implementation of both the New Zealand Disability Strategy (also referred to herein as “the Strategy”) and The Convention by the New Zealand Government, is somewhat disorganised, with each department developing their own implementation plans, which often lack consistency or coherence. (See ChapterThree: Systemic monitoring).

The need for the New Zealand Government and its agencies to partner far more extensively with Disabled people, through disabled peoples’ organisations, was a strong theme evident throughout the consultation phase of this project. These themes specifically covered:

- Development of a strategy to fully implement The Convention.
- Reviewing “reasonable accommodations” every four years, in conjunction with New Zealand’s requirement to monitor the implementation of The Convention.
- Revising and updating the New Zealand Disability Strategy to enable it to become the operational mechanism for implementation of the various articles of The Convention.
- Requiring State Services, Crown Entities and local bodies, to collect and publish disaggregated disability data in their annual reports.

- Developing and implementing of fully flexible Individualised funding for those who require this, based on consistent nation-wide policy and practice.
- Investigation of the production of accessible health related brochures and medication labelling.

Other frequently occurring themes included:

- The need for immediate ratification of the Optional Protocol to The Convention.
- An extension of the right to compensation for the costs of disability to all disabled people.
- The need for a full enquiry into the work and remuneration of aged-care and home-based support workers.
- The elimination of seclusion from all mental health-related detention facilities.
- A public apology to all formerly institutionalised disabled people.
- The Creation of a Disability Commission.

CHAPTER TWO — HISTORICAL SYSTEMIC DISCRIMINATION IN NEW ZEALAND

Systemic discrimination has had a major impact on the lives of disabled people in New Zealand. Since the United Nations International Year of Disabled Persons in 1981, successive New Zealand Governments have introduced policies, programmes and laws to make New Zealand a more equitable place for disabled people. However, it is crucial that we document the history of systemic discrimination: to recognise the journey of disabled people; and to ensure we don’t repeat the mistakes of the past.

Deaf people in education

The inclusion of Deaf people has always been something New Zealand's education system has struggled with. Education authorities thought the best approach was to assimilate Deaf students into the hearing world, thus adhering to a policy that forbade Deaf students from using sign language in schools.[1]

As a result of this policy, Deaf students were punished for using sign language or for poor vocalization and sometimes this punishment was physical.[2] While in that era physical punishment was considered appropriate, it should be recognised that punishing Deaf people for being Deaf is nothing less than persecution.

From 1994 onwards the Deaf Community have repeatedly tried to improve access to education for Deaf children. When it became clear that these approaches were not gaining any traction, a complaint was filed with the Human Rights Commission on March 11, 2009. The discrimination reported was both historical and contemporary/ongoing.

The complaint relates to:

> "…acts and omissions of Government that discriminate against deaf children by not providing access to:
>
> a) Education in New Zealand Sign Language, and
>
> b) Deaf identity and culture."

Most educational professionals are neither fluent in sign language nor familiar with Deaf culture. This includes Advisors on Deaf children who provide families of Deaf children with "inadequate, biased and sometimes incorrect information."[3]

Funding is available to provide specialist assistance to meet the needs of children, including Deaf children, in special education. However, New Zealand Sign Language

Interpreters and educational professionals, who have achieved specified standards in sign language are not included on the list of approved specialists.

Likewise, funding mechanisms fail to acknowledge fluency in sign language as expertise. Consequently, interpreters can only be employed and paid as teacher aides, whose remuneration is much lower than that of interpreters. Not surprisingly then, few interpreters undertake this work and there is no provision to train other staff to become educational interpreters. Therefore the people who are employed to meet the needs of deaf children lack the skills and knowledge required to do the job.

The eligibility for funding is based upon the degree of hearing loss, mastery of speech and use of assistive listening devices. However, level of hearing loss does not always correlate with accessible language and the cultural needs of Deaf children are generally not considered. [3]

Institutionalisation of intellectually impaired people

This began in New Zealand with the passing of “the Mental Defectives Amendment Bill” in 1928. This bill “allowed certain institutions to be set aside for the care and training of ‘mentally deficient’ children.”[4] There were many institutions; one of these institutions was Kimberley Centre, Levin, which also admitted some people with physical disabilities or experience of mental illness.

According to Human Rights Commissioner responsible for Disability, Paul Gibson[5], medical professionals and Government officials persuaded the parents of intellectually impaired children that the best thing they could do was to send their children to Kimberley Centre, where they would receive the care they needed. The parents trusted the authorities and so complied with official requests — no one listened to what the intellectually impaired children wanted.

Isolated from their families the residents of institutions like Kimberly Centre Centre had their rights violated, and some disabled people were abused. Most of the residents didn’t know they had rights. Their rights were often violated by the very officials who claimed they could look after them better than their own families.

This policy of institutionalisation tore families apart, in a similar fashion to that experienced by the aboriginal families of Australia’s Stolen Generations. Funnell (2001) found that institutionalisation caused long term emotional stress for intellectually impaired people and their families[6].

When the New Zealand Government adopted a policy of community living for intellectually impaired people in 1985, it signaled the end of such institutions in New Zealand, with the Kimberley Centre being the last to close in 2006[4].

The legacy of institutionalisation still affects the former residents and their families. Former residents have the option of private hearings with judges through the Confidential Listening Service to tell their stories. Gibson doesn’t think this goes far enough and believes that there should be a national dialogue centred on what happened at Kimberley and other institutions and that the New Zealand Government should officially apologise to the former residents and their families for the trauma they caused.

Mental health

The 1995 New Zealand Government inquiry into mental health services led by Judge Ken Mason produced what became known as “The Mason Report”. This report was critical of the mental health system and provided the impetus to establish the Mental Health Commission in 1996. In addition, funding (known as the “Blueprint” funding), was provided for mental health sector improvements, along with a national anti-stigma initiative which led to the establishment of the Like Minds — Like Mine campaign.

In 1998 a “*Blueprint for Mental Health Services*” was published and major changes to the structure of the mental health system began. A range of new policies were developed including "*Our Lives in 2014: A recovery vision of people with experience of mental illness*."

The Mental Health Commission's role has changed over time, and its power to influence government gradually reduced, together with a reduced capacity to engage with consumers. A second "*Blueprint II*" was produced, published by the Ministry of Health, in June 2012. *Blueprint II* signalled the end of the Mental Health Commission.[7]

This change in mental health policy has disempowered consumers and is inconsistent with New Zealand's obligations under The Convention. In particular, it is inconsistent with General Obligation 3.

> "*In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.*"

Funding for the Like Minds — Like Mine project, which has been modestly successful in improving public attitudes towards mental Illness, is at risk in the current fiscal climate.[7] The Like Minds — Like Mine project complies with Article 8 of the Convention Awareness-Raising. Preserving this funding would signal that the New Zealand Government is prepared to honour obligations agreed to under The Convention.

Government support

Starting in 1981, the New Zealand government has supported the disability rights movement and worked towards ending discriminatory practices and policies. The New Zealand Government actively engaged the disabled community to develop the New Zealand Disability Strategy. The Strategy requires State Services to develop plans for implementation and to monitor this implementation. The Strategy however, is limited to the State Services. Furthermore, the Strategy is a statement of intent that cannot be enforced by law. The Human Rights Commission commented that data from the household disability surveys in 1996, 2001 and 2006 showed that:

> "*The position of disabled people relative to the general population has barely changed in that period. In areas as fundamental as employment, education, adequate standard of living and accessible public transport, disabled people are significantly disadvantaged. This shows that The Strategy has had little impact on disabled people's everyday lives*."[8]

The implementation and monitoring of the Strategy has been disorganised and largely dependent on varying levels of disability awareness and support in each department.

> "*Over the last eight years, it has been evident the implementation of the New Zealand Disability Strategy has lacked direction. It seems that, while the very essence of the Strategy was to have a whole-of-government approach, most agencies act in a mutually exclusive way with no discernible end goal*."
>
> (Gary Williams. Chief Executive, Disabled Persons Assembly (New Zealand) Inc.
> Work in Progress, 2009) [8]

New Zealand was one of the only countries to include disabled people in the delegation which negotiated the United Nations Convention on the Rights of Disabled Persons. Robert Martin, from New Zealand in his role as the 3rd Vice President of Inclusion International, was the first person with a learning disability to address the United Nations. Despite playing a leading role in negotiating The Convention, New Zealand has not yet ratified the Optional Protocol.

New Zealand's ratification of The Convention was a major step in the journey towards equity as it applies to all sectors of society. The New Zealand Government reviewed various pieces of legislation before ratifying The Convention and consequently changed legislation disqualifying people with "mental disorders" from standing for public office, and also made some changes to some sections of the Human Rights Act concerning reasonable accommodation.[8]

New Zealanders do not know very much about human rights, let alone disability rights. Therefore promoting The Convention to the wider community is a challenge that needs to be met if we are to achieve a non-disabling society. Despite playing a leading role in negotiating The Convention, New Zealand has not ratified the Optional Protocol.

The New Zealand Government has provided funding to enable disabled people to monitor the implementation of The Convention. The Convention Coalition used this funding in 2010 to train a group of disabled people to monitor disabled peoples' human rights using monitoring training provided by Disability Rights Promotion International. New Zealand was the first country in the world to involve disabled people in the monitoring process.

The earthquake which struck the Canterbury region on 22 February 2011 at 12:51pm local time, killing 185 people, has had a profound effect on all New Zealand citizens — including disabled people.

For the first time authorities used interpreters when making Civil Defence announcements so Deaf people in Christchurch and the rest of the country were kept up to date with developments. Television coverage allowed many people to see the interpreters in action, boosting the profile of sign language and causing people to consider the needs of the Deaf community. The destruction of infrastructure further exacerbated accessibility issues and made it even harder for disabled people to get out and about. The New Zealand Government has committed to improve accessibility during the rebuild and disabled people are represented on committees relating to the rebuild.

The 2011 Census of Population and Dwellings and the New Zealand Household Disability Survey were delayed until 2013 due to the disruption caused by the earthquake. The Household Disability Survey is one of the few ways that New Zealand gathers statistical data on disabled people, and it only occurs at five yearly intervals. Therefore the most recent data available came from 2006.

Policy researcher for the Disabled Person's Assembly, Wendi Wicks, sees the lack of disability statistics as an ongoing systemic issue for disabled people.[9] Paul Gibson agrees, identifying it as the biggest systemic issue facing disabled people.[5]

New Zealand appoints its first Disability Rights Commissioner

The Human Rights Commission announced the appointment of a disabled man, Paul Gibson, to the new role of Disability Rights Commissioner on September 26, 2011 — three years to the day since New Zealand ratified The Convention. The high profile of his position recognises disability is one of the leading grounds for human rights complaints and therefore needs a disability commissioner to more visibly advocate for disabled people's human rights.

New Zealand's first Deaf Member of Parliament

After the November elections in 2011, a Deaf woman, Mojo Mathers, became New Zealand's first Deaf Member of Parliament. While other Members of Parliament have identified as being disabled none have required accommodations to enable them to participate in Parliament, or raised disability issues in the political arena. Mathers was initially denied access to technology she needed to follow parliamentary debates by Parliamentary Services. This was eventually overturned after much debate, both within and outside the house.

Mather's participation in parliament means our political parties are being exposed to the notion of reasonable accommodations and issues of accessibility for the first time. The debate that followed Mather's treatment was covered by the media in a way that hasn't happened before, thus raising awareness for both politicians and the public alike.

Monitoring work prior to this report

A strong theme emerging from the 2010 monitoring report of individual experiences was the disabling practices of bureaucracy. Many participants identified systemic causes of discrimination, the most prevalent being a lack of awareness and understanding by staff of State Services and communication issues.[10] Departments rigidly adhere to policies that discriminate against disabled people and this, coupled with a lack of disability awareness training for staff, creates systems that are not responsive to the needs of disabled people.

Coincidentally one of the most common recommendations from 2010 was the need for disability awareness training, by qualified disabled people. This has been echoed by the disabled people we have consulted for this project.

Another theme emerging from 2010 was that disabled people often did not receive services or support in a timely fashion. This is especially important when those services include income protection schemes and the provision of, or repairs to, adaptive technology that disabled people require, in order to participate in the community. Disabled people often had to wait several months, or sometimes years, for the provision of housing modifications and adaptive technologies and also endured long waits for repairs when such equipment needed fixing.[10]

It is reasonable to expect that the provision of adaptive technology and services are carried out in a timely fashion. The fact that those interviewed endured much undue hardship waiting for staff of State Services to organise those services is disempowering, and in itself a form of systemic discrimination.

New partners for the Convention Coalition

Balance New Zealand Bipolar and Depression Network joined the Convention Coalition in 2011. More recently, Deafblind (NZ) Incorporated joined the Convention Coalition in 2012.

Bibliography

1. Kennedy, G. (Ed). (2008) *A concise dictionary of New Zealand Sign Language*, (Wellington, New Zealand: Bridget Williams Books cited in Disability Rights in Aotearoa, New Zealand, 2010.

2. Appendix to the Journal of the House of Representatives AJHR 1892(1) E-4A

3. Deaf Aotearoa, Complaint to the Human Rights Commission March 11, 2009.

4. http://www.donaldbeasley.org.nz/publications/DBI_Kimberley CentreReports_Family.pdf.

5. Interview with Paul Gibson May, 2012

6. Funnell, B. (2001). *Telling the untold: Families, disability and institutions — Stories of bannedand unrequited love.* Brisbane: Community Resource Unit Inc.

7. Anonymous submission (2012)

8. http://www.hrc.co.nz/hrc_new/hrc/cms/files/documents/06-May-2010_16-34-42_Rights_of_disabled_people.html

9. Interview with Wendi Wicks June, 2012.

10. Disability Rights in Aotearoa, New Zealand 2010.

CHAPTER THREE — SYSTEMIC MONITORING

This section summarises findings relating to systemic monitoring of Articles 9, 17, 19, 25, 27 and 29.

Summary of Article 9: Accessibility

Do the laws or government policies guarantee to persons with disabilities access to the physical environment, transportation, information and communications, both in rural and urban areas?

The following are examples of legislation regarding these areas:

- Sections 117-124 of the Building Act 2004 stipulate public access requirements to buildings and other parts of the built environment as part of the accessible journey so that disabled people can access public buildings and other facilities in a manner similar to that of non-disabled people. Further, section 170(b) of the Building Act requires the Department for Building and Housing to consult with the Office for Disability Issues on disability related matters.

- New Zealand Standard 4121 is the standard code designating best practice accessible and public space building design in New Zealand and is issued under the terms of section 119 of the Building Act.

- The Public Transport Management Act 2008 regulates most modes of public land passenger transport services by mandating that regional councils prepare and publish regional public transport plans. Under section 10(1)(iii) plans have to outline how they will support the needs of “transport disadvantaged groups” including disabled people. Section 14(1)(v) requires councils to ask providers about the quality of their services including accessibility.

- Section 68 of the Land Transport Management Act 2003 requires the Minister of Transport to have regard to “improving access and mobility” when preparing national land transport strategies. Section 75 of the Act stipulates that regional land transport committees must also take into account “improving access and mobility” in the preparation of regional land transport strategies.

- Section 75 of the Dog Control Act 1996 permits any guide dogs or companion dogs reasonable access to any public place.

- The New Zealand Sign Language Act 2006 makes New Zealand Sign Language as one of New Zealand's three official languages. Section 9 outlines the general principles that Government departments must adhere to including that the promotion of Government services and the delivery of Government services and information be made accessible to the Deaf community.

Although the intention of the legislation is clearly inclusion of disabled people, there are ongoing problems with enacting the laws.

For instance, the Government's Office for Disability Issues website notes that there are ongoing challenges to the right of disabled people to move around independently through their interaction with the built environment. These include, firstly, the Department for Building and Housing finding in many instances that territorial local authorities issue determinations stating that a building complies with the access code when, in actual fact, the building concerned does not comply. Secondly, research shows that much of New Zealand's housing stock does not currently meet the needs of disabled people. Some building owners are also reticent about the costs of meeting additional access and health and safety requirements.

The Government in 2010 moved on promoting the concept of lifetime design for private homes as part of moves towards making more of them livable for disabled people. Budget 2010 allocated $1.5 million towards promoting the idea of designing more private dwellings to make them so.

The rebuild of Christchurch following the earthquakes of 2010 and 2011 forms the centre of the Government's Disability Action Plan for 2011, with Cabinet directing that particular attention be paid to improving the accessibility of public buildings and social housing in the city. Lifetime design standards will also be promoted in the rebuild of Canterbury.

Paul Gibson (Human Rights Commissioner and key informant interviewee) stated:

> “*The Human Rights Commission expects that as buses, including Intercity buses, are replaced the replacement buses are accessible as part of reasonable accommodation.*”

In spite of these intentions, in 2011, Australian-owned Jetstar airlines (which operates internal flights within New Zealand) had two high profile disabled New Zealanders complain about the airline’s refusal to board them without a guarantee that they would have a carer accompany them as per airline policy. The two complainants stated that they did not need this level of assistance in their daily lives and had previously flown on Jetstar and other airlines without any problems.

In a decision released in February 2011 in the case of *Smith* v *Air New Zealand* (2011), the Court of Appeal reinstated a finding of discrimination by Air New Zealand against a disabled passenger but also found that the airline acted reasonably in accommodating the needs of the passenger, Valerie Smith, who suffers a congenital respiratory disorder which means she needs extra oxygen when she travels by air. In 2002, Valerie Smith complained to the Commission that Air New Zealand charged her extra for oxygen when she flew and she regarded this as discriminatory and a violation of the Human Rights Act.

Dignity New Zealand has a deserved reputation as a leader in building accessibility. The existence of standards and legislation in this regard has been important in facilitating improvements to public building access over the course of the last 40 years. This has enabled disabled people to access the environment in a dignified way most of the time. However, continuing issues relating to transport accessibility hamper the right of all disabled New Zealanders to travel with dignity, (as exemplified by the case of the anonymous interviewee) even given the improvements that have been made in this area.

Rating: ** Needs significant improvement

Autonomy: The autonomy of disabled people can be enhanced when they live in fully accessible homes and use accessible and inclusively designed public buildings and spaces. The same applies when disabled people find they can access the internet and other communications technologies independently and with minimal effort. The Government’s (and local government’s) efforts to improve building and transport accessibility, promote universal housing design and increase the level of website and information technology accessibility are all encouraging signs in this regard. Improvement will of course be ongoing. But the lack of awareness around what constitutes accessible buildings and facilities and the still comparatively low number of modified, livable homes means that disabled people’s autonomy in being able to access their environment independently can depend on such factors as where they live within New Zealand and what funding they can secure for accessibility improvements to their homes from Government agencies.

Rating: ** Needs significant improvement

Participation, Inclusion and Accessibility: New Zealand has a good official record of promoting participation, inclusion and accessibility for all disabled people. However, official practice can differ from declared policy as when, for example, Deaf people face issues in using New Zealand Sign Language within Government agencies. As noted above, the level of public building accessibility can vary according to whether or not a local authority has actually used the New Zealand Standard 4121 design specifications, or whether a certain area has fully accessible bus services, or whether a Government agency is doing enough to improve its web accessibility. Therefore, the level of participation, inclusion and accessibility can vary from region to region, city to city and Government agency to Government agency. Greater consistency is needed in all these areas.

Rating: ** Needs significant improvement

Non-discrimination and equality: Well designed, accessible, inclusive environments and services can make all the difference to disabled people being able to access society. New Zealand has a plethora of laws and policies surrounding non-discrimination in terms of access to buildings and public places, Government services and places. As has been noted, however, these laws tend to be observed more in the breach than in observance. Therefore, discrimination and inequality occurs when local authority building officers do not “make the right call” on whether a building is accessible or not; whenever a person cannot find housing that accommodates their impairment related needs; whenever a Government department does not communicate appropriately or in a manner that is easily understood by a disabled person due to vision, intellectual or hearing impairment; and whenever a disabled person is treated differently by an airline through having assumptions made about them and their needs (as in the Jetstar case) or being denied essential medical support to make their journey easier (as in the case of *Smith* v *Air New Zealand*).

Rating: ** Needs significant improvement

Respect for difference: The New Zealand Sign Language Act is one example of how Government has legislated to respect difference in terms of its service delivery to Deaf and hearing impaired New Zealanders. In terms of New Zealand Standard 4121, it seeks to take account of the access needs of different impairment-based groups including blind and vision impaired, mobility impaired, and hearing impaired. This respect extends to the Government's broadcasting funding body New Zealand on Air co-operating to fund closed caption DVDs. Conversely, the *Smith* v *Air New Zealand* case showed how a significantly Government-owned airline could disrespect the genuinely different needs of a passenger for something as simple and life sustaining as oxygen.

Rating: *** Generally compliant or needs only slight adjustment

Summary of Article 17: Integrity of the person

Is there a law or Government policy that ensures every person with a disability to respect for his or her physical and mental integrity on an equal basis with others? Yes, but there are exceptions.

This Article focuses on respecting physical and mental integrity, which includes, for example, protecting persons with disabilities from medical or other treatment given without the free and informed consent of the person, as well as protecting girls and women with disabilities from forced sterilization or from forced abortion.

Under New Zealand law (the Bill of Rights Act 1990 part 2.11) everyone has the right to refuse to undergo any medical treatment. For those people deemed to lack competency this right is specified under the Protection of Personal and Property Act 1988 Part 2, 18(f):

> “*No court shall empower a welfare guardian, and no welfare guardian shall have power, —*
>
> *(f) to consent to that person's taking part in any medical experiment other than one to be conducted for the purpose of saving that person's life or of preventing serious damage to that person's health*.”

Under New Zealand law, this may lead to some ambiguity where it is a characteristic of disability that is the basis for a compulsory intervention. There are concerns that these compulsory interventions are often the first resort rather than the last.

For instance, in the case of sterilisation of girls and women with disabilities in New Zealand, the right to refuse medical treatment has been challenged in the courts for clarification, resulting in compulsory sterilisation.

The Health and Disability Commissioner Code of Rights Act 1990 which is set out in the Code of Health and Disability Services Consumers' Rights, ensures that:

> “*All persons accessing health and disability services must be informed of their rights, be treated with respect and receive services in a manner that has regard to their dignity, privacy and independence*.”

The exception is when in most circumstances the individual must give informed consent before a service is provided and while this includes sterilisation, if the courts have overridden any legislation to allow for sterilisation, while technically illegal, sterilisation can occur in New Zealand under limited circumstances. Intellectually impaired people may be sterilised, without their consent, under New Zealand law, and court authorisation is not always necessary.

The right to refuse to undergo any medical treatment only applies to those deemed to be competent. People with learning/intellectual disabilities are often deemed to lack mental and legal competency to make good decisions in their own right. As a result others are often required to make decisions on their behalf.

When sterilisation is approved for a person with learning/intellectual impairment deemed to lack capacity it is considered to be appropriate, yet if someone who has mental capacity to consent is involuntarily sterilised or has medical treatment against their will, it is seen as a violation of the respect for their autonomy.

Even if the informed consent of those deemed incompetent has no legal bearing, informed consent must still be sought at all stages of assessment.

New Zealand uses substituted decision-making which is not consistent with Article 12 of The Convention, which advocates for supported decision-making.

Autonomy cannot currently be respected in law if it is seen as not existing in a person. The Protection of Personal Property Rights Act 1988 has safeguards where the court makes all decisions under the area of medical treatment for persons deemed to lack legal capacity. If the person is a minor then the Care of Children Act 2004 applies where the guardians/parents and medical authorities through the high court make the decisions regarding sterilisation.

While sterilisation is seen as an extreme measure and should not be undertaken without consultation and consents through the court system, it is still occurring in New Zealand.

The *KR* v *MR* {2004} 2 NZLR 847 (HC) case is an example in hand where it was deemed to be a “special case that goes beyond the competence of a guardian and will be authorised by the court only where the affected person lacks sufficient competence and where no lesser measure would be effective”. No sterilisation is allowed to occur where there is no special consideration made in the courts and the consideration must go beyond simply the need to control menstruation or fertility of girls with learning/intellectual disabilities.

There may have been more recent cases but we have been unable to access these.

The flaw in the Care of Children Act 2004 is that the guardians/parents and medical specialists can make the decision together and it will only go to court if the parents/guardians cannot agree to having their child sterilised. This process is a big risk to the autonomy of girls with learning/intellectual impairments and again contravenes New Zealand having signed and ratified The Convention.

Summary of Article 19: Inclusion in society.

Does any law or Government policy ensure that persons with disabilities can live independently and be included in the community?

Although Article 19 was not previously included in existing human rights treaties it is in principle supported by the Bill of Rights ACT 1990. The Bill of Rights Act sets out to “affirm, protect, and promote human rights and fundamental freedoms in New Zealand”.

Further, section 28 of the Bill of Rights Act states that “an existing right or freedom shall not be held to be abrogated or restricted by reason only that the right or freedom is not included in this Bill of Rights or is included only in part”.

The New Zealand Disability Strategy, which does support independent living, only applies to Government departments or ministries. Privately-owned facilities are not required to comply. Moreover, in the eleven years since its inception, the NZDS has had very little effect in promoting independent living.

The New Zealand Government, in response to the Social Services Select Committee’s 2008 “*Inquiry into the Quality of Care and Service Provision for People with Disabilities*”, is piloting programmes consistent with the principles of The Convention. At this stage the trials only involve a very small percentage of those eligible and there is no guarantee those programmes will be expanded nationally.

Feedback from disabled people in group homes indicates they still experience oppressive living arrangements and are not allowed to live with their partners, families or friends. This is inconsistent with the principle of non-discrimination and equality.

Individual autonomy regarding socializing and recreation is subordinate to the needs of the group, or more accurately to the needs of the non-disabled support workers. This can cause separation between disabled people and their families.

Also most New Zealand homes and apartments are not accessible so physically disabled people’s autonomy is limited when determining where they want to live. In 2010 the Government began to promote the concept of “lifetime design” for private homes to improve access for disabled people, and is committed to improving the accessibility of access to housing in the Christchurch rebuild. It will take considerable time before disabled people see significant improvements.

For young physically disabled people the lack of age-appropriate residential facilities severely restricts their choices and sometimes forces them to live in rest homes or to move away from their families to live in one of the few age appropriate residential facilities. Again autonomy is compromised.

The Ministry of Health has adopted a policy that their clients cannot employ family/whānau, living in the same residence, as caregivers. This is inconsistent with the principle of autonomy as it denies disabled people the right to choose who provides their care. It also is culturally appropriate for disabled Māori and Pacific peoples that family/whānau look after them.

In January 2010, in the case of *Ministry of Health* v *Atkinson &Ors*, the Human Rights Review Tribunal found that nine people were discriminated against by reason of their family status because of the Ministry of Health policy. The claimants stated that a Ministry of Health policy excluded them unlawfully from payment for the provision of disability care services to their disabled adult children that they would otherwise be entitled to.

We would expect the Ministry of Health to abolish this policy in view of the findings of the Tribunal.

Many of those in group homes do not have access to their own mail, or bank accounts. This is inconsistent with the respect for difference principle (Consultations with Disabled People, May 2012; Disability Rights in Aotearoa New Zealand, 2010).

Rating: ** Needs significant improvement.

Summary of Article 25: Health

Does the law or policy of the State ensure to all persons with disabilities the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability? No.

New Zealand’s health services are administered by 20 District Health Boards which are required to plan and deliver services regionally, as well as in their own individual areas, within national guidelines and standards. There is an issue of how consistently District Health Boards treat disability issues.

Each District Health Board has a Disability Services Advisory Committee (DSAC). Ford found that the role of DSACs has not been clearly defined by the Public Health and Disability Act, enabling some District Health Boards (such as the former Otago Board) to argue that it only covers aged care issues whereas others (such as Capital and Coast) have stressed that these committees have a broad remit to cover wider disability and health issues. These differences have affected the right of disabled people to receive the same range, quality and standard of free or affordable health care as this can sometimes vary between regions.

The New Zealand Government’s Budget 2012 moves to increase prescription charges and remove certain pharmaceutical and alternative treatment regimes from Disability Allowance coverage will likely infringe the right of disabled people under The Convention to enjoy the same range, quality and standard of free or affordable health care and programmes as provided to other persons. It could also affect the right of disabled New Zealanders to access programmes which seek to minimize and prevent further disabilities.

The Acclaim Group's allegations that some injury-disabled New Zealanders are effectively being coerced into consenting to surgery violate the right of disabled people to receive care on the basis of free and informed consent.

The Justice and Electoral Committee's Report on the Convention Bill notes that "disabled people usually have … more unmet health needs than non-disabled people".

The Government's National Health Committee published their "*To Have an Ordinary Life — Kia Whai Oranga Noa*" (2003) report on barriers to community living for people with a learning/intellectual disability. Amongst the report's main findings were that the health status of people with learning/intellectual disabilities was worse than that of the average population across many indicators including life expectancy. One of the more alarming indicators was the inappropriate prescribing of outlawed medicines and over prescribing of psychotropic and other psychotic medications to people with learning/intellectual disabilities, without any psychiatric consultation or diagnosis.

The report outlined various reasons for the poor health status of people with learning/intellectual disabilities. These included, chiefly, systemic discrimination within the health system on the part of health professionals who failed to diagnose and treat conditions due to poor communication between themselves and patients with learning/intellectual disabilities. To rectify these issues, the report recommended that the Ministers of Health and Disability Issues instruct District Health Boards to improve service access issues through developing comprehensive policies relating to service access, comprehensive health assessment tools for people with learning/intellectual disabilities and appropriate staff education programmes. Another key recommendation was that health promotion materials be designed in such a way that they would be accessible for this population.

A report published by the Ministry of Health in 2011, entitled *Health Indicators for New Zealanders with an Intellectual Disability*, made further reference to the ongoing health disadvantage being faced by people with intellectual disabilities. As with previous reports, it again referred to this disadvantage being expressed in terms of lower than average life expectancy, and greater susceptibility to illness for people with intellectual disabilities as compared to the non-intellectually impaired population. Furthermore, it highlighted (as had *To Have an Ordinary Life*) the higher than average dispensing to people with intellectual disabilities of prescription medications (more than twice the average rate than for people with non-intellectual impairments).

The Ministry of Health confirmed in an Official Information Act response in June 2012 that minimal progress had been made on dealing with the health care issues facing people with intellectual impairments. The Ministry confirmed that it had no information regarding the inappropriate prescribing of outlawed medicines and other psychotropic medications for people with intellectual impairments in the five-year period covered by this monitoring review (2007-2012).

The Ministry, however, stated that it had progressed some work on the *To Have an Ordinary Life's* report recommendations relating to health care provision. This included the publication of the health indicators report and supporting the roll out of the Health Passport. It also referred to the enhancements being made in community pharmacy services, including for people with intellectual impairments. On this last point, however, the Ministry did not specifically address the question asked about the dispensing of outlawed and psychotropic medications asked of it.

In 2012, two informant interviewees from the intellectual disability sector noted that minimal progress had been made in addressing the issues raised within the *To Have An Ordinary Life* report. The interviewees noted that amongst the positives had been action on introducing a Health Passport system (see below) aimed at people with intellectual impairments, the example of the employment of a specialist learning disability nurse by Mid Central District Health Board (North Island) and the work done by Special Olympics New Zealand in rolling out the Healthy Athletes screening programme and their Health and Wellness Programme.

Chief Human Rights Commissioner David Rutherford has also continued to advocate on the issue of needing to remedy the poor health status of people with intellectual impairments. However, the interviewees noted that whatever positives there had been had been rare, otherwise, in their view, successive Governments had not significantly acted on the report's recommendations. They both reiterated that serious systemic discrimination continued in the form of, for example, medical specialists advising families to terminate life support for people with intellectual impairments who had serious but still treatable illnesses, for example, pneumonia.

Neither has any Government funded systemic health screening programme for people with intellectual impairments been established as per the report's recommendations. The New Zealand Special Olympics Healthy Athletes programme and the nation's largest community supported living provider are the only providers of regular health screening programmes. Furthermore, the interviewees stressed that intellectual disability service providers and not central Government had carried the cost of setting up and administering intellectual disability-focused health initiatives. The interviewees believed that there was a need for another *To Have an Ordinary Life* report outlining progress to date and the deficits that remained. They strongly believed that the Ministry of Health should convene a group of interested parties to develop a blueprint for systemic change in the area of health care for people with intellectual impairments using overseas models as a guide and developing a publication surrounding best practice in this area.

The Health Passport initiative is currently being trialed and it is hoped it will be progressively implemented within District Health Boards around New Zealand. This passport enables disabled people to record information about their impairment and how it impacts on them when using a health service or accessing a hospital stay. This would enable health services staff to have a better understanding of a person's impairment based needs and facilitating better communication between them and disabled service users and their families.

As of 2011/2012, Hutt Valley District Health Board, Capital and Coast District Health Board and Waitemata District Health Board are piloting this initiative. Staff are being trained to support disabled health service users to use the passport effectively. The two informant interviewees from the intellectual disability sector acknowledged the usefulness of the system but also disclosed that some hospitals were not recording the identified needs of Health Passport users on their permanent hospital files for future reference. Instead, these hospitals were expecting Health Passport holders (or their family members) to remember to bring their information with them to every visit, meaning greater potential inconvenience for all parties concerned.

Overall, though, feedback compiled by the Health and Disability Commissioner (2010) found that many disabled health consumers and their families were positive about the Health Passport concept and even suggested its extension into other health service environments including rest homes and mental health service settings. This programme has the potential to improve access to the same range, quality and standard of health without discrimination on the basis of disability. Further, the programme will go some way towards promulgating more ethical standards in health care for disabled people and, in particular, could assist in improving health outcomes for people with intellectual impairment.

Convention Coalition members noted two specific issues around health consent and disability. These pertained to doctors ignoring advanced directives to resuscitate that have been made by disabled people and also that the Mental Health (Compulsory

Assessment and Treatment) Act 1992 makes no reference to the right of mentally ill people to refuse treatment on the same basis as non-mentally ill people.

Dignity: New Zealand only does the minimum necessary to ensure that disabled people can receive health care services with dignity. More is being done to improve this situation in terms of developing programmes (such as the Health Passport) which stresses the rights of disabled people to receive adequate health care on the same basis as non-disabled people.

Autonomy: New Zealand has made progress in this regard but still has a considerable distance to travel in terms of fully permitting ALL disabled people to make more decisions regarding their health care independently (with the support of advocates where appropriate). This is highlighted by the issues around the inappropriate prescribing of illegal and psychotropic medications to people with intellectual impairments. However, the development of the Health Passport and the employment of specialist nurses do portend positive developments that could go some way towards addressing these and other disability-related health access issues.

Participation, Inclusion and Accessibility: New Zealand has made progress in involving disabled people in wider decision making relating to health care issues affecting them. Inclusion and accessibility has also been addressed in some regions of the country as evidenced by the case of the Capital and Coast District Health Board seeking to make its health services and decision-making processes more accessible and inclusive for all disabled people. However, this is counterbalanced by the fact that different District Health Board regions have taken different approaches to disability issues meaning that the level of participation by disabled people in decision making and their access to services varies from region-to-region. While the Ministry of Health has intervened to address equity issues for disabled people within the health system, the evidence suggests that this is not happening in a significant enough way to effect wider, nationally consistent, systemic change. Physical access issues regarding screening and family planning programmes, particularly for disabled women, also need to be addressed.

Non-discrimination and equality: Much evidence points to the fact that despite the improvements to health service access for disabled people that have been noted, there has been minimal discernible change in the health status of disabled people. The empirical evidence that people with intellectual impairments experience far poorer health outcomes than the general population is proof of the fact that disabled people (and especially this group) cannot access health services in an equal and non-discriminatory way. While the Health Passport and other initiatives mentioned in this document are seeking to redress these inequalities, there are other slated policy moves (such as the Government’s proposed increase in prescription charges) which could undermine any further progress in improving the health status of disabled New Zealanders.

Respect for difference: Given the evidence around how medical professionals treat intellectual and other impairments (in terms of reproductive rights for women pregnant with children who may have Down syndrome), the medical profession and health workers in general need to gain a better, social model based understanding of disability issues. Initiatives, including the appointment of specialist nurses in the field of intellectual disability, do show some promise in this regard.

Overall rating: ** Needs significant improvement.

Summary of Article 27: Employment

Do the laws or the Government policy ensure that people with disabilities can access work on an equal basis with others?

Section 22 of the Human Rights Act 1993 prohibits discrimination in employment on one or more of the prohibited grounds of discrimination in section 21.

There is, however, provision where an employer does not have to provide remedial means to accommodate an employee with a disability if it is deemed as unreasonable for the employer to do so or if doing so would result in an unreasonable risk of harm (Human Rights Act 1993, section 29).

Under section 104 of the Employment Relations Act 2000 an employee is seen to be discriminated against if the employer refuses to offer the employee similar terms of employment, remuneration, training, or promotion in the same way as other employees of substantially similar qualifications and experience based on one of the prohibited grounds of discrimination. The prohibited grounds of discrimination under section 105 replicate the prohibited grounds of discrimination in the Human Rights Act 1993.

In 2008, the largest number (27.7 %) of complaints concerning disability discrimination to the Human Rights Commission were regarding employment. Human Rights Commission and the Office of Human Rights Proceedings “*Annual Report 2008*” (2009) www.hrc.co.nz, "*Annual Report 2009*" (2010) www.hrc.co.nz, and "*Annual Report 2010*" (2011) all show discrimination in employment for disabled people.

The Equal Employment Opportunities Trust stated that only 43.6 % of persons with disabilities participate in the workforce compared with 69.8% of persons who do not have disabilities. Statistics show that employment rates for adults with disabilities are: Māori 45% (67% non-disabled Māori adults); non-Māori 62% (77% non-Māori non-disabled adults). Equal Employment Opportunities Trust “*Disability Factsheet*” www.eeo.org.nz shows there are, however, instances (although not many) of people with disabilities being employed and being well accommodated in the workforce.

In *Isaac* v *Chief Executive of Ministry of Social Development* the Judge held that the Ministry (the employer) “not only took all practicable steps to assist Ms Isaac in her daily functions, but went the extra distance.”

In *Aubrey* v *Department of Child, Youth and Family Services* the Judge also held that Mrs Aubrey was not discriminated against because of her disability because her needs were sufficiently ascertained and met.

Other than the anti-discrimination principles as set out in the Bill of Rights Act 1990, the State has no policy that encapsulates the principle of equality of opportunity for disabled people. Several statutes and organisations however have equal employment opportunities policies and provisions. Examples are: Local Government Act 2002 s40, the State Sector Act 1988, Long Title, and the Crown Entities Act 2004, s12.

Section 77D of the State Sector Act 1988 defines an equal employment opportunity programme as one that is aimed specifically at the identification and elimination of all aspects of policies, procedures, and other institutional barriers that cause or perpetuate inequality in respect to the employment of any persons or group of persons. There is also an Equal Employment Opportunities Trust which provides help to employers on diversity issues, including on accommodating persons with disabilities.

Disabled people have the same access to most legal safeguards as all other workers, including protection against harassment, unfair dismissal, and trade union rights. Discrimination on the grounds of disability in employment is unlawful both under employment law and under general anti-discrimination law, which impose a duty of reasonable accommodation. It is however also reasonable accommodation that allows for exemption of employers from employing disabled people on certain grounds.

Anti-discrimination law does not accommodate for affirmative action measures to be used to redress disadvantage experienced by disabled people.

All employers' health and safety obligations require employers to take all practical steps to eliminate hazards, which could include harm arising from bullying or harassment, whether by the employer, by other employees or otherwise.

The law requires both public and private sector employers to be subject to particular duties towards disabled people.

Within the public sector, the State Sector Act 1988, the Crown Entities Act 2004 and the Local Government Act 2002 promote the interests of disabled people through the promotion of equal employment opportunities.

Public sector employers are subject to a specific duty to act as a “good employer”. Particular emphasis is placed on public sector employers to provide the following:

- good and safe working conditions for all;

- impartial selection of suitably qualified personnel for appointment; and
- recognition of the aims, aspirations and employment requirements of disadvantaged groups, including disabled people.

In contrast, private sector employers are subject to less specific duties of good faith and mutual trust and confidence, which reflect similar principles.

Wage rates, including minimum wage protections, make no distinctions for disabled people. Under New Zealand’s former sheltered employment system, people working in sheltered employment were exempt from general wage. With the closure of sheltered employment, the general exemption of their employment from general wage and working conditions ceased in March 2007. In its place, there is a limited scheme for individually-assessed exemptions that allow reduced wages to be paid according to individual productivity. Approximately 1,200 individual workers remain under such exceptions, principally in the remaining sheltered workplaces, now called business enterprises.

The Minimum Wage Act 1983 gives provision for Labour Inspectors from the Department of Labour to consider issuing minimum wage exemption permits to workers who are limited by a disability in carrying out the requirements of their work. This means a lower minimum wage rate is set for a particular person in a particular job for the period in the permit.

In summary, although anti-discrimination law is outlined in the Bill of Rights Act and Human Rights Act, there are no affirmative action policies for disabled people in employment, despite a higher than average number remaining unemployed. There are exemptions in law for employers, under the guise of reasonable accommodation, to be able to be exempted from employing disabled people and there are exemptions under the Minimum Wage Act to pay some disabled people on assessment less than the minimum wage. Under Welfare Reform, the Government is in the process of introducing an investment approach — providing more help to obtain employment for those who are most at risk of long-term benefit dependency. In the current economic climate, it is a concern as to how this will be achieved fairly and equally, if at all.

Summary of Article 29: Participation in public and political life

Do the laws or Government policies ensure that persons with disabilities can fully participate in political and public life on an equal basis with others? No.

No one is denied the right to vote but not all disabled people are able to exercise their right to vote, or, because ballot papers are not provided in accessible formats (for example, Easy Read, Braille or electronic formats), to exercise their right to vote independently. They can nominate a person to assist them but then they must rely on the integrity of others to honour their voting choice. Online voting would resolve some of these issues.

The Ministry of Justice provides information on accessible polling booths, and provides election workers with disability awareness training. Some resources were developed to educate the community about the election process.

However, there is no provision to accommodate people (including disabled people) who are unable to get to a polling booth (although the website states that people who are unable to get to a polling place or advance voting place in their electorate can apply for special declaration voting papers to be sent to them). Lack of accessible transport may make it impossible for some disabled people to get to polling booths.

Other disabled people are denied access to the information required to make an informed vote. Televised political broadcasts are not captioned, excluding Deaf and hearing impaired people from accessing a major source of pre-election political information.

Political parties do not qualify for funding for sign language interpreters at political meetings which means that Deaf people may be unable to access information on the policies of various political parties in an equitable fashion. However, even if this issue was remedied there is a second systemic issue that excludes Deaf people from political information, namely the lack of sign language interpreters. For instance, Blenheim, a town with a population of 30,000, has a sizeable Deaf community but no resident interpreters.

The lack of interpreters is even greater for Māori Deaf, with just two trilingual interpreters in New Zealand. The issues around funding for sign language interpreters and the lack of captioning on political broadcasts demonstrate gaps in the Electoral Act 1993 and in the New Zealand Sign Language Act 2006. These gaps prevent significant numbers of disabled people from accessing the required information needed to make an informed vote.

In 2010 a participant mentioned that the offices of several political candidates were in inaccessible buildings. If political meetings are held in inaccessible environments physically disabled people are unable to participate.

In Auckland, the local government created ethnic advisory boards but not disability advisory boards despite many submissions to do so. None of the existing disability advisory committees are protected by law at local government level and could be disbanded on the whim of the elected officials.

Māori disabled do not participate in non-governmental organisations and in political parties as much as non Māori disabled, despite having higher levels of disability than non-Māori.

Autonomy: The lack of online voting means that many disabled people who would like to vote independently are unable to, which violates the principle of autonomy. Also disabled people who are unable to physically get to a polling booth cannot exercise their right to vote.

Non-discrimination and equality: Not all, but significant numbers of disabled people, cannot exercise their right to vote in the same way as non-disabled people, in both local and central government elections. The lack of provisions for disabled people violates the principle of non-discrimination and equality.

Overall rating: Needs significant improvement.

Summary

Ratings for Articles

Article 9	Accessibility
	Rating: ** Needs significant improvement (x4)
	Rating: *** Generally compliant or needs only slight adjustment
Article 17	Integrity of the Person
	Rating: Not rated
Article 19	Inclusion in Society
	Rating: ** Needs significant improvement
Article 25	Health
	Rating: ** Needs significant improvement
Article 27	Employment
	Rating: Not rated
Article 29	Participation in public and political life

Rating: ** Needs significant improvement

In almost all cases, monitors found that significant improvement is required in regard to the aspects investigated. Most systems were found lacking in the extent to which autonomy and non-discrimination and equality are legislated and/or practiced. In some cases, dignity (articles 9 and 25), participation, inclusion and accessibility (articles 9 and 25), and respect for difference (articles 9, 19 and 25) were also found wanting.

CHAPTER FOUR — COMMON THEMES AND IDEAS FROM CONSULTATIONS

Introduction

The following is a synthesis of information gathered during the consultation phase of the project. Each of the six key areas is discussed in terms of issues raised by respondents. It also includes ideas from them relating to how things might be improved for disabled New Zealanders in future.

Lack of access was the issue most often raised by project participants, together with negative societal attitudes. Access issues included lack of accessible transport, housing, public buildings, information and inclusive education. Also mentioned by many participants was a lack of choice about where to live and with whom.

Social isolation

It was frequently noted by project participants that disabled people are not valued by society. Little opportunity exists for disabled people to join in recreational activities and many other aspects of daily life, due to lack of acceptance and lack of money, exacerbated by lack of access to employment opportunities.

Non-compliance with the Building code featured strongly in discussions, with many calling for this to be updated, strengthened and above all, enforced.

Many people spoke of their past experiences of education as disabled children, while others provided information about the present day situation for disabled children. Issues included:

- Lack of robust education policy regarding inclusion of disabled children — “*schools don’t have to accept disabled students*”.
- Lack of willingness by teaching staff to ensure disabled children are included in structured or informal play.
- Several people spoke of Teacher Aids paid to support disabled children, being used to assist with other children in the class, “while the disabled child languishes at the back of the room”.

Ideas for improvement

- A number of people noted that New Zealand has generally sound legislation but that this needs to be well enforced — “*We’ve relied on good will for too long, it’s now time to enforce the legislation we already have, including stronger penalties for non-compliance*.”
- Instead of the current in-house Accident Compensation Corporation complaints system, a more comprehensive and independently robust

complaints authority should be established with urgency — perhaps one managed by the NZ Law Society?

- All stages of planning and implementation of public building and transport systems must include disabled people as partners.

- All grants from the Lotteries Commission for building projects, should carry a proviso that ensures buildings are universally designed, built and audited for access.

- Review, update and strengthen the Building Code and ensure penalties for non-compliance of updated mandatory standards.

- Fund remote microphones in classrooms, for children with auditory processing disorders.

- Include disability studies and disabled people as part of the general school curriculum.

- Fund the provision of disability focused customer service training to private sector businesses, funded by the private sector and provided by qualified disabled trainers.

- All funds granted for sporting or artistic/cultural endeavors should include a disability focused portion, to ensure inclusion of disabled people.

- Disability sector agencies should provide more opportunities for social interaction.

- Flexible Individualised Funding for those who require this, would greatly improve access to recreational opportunities and inclusion by disabled people.

Health

A recent rehabilitation workforce service forecast, recognised that:

> "*There is no comprehensive rehabilitation system in New Zealand. Provision of, and access to, rehabilitation services is fragmented and varies greatly between regions. The main funders of rehabilitation — the Ministry of Health, Accident Compensation Corporation and District Health Boards — all purchase different components of rehabilitation leading to the provision of varied and often inequitable services and therefore, different outcomes for clients. Services are provided through public and private providers in in-patient, outpatient, community and home based settings*."

It is further noted that, as a population, Māori have on average the poorest health status of any ethnic group in New Zealand — see http://bit.ly/JyrFmW.

Many disabled people spoke of their lack of access to information, in alternative formats including Easy Read. One blind respondent noted:

> *"...the health system does not provide information to blind people in ways which are accessible. Prescriptions have printed labels, and we can never be sure that the directions are read in full or correctly. Lack of information about what is being prescribed, and when it should be taken, presents a significant health risk*."

There were many calls for better pay and working conditions, for home help workers, funded through the Needs Assessment and Services Coordination services. There were also many who felt they do not receive the level of support appropriate to their circumstances. One DeafBlind person said:

> "*Over the past twelve years I've had help with household cleaning from health-funded agencies. The idea is good … but whether services are successful depends on the quality of staff and of management. I have found most agencies to be unreliable, sometimes dangerously so. I have been let down after surgery several times and was left to cope recently, after catching the hospital bug. I should have had someone at my home in the mornings for showering, breakfast*

> *and help with drugs. The agency simply refused to provide this service. My Needs Assessment gives me seven hours weekly but no agency has ever allowed this. I currently get one hours' cleaning weekly. No provision is made for emergencies or emergency food shopping. Because I cannot use the telephone the agency never advises when arrangements are changed, even though I have email and fax*."

There is a strong need to focus attention on those communities which are most likely to miss out on care. These are frequently the same communities that suffer poor health in many other respects and have most difficulty accessing high quality and timely health care.

> "*The Māori population is disproportionately affected by impairment — for example, the overall prevalence of vision impairment and blindness in Māori aged 45 to 74 years is twice that of non-Māori*."

Many disabled people expressed the view that people sustaining injury and incapacity as a result of an accident fare better in terms of service delivery, rehabilitation and care than do people who have sustained incapacity through illness or congenital disability.

> "*If a leg or sight is lost through diabetes, the overall outcomes are likely to be less favorable than if sight or a leg was lost as the result of an accident*."

A detailed submission from the Phoenix Group (contained in Appendix Four) discusses the use of seclusion under the Mental Health (Compulsory Assessment and Treatment) Act 1992.

> "*While there are provisions under the Mental Health (Compulsory Assessment and Treatment) Act 1992 that provide safeguards as described in Article 12-4, we do not believe that those safeguards are sufficient, nor are they 'proportional to the degree to which such measures affect the person's rights and interests'. We believe that the use of involuntary seclusion (also known in prisons as detention in an 'At Risk Unit'), i.e., the isolation of individuals in a locked room without their consent, contravenes the rights of such persons under Article 15 — 'Freedom from torture or cruel, inhuman or degrading treatment or punishment'.*

> *There is considerable research evidence internationally to support the view that seclusion is harmful, and that it can be avoided by adopting models of care that preclude its use, and provide for sufficient staffing and adequate facilities to protect the safety of all persons involved in the support of people enduring severe mental distress*."

One mental health consumer consulted for the report stated:

> "*In New Zealand people can remain under a compulsory treatment order for an indefinite time, and patients can remain under the act for many years. There is no finite term providing the patient continues to meet the criteria of being 'mentally disordered'. This has an effect on where a person can live, driving restrictions and overseas travel*."

Other issues raised included:

- a lack of statistics about disabled people using health services;
- mobile breast screening vans being inaccessible;
- disabled people not being informed of side-effects of prescribed medications;
- advanced directives being overruled by clinicians.

It was reported that people with intellectual impairments live an average of twenty years less than the general New Zealand population. It was also noted that abortions are arranged on the basis of disability past the normal cut-off date for non-disabled fetuses. One participant told of "underground hysterectomies still being forced on disabled girls".

The issue of negative attitudes on the part of health practitioners arose frequently. This most often related to one of three issues:

- people with existing impairments being denied access to mainstream health care, such as breast and cervical screening and flu vaccinations;

- people with dual diagnosis being unable to access treatment for a range of illnesses; and

- those seeking assistance with health problems not related to their impairment, nevertheless having the health problem attributed to this.

A “no cure, no treatment” attitude also seems to prevail.

> “*It took me three months to get a simple cataract operation to enable me to go off strong pain medication and go back to work, but the specialist fought it all the way, because I would still be blind at the end of it*!”

One contributor said her dealings with the Accident Compensation Corporation amounted to “bullying, lies and cheating,” on the part of the Corporation. She pointed to many assessments and reviews of her case, noting this has cost many thousands of dollars over the years since her injury.

> *“Some claimants have taken their own lives, some have lost partners through breakdown in their relationships and others have lost not just their ability to provide themselves with an income, but sadly have lost their homes too!”*

Ideas for improvement

- All brochures and medication labels should reflect the European Blind Union’s standards and be written in an Easy Read format.
- Ensure disabled people have equitable access to our own medical information, in a way most accessible to us.
- Fund training provided by qualified disabled people, about disability rights and supported decision making, for health professionals.
- Ensure that all District Health Board contracts require disabled people to be included as partners, in all aspects of contract planning and development; and that this is monitored, perhaps by the Health and Disability Commissioner.
- Include disabled people as part of the general population, in health promotion campaigns.
- The New Zealand Government must hold a full enquiry into the work and remuneration of carers/support workers, with a view to increasing expectations, that is, more highly qualified staff who receive better pay.
- Disabled mystery shoppers could be employed to check out various health services/providers and report back to the Ministry of Health and/or Accident Compensation Corporation.
- The New Zealand Government should legislate to eliminate seclusion from all mental health-related detention facilities, including “At Risk Units” in prisons.
- Introduce the Health Passport.

Employment

> "*I have a Masters degree and heaps of life experience but it's really hard to get these taken seriously when all employers can see is my guide dog*!"

The importance of work in New Zealand society can not be overstated. Employment is very often viewed as the major defining measure of a person's worth and social status. Paid work is an important source of self-esteem and financial independence, for those allowed to participate.

Despite business interest in the advantages of programmes promoting equal employment opportunities for groups such as women and Māori since the late 1980s, disabled people continue to be greatly under-represented in regular public and private employment settings. Health and safety considerations are often cited by employers as reasons not to employ disabled people. Even when disabled people are employed, we are subject to occupational segregation, often working at basic grade casualised, and part-time jobs, for minimal remuneration, with few opportunities for upward mobility.

Many project participants quoted the statistic: that 60% of disabled New Zealanders of working age are unemployed.

Several unemployed disabled people participating in the project expressed the view that the Mainstream Employment Programme, provided by Work and Income New Zealand, is grossly underutilised.

Much discussion took place about both the 90-day rule and Minimum Wage Exemption Permits.

The Department of Labour website notes that: "Employers can make an offer of employment that includes a trial period of up to 90 days. Trial periods are voluntary, and must be agreed in writing and negotiated in good faith as part of the employment agreement." This is known as the 90-day rule. Many disabled people said they had been "let go" after 90 days in a job and that they were sure this was due to their impairment(s), rather than their ability to do the job.

The Minimum Wage Exemption (formerly the Under-Rate Worker's Permit) was discussed at some length and many respondents said they had been employed via these permits. The Department of Labour website states that: "The Minimum Wage Act 1983 provides that Labour Inspectors from the Department of Labour may issue minimum wage exemption permits to workers who are limited by a disability in carrying out the requirements of their work.“ This means a lower minimum wage rate is set for a particular person in a particular job for the period in the permit. "I was employed in a factory for over a year before some kind person told the boss he could get away with paying far less for me than he had been paying" Disabled people are the only group in New Zealand discriminated against in this way. It was felt that the very existence of the exemption contributes to the negative attitudes of employers towards disabled people.

Other issues discussed by project participants included:

- Recruitment agencies being used by most State Service departments and many disability sector agencies, "to filter disabled people and other undesirables out of the recruitment process".

- Lack of flexibility regarding working hours — many disabled people want part-time work.

- Lack of second-hand computer technology for blind and vision impaired people seeking work — to enable "a foot in the door" while awaiting approval and arrival of up-to-date equipment.
- Employment costs disabled people additional money which is not recognised.
- Entitlement to home care support is withdrawn from employed disabled people — who feel they need the support even more when working. *"... if people get good quality home help services, the notion of 'an ordinary life' has real meaning because work becomes more possible*."
- Lack of funding for creative solutions for a variety of employment options.
- Unnecessarily complex employment contracts –"*people can end up in debt because they don't understand the terms of their contract*."

Ideas for improvement

- Make the Disability Allowance available "as of right" to all disabled people, regardless of employment or marital status, at a realistic amount.

- Abolish the minimum wage exemption permit and the 90-day rule.

- Temporarily introduce a quota system, to ensure disabled people are exposed to the labor market.

- Train employers about what job-related "reasonable accommodation" is, how to interview someone who is deaf, blind etc, and how to make the workplace accessible.

- Establish an equipment bank and provide older technology items to disabled jobseekers for free, to get them started in work.

- Introduce penalties for employers who discriminate on the basis of disability and make the burden of proof the employer's instead of the disabled person's.

- Fund the provision of training, by qualified disabled people, to recruitment agencies.

- Recognise and promote good employers.

- All Government Ministries and Departments should have a policy which ensures that any disabled staff, disabled contractor or disabled committee member receives the support they require to do their job, as of right and without having to constantly request this.

- Gather together a group of accessible employers and paid disabled people, to undertake a road show to illustrate how it can be done!

- Fund the provision of employment-related mentoring programmes, by and for disabled people.

Access to disability related services and supports

Lack of consistency, choice, funding and respect for consumers dominated this area of discussion.

A major issue highlighted was the need for well qualified and well paid support staff in all agencies working with aged and disabled people. It was strongly felt that care is variable and consumers are more vulnerable to exploitation.

> "*You know you are not valued by society when you are cared for by someone who is paid just $13 an hour to provide personal support. No wonder that these roles often attract people who commit offences against the people they are meant to be caring for.*"

It was felt that Government funding is generally inadequate to ensure high and consistent standards of service are provided by disability support agencies to consumers. Poor funding was felt to lead to the employment of poorly or completely unqualified disability support agency staff who are paid only the minimum wage — sometimes leading to bullying and coercion of consumers. There was a general call for greater accountability from disability support agencies and greater participation by disabled people in their management.

Many disabled people in 24-hour care, do not have any rights to choose, independence or privacy. People with intellectual impairments often do not know what the policies are in their homes. "*We sometimes have new staff every week. There is no choice for us. We want to be treated like adults and live with people we choose*."

There has been no apology for abuse in institutions. "*What settlements there have been, have been hushed up and made on a case by case basis*."

Many people with intellectual impairments made similar observations to this: "*We're not listened to, not taken seriously — like staff smoking, there seem to be different rules for staff and residents*."

Although not strictly relevant to this section, some people spoke of: "*The Adoption Act (section 82) — disabled parents can have kids removed without consent*." "*Right to be a parent denied — initial work done but not followed up*." "*Disabled people continue to have children removed at birth*."

Ideas for improvement

- Establish self-determination related systems within disability sector agencies, where boards and staff of service providers are disabled people.

- Fund general advocacy and self-advocacy services.

- Provide access to supported decision making for all disabled people who need this.

- Produce more information regarding services, in all available accessible formats, to help disabled people choose the right service for them.

- Establish a working group of qualified disabled people and Workbridge staff, to review the administration of Support Funds, using the Individualised Funding model, enabling disabled people to decide how their funds are used, for example, for Sign Language Interpreters, within each year, rather than being restricted to a certain amount per month and losing any residue.

- Provide effective monitoring, auditing and evaluation of disability support services, by disabled people.

- Establish policies whereby disabled people, living in residential services, sit on interview panels for their staff.

Barriers to making complaints

Disabled people have access to a number of mechanisms for laying complaints. A degree of knowledge and skill is required in order for these to be effective. Complaints are often about aspects of the disability support system, but they need not be. The right to complain applies to everyone, and disabled people can and do have grievances identical to non-disabled people – with banks, utility companies and so on.

> "*Becoming disabled through injury by accident, whether by occupation, home or sports origin, that person will have their life permanently changed. We do not ask to have the disability our consequences present and it is in many cases a major challenge to us to learn to cope daily and live with how we are now. In my 22 years of living with my occupational injuries I have experienced barriers to making a complaint, which at times have become insurmountable*."

Disabled people report feeling insecure and unsafe complaining, particularly where services are provided in isolation - fear of retribution and not receiving any ongoing service if they complain.

Issues raised about making complaints included:

- Many disabled people simply do not know who to complain to.

- Lack of time and energy to complete lengthy complaints processes - slowness of results.

- Complaints processes are often inaccessible.

- Process is often too complex and long-winded.

- Too many people involved.

- No follow-up.

- "*Complaints are a waste of time, because nothing changes*."

One participant spoke of his disappointment at having the information he had forwarded to a staff member at the Human Rights Commission, lost on the day of the conciliation meeting.

Ideas for improvement

- Fund independent advocacy services that put disabled people at the centre of the process.

- Streamline complaints processes, to make these accessible and simple, include a peer support person (a navigator) where necessary, and ensure outcomes are timely.

A resolution was unanimously passed at the Auckland forum, calling on the New Zealand Government to ratify the Optional Protocol to The Convention.

Lack of disability awareness

All those who participated in the project agreed that "*awareness is not enough, we need responsiveness, empowerment and respect*." Nothing about us, without us was heard often during the consultations.

Many people felt that much of the problem relates to the negative images and stereotypes of disabled people portrayed in the media. Reporters and others continue to refer to “the handicapped”, “the wheelchair bound” and describe people as suffering from and being victims of, their impairment(s).

> “*A few days ago I heard a radio announcer ... saying that in his opinion he thought that people with mental illnesses should be placed into an institution and given shock treatment like they did fifty years ago to make them behave*.”

People also spoke of the “supercrip” syndrome, whereby disabled people are promoted only if they “*look good*”, “*can perform an amusing party trick for the camera*” or “*do some pretty ordinary thing which the journalists consider amazing, because the person is disabled*”.

Ideas for improvement

- Fund training of disabled people, by disabled people, about rights and self-advocacy — this investment will assist disabled people to display their own capabilities.
- Bring disability in from the margins — include disability related programmes in prime time viewing and listening.
- Establish a Disability Commission and appoint a Disability Commissioner.
- Hold a national campaign, similar to Like Minds, to promote positive and favorable attitudes towards disabled people.
- Ensure recipients of complaints accommodate the communication techniques of the complainant.

Issues and ideas for improvement identified by Māori

In summary, all aspects of disability support services focus on treating the disabled individual. The needs of the whānau are not considered, often to the detriment of both the whānau and disabled people. They have to fight for everything and the strain has proved too much for some, it is not uncommon for whānau to split up as they struggle to care for disabled relatives. Focusing on and supporting the needs of the whānau will ultimately ensure better outcomes for disabled people too.

Social isolation

As parents of teenagers with disabilities social inclusion for their children is problematic. Attitudes from all sectors of society and at all levels is a barrier to inclusion.

On one occasion an autistic teenager was transported to his destination and told by the taxi driver that he could not bring him home. The driver failed to let the boy's mother know and if not for the boy's teacher passing by he would have been abandoned. On another occasion he was not strapped in to the taxi correctly as the driver was in a hurry and he was instead told to 'hang on' to the inside bar. Experiences like this scare disabled people and their whānau sometimes to the point where they won't use public transport.

When wheelchair users go to concerts they must sit in the designated wheelchair area but their non-disabled friends can't sit with them.

Implicit beliefs about disabled people not needing the same rights that other people have, and the lack of willingness from individuals and organizations, leads to young disabled people not being included in activities with their mates.

The whānau of disabled people also experience social exclusion, for example, during family outings. They are socially excluded because of physical and other barriers. As one mother said, “*We can't take our kids to places that we would like to go to. It doesn't only affect our kids, it changes our lives too*.” Moreover, inadequate support means that parents of disabled children have to sacrifice their own social lives to look after them.

Social isolation is one of the results of a society which does not value people (and their whānau) who live with disabilities.

Health

A lack of understanding and disability awareness within the health system has caused problems for disabled Māori.

On one occasion a mother’s multiply impaired son needed dental work done. After it was completed in hospital his mother was told that she was “to take him home”. She said that she objected to this as her past experience was that he needed to stay in for a while to ensure that he would be okay and to allow her to reactivate carer support. The hospital staff saw her as a nuisance because her son was “bed-blocking”. However, it takes time to organise people to care for her son and she cannot get her teenage son out of bed because he is too heavy and has to stay in bed all day.

The whānau of a disabled teenage girl found that hospital staff do not appreciate that she and her whānau do not want male nurses looking after her.

The whānau stay and provide the care themselves and are seen by the staff as “interfering and difficult”.

Recently the girl had eye problems and the family were told on more than one occasion when seeking medical advice, to just “wash her eyes with baby shampoo”. Not being satisfied with this the mother took her daughter to see a specialist privately. The specialist said that she needed an operation and that this should have been “picked up” by the medical staff who had looked at her daughter's eye.

Hospital staff expected the whānau of disabled Māori to know and remember all of the details of their children's hospital admissions going back years or even decades. When asked if they used Health passports one mother replied: “*What is the chance that they (the medical staff) are going to read the passports — they don't read the notes now. They just don't know how to manage or speak to our kids and they expect us to have to “educate them.*”

Health systems are problematic because of their reluctance to value and understand and therefore respond appropriately to the needs of a person with a disability and their whānau.

Employment

The mother of a disabled teenage boy said that it is not possible for her to work any longer because of the problems that she faces with managing her son’s care. She gave up work to look after him because carers and care agencies aren’t reliable. If she isn’t there her son can’t advocate for himself and his needs go unmet. She would have liked to have a normal life and job but managing her son's multiple needs was “just too difficult” for a system which is “strapped for cash” and therefore does not provide the support necessary for care to be provided for a parent to work.

Looking after her son on a benefit is tough and any work she has done for her son is unpaid due to the Ministry of Health policy of not funding family/whānau to support their disabled children.

Another mother of a disabled girl had undertaken librarian training however, she soon realised that it was “easier” for her to do paid work in the disability sector herself because when she had to be there for her girl they understood. Even so, it is a tremendous strain and while it would be easy to chuck in her job she wants to set a good example for her daughter and needs it for her own self-esteem.

The young disabled people have their own aspirations but based on how society treats them they had ‘little faith’ that the system would find them jobs.

Work and employment is a barrier for both people with a disability and their whānau as all struggle to manage the day to day problems that arise from living in a society which does not make a place for difference, does not provide the resources necessary and does not appreciate the difficulties.

Access to disability related services and supports

The whānau of disabled teens want to employ support workers of a similar age, but because of the way that the system is funded young people “don’t want to do their own PAYE—– so they don't apply”.

Also the whānau indicated that the Accident Compensation Corporation accommodating disability needs often required them to sacrifice their culture.

> “*Our culture is Māori, our children are Māori first and they just happen to have a disability. Instead we are expected to choose between the two all the time and sometimes we have to because of the way the services are structured*.”

This means that the workers who they employ to support their children are not always the people they would choose to employ.

Access to disability related services and supports was seen as being “patchy” and disconnected and fragmented. Everyone you speak to tells you something different.

Disabled Māori are tired of agencies that don’t appreciate the demands it places on them and their whānau and don’t do anything about it.

One disabled man had not been seen by his coordinator for five years, the coordinator did all his assessments by phone. When he complained about his footpath being inaccessible the agency wouldn’t come and view it unless he was there too. This meant he had to make himself available to satisfy the agency’s policy needs. They could easily have viewed the footpath without him being there.

The only option for respite care are rest homes where young high needs disabled people feel very upset at being lumped in with elderly people, whom they can’t relate to.

One solo mother hurt her back and requested extra help from the agency to support her disabled son three weeks later she got a reply. The agency wouldn’t help her because they could only fund her son’s needs.

The way disability services are run is seen as a barrier because of the separation of different groups and services. There is often a lack of follow-up which perpetuates a sense of isolation for families.

Barriers to making complaints

Barriers to making complaints were seen as a problem particularly because of the lack of understanding and awareness of what it is “like” to have a disability.

Whānau are frustrated by various sectors of society and government bodies and of being “stone-walled” as a result of there not being any one person or group in charge who has the ability and the resources to be able to effect positive change.

The main reason that they said that they felt this way is that there was a lack of understanding and appreciation and interest in their children. No-one understands what it is like to live day to day for the whānau of disabled people.

Not many people complain and those who do you are seen as trouble makers. One mother decided to take matters into her own hands over an education concern she had repeatedly spoken with the “right” people about. When nothing changed she decided to act herself and was ostracised for doing so.

Even complaints to the Human Rights Commission did little to help because of a lack of follow up. “*We are in the too hard basket and nobody wants to know*.”

The barriers that exist are structural, organisational, systemic, and arise from a belief that a person with a disability does not have the same rights and entitlements as an able-bodied person. They are marginalised because they are seen as not worthy and unimportant.

Lack of disability awareness

The whānau of disabled children indicated that neither they nor their children are supported or understood by a society that tries to “*make disability go away by ignoring it*”.

One mother’s child had started at a local bilingual high school but then after the powhiri she was asked to take her daughter home until the school was “*ready for her*”. This mother rang regularly to check on progress and after six weeks her daughter finally started school. The school hadn’t made any preparations so the mother assumed they were just hoping she and her daughter would go away.

Both mothers said that their lives were different from other people's lives in so many ways and that having a child with a disability meant that they too were constantly living with challenges, worries and disappointments. Disappointments were not as a result of having a child with a disability but rather living in a world that did not support their children and did little to understand or support them to live the best lives that they could.

Disabled people and their whānau are excluded from their communities by a lack of accessible and gender-neutral toilets. The mother of a disabled son said they toss a coin to decide whether they used women's or men's toilets. This also is an issue when carers of the opposite gender need to toilet disabled people.

In the post-earthquake environment in Christchurch, things that were already difficult are now even more so. Most accessible portable toilets were assigned to rest homes and institutions. Accessing medication was extremely difficult and of course the structural damage restricted access even more.

Ideas for improvement

- Make service providers and Government departments accountable at all levels for ensuring that we receive better outcomes. Please listen to what we are asking for, don't assume and don't make choices for us. We don't want pity —– we want support to do the best we can for our children. To do this it is imperative that whānau are supported. If a service provider does not believe in the work that they are doing and does not believe in us then they should not be there.

- Provide appropriate resources to enable our kids to get what they need and deserve so we can support them to reach their potential.

- Provide gender neutral or family disabled toilets so female carers/relatives don’t feel awkward about using male toilets and vice versa.

Commentary

Difficulties appear to be compounded for indigenous disabled people where disability remains an issue treated as something of causation rather than identity and where there is no article in The Convention. While indigenous disabled people are mentioned in the preamble, this was not developed further. Instead of having the ability to intervene in the planning stages of developing The Convention, indigenous disabled people were excluded and are subsequently facing invisibility through the lack of recognition of their identity as a specific marginalised group within an already marginalised group. Indigenous disabled people are a group not characterised as equal through their exclusion as an identity within the proposed Conventions and through their own multiple marginalisation. This is a problem specific to indigenous disabled people who have been colonised, although aspects of exclusion may also exist for “other” indigenous persons and sub-altern identities because of their identity as disabled people being classed as invalid alongside their peers.

While little is written on indigenous disability identity, work has been extensive in the area of colour and disability (Lawson & Gooding, 2005). Therefore, as indigenous disabled people are not included as a specific group in the text of The Convention, achieving equality has become more difficult as compared with their non-indigenous disabled peers, as they are inequitable in status and recognition. Given the statistics which show indigenous/first nations’ persons as being among the poorest of the poor (Quane, 2005), it makes sense to conclude that indigenous disabled people would be highly represented in those statistics. It is of significance to note the United Nations Declaration on the Rights of Indigenous Peoples (2007) does recognize the issue of marginalization for indigenous disabled people in Articles 21 and 22.

The problem is that countries such as the United States of America, Canada, Australia, and New Zealand have refused to recognise the United Nations Declaration on the Rights of Indigenous Persons as anything more than an aspirational document. This declaration therefore can only have strength if The Convention acknowledges it within its own structure and works towards action to improve the voice of indigenous disabled people. This action has yet to occur.

All three documents must be pulled together to ensure Māori with disabilities can break out of the negative statistics and under-representation in the disability and health sector.

References

Lawson, A. & Gooding, C. (Eds.).(2005). *Disability rights in Europe from theory to practice, essays in European law*. USA: Hart Publishing.

Quane, H. (2005). *The rights of indigenous peoples and the development process*. Human Rights Quarterly, 27(2), 652-682.

United Nations General Assembly, (2007. *Declaration on the Rights of Indigenous Peoples*.

Issues and ideas for improvement identified by Pasefika

Social isolation

Prolonged detention of mental health consumers prevents social inclusion.

Lack of Government employment programmes means disabled people don't have the income to participate in society. This also has implications for how they access health.

Lack of funding limits how many disabled people can access Government initiatives.

The language of policies and legislation is not user friendly. Even if a document is translated into a foreign language, for example, Samoan, there are some English words which don't translate into Samoan and vice versa. There is a cultural divide. Government agencies don't tell people what they are entitled to. Lots of Pasefika disabled people don't know they can access funding, for example, to assist with dental care or specialist appointments.

Disabled parents are only allowed to take one child at a time with them to social events, for example rugby, music concerts, etc.

The budget and monetary policies of Government Departments cause problems, that is, the need to spend what is allocated as any unused budget is subtracted from next year’s budget.

When partners separate/divorce, non-disabled spouses are entitled to claim half the value of disability modifications. For example a woman has modifications to her house for accessible bathroom, etc, valued at $16,000, and a wheelchair vehicle with hoist and hand controls valued at $100,000. The spouse is entitled to receive half of $116,000 under current divorce laws.

Health

Mental health users tend to be viewed as a risk financially and not included. Mental health consumers who show up to Accident and Emergency departments do not get treated for their illness/injury. Instead, the Crisis Assessment and Treatment Team is called in. Mental health consumers with broken bones are made to wait for hours without pain relief because of this District Health Board policy.

Some disabled people can’t get health insurance, or can only get it at exorbitant premiums.

Staff at mental health facilities violate patient’s rights by swearing at them in front of anyone nearby and by making them sleep on floors.

Abuse of seclusion: Seclusion/the threat of seclusion is used as a means of enforcing patient compliance when there is no risk of harm to self or others.

Families of mental health consumers are not allowed to bring food to their relatives.

Dissolution of Pacific staff units means Pasefika disabled are no longer assured their cultural needs will be met.

Employment

Good employers are few and far between

Employers see catering to needs as extra costs over and above employing non-disabled people. Employers aren't aware of funding to cover disability needs via Workbridge.

A hearing-impaired woman asked for a device ($300.00) to help her answer phones. When her work thought they would have to pay they said no, but after five months they applied to Workbridge and one month later she got her device.

Policies to get people into work have a "one approach fits all model" which doesn't suit people with a wide range of impairments.

Access to disability related services and supports

Attitudes of staff

Work and Income New Zealand found work for a disabled woman but it paid less than the benefit.

Home support

Health and safety regulations mean certain tasks don’t get done. For example, home support workers aren’t allowed to clean above a certain height for fear of injury but wheelchair users can’t reach the top of the fridge to clean it. There could be hygiene issues for disabled people in this situation.

Inaccurate assessment of client’s needs, agencies listen to needs assessors not clients. Disabled people assigned to unsuitable houses.

Clients sometimes assessed twice once by Needs Assessment and Services Coordination and once by service provider.

Disabled Parents don’t get extra help if they have babies and/or young children.

Barriers to making complaints

Human rights infringements and abuse are hushed up.

Culturally pacific people don’t want to cause a fuss and are reluctant to follow up complaints or challenge decisions. Also they don’t want to bring shame on their family.

Fear of retribution, for example, blacklisting, loss of support.

Not understanding rights/ breach of rights including the right to advocacy, or how to complain. Online complaints are difficult for pacific people due to lack of technological savvy and language issues.

Mental Health professionals dismissive of peer advocates and won’t let them in to advocate for others.

Mental health consumers threatened with institutionalisation for speaking up.

Lack of disability awareness

Most disabled people in ads on TV are able bodied actors.

Lack of Māori/pacific faces on the Attitude programme.

Ideas for improvement

- Government needs to frame policies and laws which include the cultural perspective of Pacific Nations peoples.
- Disability modifications/ equipment must be exempt from spousal divorce settlements.
- Television should show more examples of the positive aspects of disability in daily life, not just athletes and high achievers.
- Would like to see a disability perspective on the television show: TagataPasifika.
- The family of the disabled person is cursed, disabled people are broken and sick, many of the pacific words for disability have negative/derogatory connotations. Pacific People shocked at thoughts of disabled people having

sex/raising children. Disabled Pasefika people need to challenge those perceptions and develop words with positive disability connotations.

- Hold camps for disabled pacific people so they can socialise and have fun as well as giving carers a break.

- Need to engage with mainstream disability community to share knowledge and keep up to date with developments and opportunities.

Online Survey

It should be noted that the online survey was limited to those with the literacy and the computer skills to complete it. It does not capture the voice of people without these.

Seventy-three people took part in the online survey and one person submitted their survey in hard-copy. The following provides a brief overview of the questions asked and some of the feedback provided by contributors.

Social isolation

1. **Do you believe there are policies, programmes or laws that stop you from participating fully in society?**

Thirty-four (47.2%) of the 73 respondents agreed with the question. Of these, 35 people provided comments.

Most of the feedback related to disabled people feeling isolated due to lack of income and therefore choice. Funding for essential communications equipment such as hearing aids, and services such as Interpreters, also featured strongly.

Health

2. Are there any policies, programmes or laws which stop you from accessing good healthcare, such as immunization or breast screening?

Twenty-four (34.3%) of the 70 respondents agreed with the question. Twenty-six people provided comments.

Again, many people noted that funding was an issue with respect to accessing good healthcare and appropriate medication. Physical access to doctors' surgeries, the hospital environment and to mobile screening clinics, was noted by many contributors as difficult and sometimes impossible. Lack of access to information in accessible formats, such as Easy Read, Braille, large print or electronic formats and New Zealand Sign Language, was also a recurring theme.

Issues relating to discrimination in areas of everyday life were frequent. "As a mental health consumer I am not covered for travel insurance for my mental illness, although not having had an episode for 20 years."

Employment

3. Are you employed?

Forty-three (60.6%) of the 71 who answered the question said yes.

There were 28(39.4%) who said no and were asked to comment on any policies, programmes or laws that stopped them from finding the job they wanted. 26 people responded.

Several respondents spoke of some disabled people being unable to cope with regular work due to their medical problems, but noted they would like the opportunity to earn money in their own way and to have greater support from Work and Income New Zealand, Workbridge and the Mainstream programme to do this.

The issue of discrimination was particularly noted by mental health consumers and Deaf people. Several people raised concerns about disability disclosure: whether to disclose; how much to disclose; and whether they will be penalized for asking for support needs to be met.

> "*The issue is not policy but perception. As someone with an Autism Spectrum Disorder condition I am extremely fearful of job interviews. I am required to disclose my condition to employers, which I do not disagree with as it can affect my ability to perform in the workplace. My fear is of prejudice and ignorance. I have held previous positions in these areas and have frequently experienced a complete disregard for how my condition affects my ability to cope with stress and perform my duties, or what support or allowances I need to perform consistently*."

A blind person had this to say in the comments field of the survey:

> "*I think the real issue for employers, and anyone who does not experience disability really, is that, even though they can see blind people like me managing full and productive lives, they immediately think to themselves, 'I couldn't do that!' This translates in their minds very quickly into, 'no-one can really do that if they're blind!' My boss told me yesterday that he was frankly scared for himself, when he was advised last year that he would be managing a blind person. He then followed this comment up however by noting I am one of the few people he knows who actually gets things done and he really appreciates this.*"

Lack of access to funding for employment related programmes was noted by several respondents as preventing them from participating in employment. Many survey participants noted the need for greater disability awareness, responsiveness and genuine commitment among employers.

Access to disability related services and supports

4. **Are you happy with the support and services you get from agencies, like IHC, CCS Disability Action (Incorporated), Work and Income New Zealand, or the Ministry of Health?**

Forty-two (59.2%) of the 71 people who answered the question were not happy with the support and services they receive.

Many respondents raised similar issues relating to Work and Income New Zealand. These included being asked to see a different case manager each time they visit the office, general lack of disability awareness of staff and zoning of these offices being out of step with the geographical location of disabled clients. Other issues raised included communication difficulties with both Work and Income and the Accident Compensation Corporation.

Barriers to making complaints

5. **Are there policies, programmes or laws that discourage or stop you from complaining about discrimination?**

Twenty-nine (40.8%) of the 71 who answered, agreed that such barriers exist.

One respondent summed up the views of many others noting:

> “*There are not so many barriers to making complaints, as there is to receiving proactive responses to them. You may receive a letter of acknowledgement and little more than that — no explanation of things put in place to stop the same mistake/event from happening again*.”

Several people expressed frustration with the lack of standardisation regarding the complaints processes of various agencies, such as the Human Rights Commission, Health and Disability Commissioner and the Office of the Ombudsman. It was also noted that these processes are often complex and depend too much on “who you get to speak to”.

The need for funded advocacy was also stressed, where people are partially or totally unable to advocate for themselves.

Lack of disability awareness

6. Do you think the way disabled people are shown in the media contributes to discrimination?

Thirty-six (50.7%) of the 71 who responded, said yes.

A number of survey participants stated that people with mental illness are especially discriminated against in society and are often portrayed in negative and highly derogatory terms.

> “*The first imperative for the media is to find and disseminate ‘the story’ and they will sensationalise any news item involving someone with a mental health condition*.”

It is not difficult to see how public fear leads inexorably to prejudice.

A general theme to emerge was that people with various impairments tend to become their condition, in the eyes of medical practitioners and the public alike. “The media often refer to people being ‘confined to a wheelchair’ or ‘wheelchair bound’, when a wheelchair neither binds nor confines, but gives independence.” “I’m tired of hearing myself referred to as ‘legally blind’ when there is no legality around blindness in New Zealand.”

Ideas for Improvement

7. What ideas do you have for addressing policies, programmes or laws that exclude you from society? Please list these.

Forty-five people provided feedback to this question. Here are a selection of the most common responses:

- The media should consult with both clinicians and (former) patients when mental illness is portrayed in the media.

- Anti-discrimination legislation contained in the Human Rights Act needs to include as unlawful, refusal of a mortgage application, on the grounds of the lender being a beneficiary — given all reasonable conditions are met.

- Travel insurance must include mental health episodes.

- Reinstate the Training Incentive Allowance to cover the costs of disability.

- At all levels, involve persons with disability directly in the decision making, rather than assuming we are incapable of having an opinion. This is imperative where a person is deaf or is unable to speak.

- The Ministry of Health should review medications available for people with mental health conditions, including which ones are subsidised.

- Accessible accommodation should include accessible washrooms for different sized and types of wheelchairs.

- More education and awareness-raising is needed regarding different disabilities at different levels starting from early childhood, schooling, university, workplace and recreational places.

- Review access and funding for hearing aids and hearing tests for the unemployed and people on low incomes.

- We must include compulsory loop systems and visual fire alarms in all cinemas and public buildings.

As well as audible information, we need more visual information in airports, railway and bus stations. For example, boarding calls.

CHAPTER FIVE — CONCLUSIONS AND RECOMMENDATIONS

Conclusion

There is no doubt that a number of measures have been taken to improve the lives of disabled New Zealanders in recent times, most notably in the following areas:

- Increased funding for disability support services and for equipment and modification services.
- Funding the monitoring of The Convention via disabled peoples' organisations.
- The development of Web Guidelines, including accessible web standards, by the Government.
- The development and piloting of the Health Passport.
- Capital and Coast District Health Board have employed a disability awareness trainer, and have devoted considerable resources towards addressing disability issues.
- Mid Central District Health Board have employed a specialist nurse to assist people with intellectual disabilities access health care.
- The Government has committed to improve accessibility of and to the physical environment during the Christchurch rebuild.
- New Zealand on Air announced funding to enable DVDs of popular television programmes and films to be closed captioned for Deaf and hearing impaired audiences and many to feature audio description for blind and vision impaired audiences.
- Actively including Interpreters in civil defense announcements following the Christchurch earthquakes.
- The New Zealand Transport Agency have published *Auditing public transport accessibility in New Zealand*,: October, 2010 (2010), which provides an auditing template and best practice guide for accessibility audits.
- The New Zealand Government began promoting the concept of lifetime design for private homes as part of moves towards making more of these livable for disabled people. Budget 2010 allocated $1.5 million towards promoting the idea of designing more private dwellings to make them so.

- The Ministry of Justice has developed initiatives to improve access for persons with disabilities to the enrolment process, to information about MMP (the New Zealand election system).
- The Ministry also provides disability awareness training for Returning Officers and Election Day Staff.
- A number of positive initiatives in response to the select committee “Inquiry into the Quality of Care and Service Provision for People with Disabilities” to promote independent living for disabled people.
- Funding for a new facility for young disabled people with high support needs from Ministry of Health.
- Southland, Hutt Valley and Capital and Coast District Health Boards have all developed plans to implement The Convention.

Notwithstanding these positive initiatives, it is clear that New Zealand has a long way to go before we can truly say that we “*live in a society that highly values our lives and continually enhances our full participation*”.(http://www.odi.govt.nz/nzds/)In order to do this, the New Zealand Government must lead the way for all citizens by embracing social inclusion as “a way of being” and ensure policies, programmes and laws are developed which wholeheartedly embrace a “universal design” philosophy. This universal design approach can be used to address the need for access to each of the six areas highlighted in this report, by creating designs usable by everyone, every time. This not only applies to the built environment but also access to information, recreation and participation in the life of Aotearoa New Zealand.

In the words of an anonymous submission writer: “The Convention cannot concern itself with the details of services reform but it can be the means of promoting strong principles of self-determination, individual choice, inclusion and partnerships.”

The following recommendations sum up the views of those who participated in this project and provide a number of practical solutions to the issues raised by the many people who simply want equality of access with their fellow citizens.

Recommendations

1 In line with General Obligation 3 of The Convention, that a central agency of Government, in equal partnership with disabled peoples' organisations (those managed for and by disabled people), develop and lead a strategy for the implementation of The Convention.

That part of this strategy include a review of "reasonable accommodations" every four years, in conjunction with New Zealand's requirements to monitor the implementation of The Convention; so that disabled peoples' rights don't lag behind technological developments.

2 That Disabled Peoples' Organisations be funded to revise and update the New Zealand Disability Strategy, to enable it to become the operational mechanism for implementation of the various articles of The Convention.

3 That the New Zealand Government, in compliance with Article 31 of the Convention, requires State Services, Crown Entities and local bodies, to collect and publish disaggregated disability data in their annual reports.

4 That, as a matter of grave urgency, the New Zealand Government ratify the Optional Protocol to The Convention.

5 That the Ministry of Building, Innovation and Employment (formerly Department of Building and Housing), in partnership with disabled people, review, update and strengthen the Building Code, and ensure penalties for non-compliance of updated mandatory standards, for example, provision of hearing loops, visual alarms and mandatory evacuation standards for disabled people in all public buildings.

6 That the Ministries of Health and Social Development convene a working group of officials and disabled peoples' organisations representatives, to develop and implement fully flexible Individualised Funding, based on consistent nation-wide policy and practice.

7 That the New Zealand Government, fully instate the right to compensation outlined in the *Woodhouse Report*,1967, to congenitally disabled New Zealanders.

8 That the Ministry of Health, in partnership with the Association of Blind Citizens of New Zealand, investigate the production of all health related brochures and medication labels using the European Blind Union’s standards for accessibility. Further, that People First be consulted for advice and information about how to produce these in Easy Read formats.

9 That the Ministry of Health hold a full enquiry into the work and remuneration of aged-care and home-based support workers, with a view to increasing expectations, that is, more highly qualified staff who receive better pay.

10 That the New Zealand Government legislate to eliminate seclusion from all mental health-related detention facilities, including “At Risk Units” in prisons.

11 That the New Zealand Government deliver a public apology to all formerly institutionalised disabled people, for abuse or mistreatment of any sort suffered by them, while they were resident in institutions.

12 That the Ministry of Health convenes an Intellectual Disability Health Care Task Force, to prepare a national plan of action to implement the recommendations of the “*To Have an Ordinary Life*” and “*Health Indicators for People with Intellectual Disabilities*” reports. Any plan to be backed up by a set of national best practice guidelines. These plans are to be developed in full partnership with people with learning/intellectual impairments.

13 That the Minister of Health direct District Health Boards, under the Public Health and Disability Act, to prepare and implement annual UNCRPD plans, working in collaboration with Disabled Peoples’ Organisations. The Ministry of Health (in partnership with Disabled Peoples’ Organisations) to monitor these plans to ensure consistency in the way that disability issues and disabled people themselves are treated by District Health Boards and all publicly funded and/or contracted health services around the country.

14 That both the UNCRPD and Intellectual Disability Health Plans incorporate achievable targets for improving physical and other service access, collation of appropriate health and disability statistics/data and enhanced training of ALL medical and other allied health service staff throughout the country in disability awareness.

15 That the New Zealand Government remove all cost barriers to disabled and other low income people accessing prescription medications.

16 That the New Zealand Government reviews all legislation regarding health and disability services consent procedures to ensure that they are consistent with the UNCRPD and other international human rights instruments; this review to outline ways in which the rights of all disabled people either consent to or refuse medical treatment can be enhanced on the same basis as for non-disabled people; the review to be undertaken in partnership with disabled people.

17 That the Ministry of Justice undertake a review of marital dissolution legislation to exclude disability related adaptations and equipment, such as housing modifications, accessible vehicles and vehicle modifications and adaptive technology —that enable disabled people to function and participate in society — from divorce settlements.

18 That the Ministries of Social Development and Health review existing disability funding structures, in order to make them simpler to access and to avoid the inconsistency, confusion and stress created by trying to access funding from multiple sources for one particular purpose.

19 That information of public interest, especially legal and governmental policy documentation and complaints procedures, is reviewed in terms of its accessibility and usability by people with a variety of impairments.

20 That definitions of "access and mobility" and "transport disadvantaged" in the Public Transport Management Act 2008 and the Land Transport Management Act 2003 are amended to include specific reference to the consideration of the needs of disabled people. Best practice documents, such as, the *Pedestrian Planning Guide* (http://www.nzta.govt.nz/resources/pedestrian-planning-

guide/)and *Is This the Right Bus?*(http://www.abcnz.org.nz/) should be used when planning operational policy and translated into practice.

21 That the New Zealand Government abolishes the minimum wage exemption permit.

22 That the infrastructure surrounding New Zealand Sign Language is within the context of Deaf people and all barriers removed.

23 Recognising the development of a policy infrastructure will ensure that the Convention can be operationalised within the context of the experiences of disabled people, the New Zealand Government create a Disability Commission.

CHAPTER SIX — APPENDICES

Appendix One — Media Release, 1 May 2012

United Nations calls for information on the status of New Zealand's disabled people.

A group of disabled persons' organisations lead by disabled New Zealanders, known as the Convention Coalition, has commissioned a systemic monitoring report on the rights of disabled people in New Zealand. This report will be submitted to the NZ Government.

"This report will investigate six key areas which impact most strongly on the quality of life of disabled New Zealanders today. These include health, employment, social inclusion and a continuing lack of disability awareness," said Rachel Noble, chair of the Convention Coalition.

The systemic monitoring report will combine feedback about the individual experiences of disabled people, an analysis of how disabled people are portrayed in the media, and a review of current legislation, policies and programmes.

"We will shortly launch an online survey and will be holding a series of meetings to gather as much information from disabled people as possible, about their experiences in the six key areas. This will all go into our report to the United Nations," said Rachel Noble today.

The consultation with disabled people begins with a fono in Porirua on Friday 18 May, followed by a forum in Kilbirnie on Saturday 19 May.

[ENDS]

For further information, contact the chair of the Convention Coalition, Rachel Noble, email rachel@dpa.org.nz, mobile +64 21 410 300(txt only); or systemic monitoring report project coordinator Pam MacNeill, mobile +64 274575 461.

Appendix Two — Monitoring project activities, May and June 2012

Fora, Fono and Hui

Meeting	City	Venue	Date	Time
Forum	Wellington	Brentwood Hotel, 16 Kemp Street, Kilbirnie	Saturday 19 May 2012	10am to 3pm
DPO forum	Wellington	Brentwood Hotel, 16 Kemp Street, Kilbirnie	Saturday 19 May 2012	1.30pm to 5pm
Fono	Lower Hutt	CCS Disability Action	Tuesday 22 May 2012	10am to 3pm
Forum	Christchurch	Aspire Canterbury, 314 Worcester Street	30 May 2012	10am to 3pm
Forum	Auckland	RNZ Foundation of the Blind Recreation Centre, 4 Maunsell Road, Parnell	13 June 2012	10am to 3pm
Hui	Christchurch	Papanui RSA, 55 Bellvue Avenue	15 June 2012	10am to 3pm

Call for Submissions

Submissions	Opened	Closed	Subject Areas	Accepted Formats	Address to Send
These relate to the Convention Coalition monitoring report	11 May 2012	8 June 2012	Social inclusion Health Work The way disability support services are run Barriers to making complaints Lack of disability awareness	Submissions can be sent in standard ink print, in Braille, as recordings on Cassette or CD, via txt to 0274 575461 or e-mail to pmacneillconsulting@gmail.com	Coalition Submissions, 435 Fergusson Drive, Heretaunga, Upper Hutt 5018

Formal Monitoring

We have brought together a small group of disabled professionals to monitor the policies, programmes and laws relating to the six areas noted above. They will provide us with additional information to include in the monitoring report.

Online Survey

This asks seven questions relating to key areas being monitored by the Convention Coalition.

The address to take the survey is: http://www.surveymonkey.com/s/9FPMX82

The survey opened on 17 May and will close on 15 June.

Appendix Three — Key informant interviews

Interview with Grant Cleland — Chief Executive Workbridge Incorporated

Workbridge is the major disability employment agency in New Zealand. It has offices all over New Zealand and provides assistance to disabled people who wish to undertake training or enter the workforce.

Grant Cleland said:

> "*I manage the largest disability focused employment agency in New Zealand but at no point has anyone come to me to discuss an employment strategy relating to the recent welfare reforms and how Workbridge might assist with this. In the next twelve months it is critical that we develop an employment action plan for disabled people which includes young people and those with high support needs, but there are major blocks to this process occurring. We actually do have the strategies, but we need more of a willingness by some officials to work with the sector in partnership*."

The Disability Employment Forum has written to Minister Turia advising her that Ministry of Social Development officials are not working in line with United Nations Convention on the Rights of Persons with Disabilities, Article 4.3, in relation to consulting with the disability sector. In 2012, the Disability Employment Forum successfully advocated for an employment summit and an action plan on employment. However, it is evident that there is an unwillingness to work with disabled people and with the disability sector as a whole, on the part of some officials.

Some officials are also demonstrating a lack of ability to work in partnership with disabled people on the Lead School Transition Project in Christchurch. There appears to be a paternalistic view that "we know what is best for you".

Over the past few years the disability sector has moved on to where they are working collaboratively. Disabled Persons Organisations (DPOs) have formed the Convention Coalition. The Disability Employment Forum is made up of DPOs and employment sector agencies for disabled people like Workbridge, the Association for Supported Employment in New Zealand, and the New Zealand Federation of Vocational and Support Services, working together to come up with creative employment solutions for disabled people.

The key issue is an overall lack of partnership with the disability community by some officials, in line with Article 4.3, on a range of initiatives that will have an impact on the future of disabled people. There is far more will at Ministerial level than official level.

As a result, a lot of innovation occurring in the sector is not being taken into consideration in development of ideas by officials, because of the lack of this partnership perspective.

Interview with Paul Gibson — Disability Rights commissioner, Human Rights Commission

Q. What do you see as the biggest systemic issues for disabled people?

The absence of disability data.

Also political parties lack a comprehensive understanding of disability Issues. There is a lot of public empathy for disability but the disability rights movement/ the social model isn't understood like women's rights or gay rights, etc.

The political parties see disability from the medical/deficit model.

So because it isn't understood it tends to be ignored.

On a positive note the associate minister of education from the Act Party has engaged with disabled people on a personal level and it has shifted the minister's thinking towards the social model.

Education receives the most complaints on the grounds of disability and families' aspirations are rising However, the education system is slow to respond and is lagging behind public expectations.

Disability and Race relations are the two biggest grounds for human rights complaints. The biggest areas for complaints are:

1. Physical access to the built environment which is understood better than say access to information in alternative formats.

2. Independent living especially for people with Intellectual Disabilities (ID).

   A Ministry of Health survey found there were approximately 750disabled people under the age of 65 in rest homes.

   A new policy recommended that within one year they be relocated into the community.

   CCS Disability Action requested information on the number of disabled people under 65 in rest homes a few years later and found it had risen to approximately 860. The policy wasn’t implemented.

3. Work

   Health and Safety legislation is often overstated as a reason for not employing disabled people. Reasonable accommodation isn’t well understood although recently there has been a legal shift in the thresh hold for defining reasonable accommodation.

   That shift hasn’t yet trickled down into work environment yet, but it will as public awareness grows.

   Employers still view disabled people as being a high risk with high costs. So they tend to pick non disabled people over disabled people.

4. Culture, recreation and sport

   Mainly focused on access to sign language and Deaf culture, plus cultural issues for Māori and Pacific peoples.

Q. Human rights legislation is over-ridden by other legislation, do you think this has a significant impact on the human rights of disabled people? Does that hamper the work of the HRC?

It does have a significant impact but it’s hard to estimate the extent of the impact. The HRC is advocating that human rights legislation should have an equal footing with other legislation and be embedded in NZ’s Constitution.

Q. **Provisions in adoption laws make it harder for disabled people to adopt children and easier for authorities to take children away from disabled people than from non disabled persons. What do you think causes such discriminatory attitudes?**

An original argument was that physically impaired women couldn’t safely hold babies, but that only matters for the first few years of a child’s life.

The CYF Act 141 was originally meant to protect disabled children but it now discriminates against them. NZ should make the same effort to keep disabled children with their parents as it does for nondisabled people.

Article 23 of the CRPD should be the basis for policies around adoption. What happens now is that support agencies intervene when a crisis occurs.

We should involve agencies earlier and plan what kind of support disabled parents need. There is an assumption that disabled people can’t cope with child rearing and that when disabled people decide to have children it is not a right but a “lifestyle choice”. Early intervention is much smarter than removing children from their families when things go wrong.

Q. HRC reports consistently show that disability is one of the major grounds for complaints but yet disability issues are largely invisible in Politics. Why do you think that is?

Politicians don't understand disability issues from a social model perspective. Their expectations for disabled people are lower than their expectations for non-disabled. They also perceive that it is someone else's job so they pass the buck. They can't envision equitable participation for disabled people in the future.

Q. Any comment on the recent struggles of Mojo Mathers?

The house of representatives should reflect the diversity of our country. Mojo is the first openly disabled MP, which is great but disabled people don't have as much representation as ethnic minorities and their representation isn't proportional to the amount of disabled people in our population.

When Parliament was unable to meet Mojo's needs to enable her to participate in parliament in a timely manner it wasn't good. However, the debate and controversy around her treatment has raised disability awareness in a way that otherwise wouldn't have happened. So the overall effect has been positive. The media's portrayal of the issues were mostly positive.

Parliament should set an example for society about reasonable accommodation. Moreover, they should do so by using their existing resources flexibly to meet disabled people's needs.

Q. **What if any positives had you seen in the development of disability policies, programmes or legislation over the last 5 years?**

By far the biggest positive was NZ's decision to ratify the CRPD. However, NZ has very much under celebrated the role they played in negotiating the treaty.

When Gary Williams and Ruth Dyson went to sign the final version they received a standing ovation from the convention representatives.

Robert Martin too had an enormous effect. He was the first person with a learning disability to address the UN. He shared his story of how his family were coerced into sending him to the Kimberly Centre institution. Within Kimberly Centre he was abused.

Robert worked at a sheltered workshop where he organised a strike so he and others could have a coffee break and enjoy other basic rights.

Robert was one of the founding members of People First NZ. The effect Robert's story had on the Convention representatives was profound. Most countries delegations had state representatives and diplomats but no disabled people.

Robert's story highlighted the need for disabled people's lived experiences voices to be told. A number of politicians remarked that after Robert shared his story the tone of the convention negotiation committee changed drastically.

Yet few people in NZ would know Robert is a world leader for people with learning disabilities.

The strength of the CRPD is that it can transform the rights of the most vulnerable people in society on a global basis. NZ needs disability champions or tall poppies to effect social change.

Observation

New Zealand's policy of institutionalising people with learning disabilities was fundamentally wrong. The view of most politicians and doctors was that the best thing for people with learning disabilities was too remove them from their families and send them to institutions. Medical experts persuaded families this was the best option for their children and they complied.

There was no scientific evidence to justify this policy just an assumption it was the right thing to do. No one listened to the disabled children. They didn't need segregation they needed their families love and support.

The results tore families apart in much the same way as it did to the families of Australia's Stolen Generations.

Kimberley Centre has ceased to exist but authorities have not formally apologised to the people they institutionalised or to their families for the trauma their policy caused.

Private audiences with judges have been used by many former residents of Kimberley Centre to tell their stories and gain compensation but those are not publicly available. Moreover, the primary motivation for most people who use this facility isn't money, but rather to hear the authorities say sorry we got it wrong.

Kimberly Centre was based in Horowhenua which has several meanings in English. One of those meanings is the breaking up of families.

The Government needs to have a public national conversation about what it did at Kimberly Centre and publicly apologise to all the people they hurt. This was not just a minor error of judgment it was catastrophically wrong.

Q. Discussion at the DPO forum suggested Government departments go through cycles of reviewing Disability policy but then don't implement the recommendations and nothing happens. For example, the Ministry Report on keeping disabled people out of rest homes. Do you see that as being discriminatory?

Yes. I mentioned the rest home situation earlier. The failure of Government departments to follow through and implement policy changes is due to complacency and not understanding disability issues.

Recently there has been media coverage of the high court decision to pay the families of disabled people who care for them. The media are referring to disabled adults as children reinforcing paternalistic negative attitudes towards disabled people.

Q. Any comments on lessons learned from the Christchurch earthquake?

Adversity causes people to come together many people got to know their neighbours some of whom were disabled intimately. They supported each other and became a true community.

Independent living

Q. The New model for supporting disabled people and the Choice in Community Living demonstrations seem to be consistent with CRPD do you have any concerns re these initiatives?

The new model of care was developed from overseas models and while they are a step in the right direction. Government departments are imposing constraints that aren't used overseas. For example, eligibility criteria prevent autistic people and people in residential care from using this approach.

This could distort the goals of the new model. We need disabled people to contribute their expertise at a strategic level to provide leadership to keep this from happening.

There was talk that if it hasn't rolled out within 6 years we should move disability support out of health and create a disability ministry. I think we should do that now disability doesn't fit well within health.

At a practical level, Choice in Community Living will enable disabled people to:

choose who provides them with support from among several contracted providers;

and have control over how and what support is provided (note: the choice ofprovider may be limited in some areas).

Q. No one in 2010 was happy with their Care support agencies and that care support agencies didn’t listen to their complaints. Is their real choice among Care support agencies? Or is this just an illusion?

Community organisations should be involved to ensure there are real choices for disabled people. Especially, earlier in life when disabled people are acquiring knowledge regarding disability support services.

Q. The Intellectually Disabled Compulsory Care and Rehabilitation Act 2003,the Criminal Procedure Mentally Impaired Persons & Mental Health (Compulsory Assessment and Treatment) Acts; can all result in lengthy detentions of disabled persons, often exceeding the prison sentence for the same offence. What do you think about this legislation is it more about social control than justice?

Firstly, this highlights one of the flaws of the DRPI project in that it can only capture the stories of people who can give consent. Which also includes disabled children.

DRPI should engage with people who can deliver that voice translating for such people if required.

These laws along with the Alcohol and Addiction Act and the PPPR Act should be altered to comply with Article 12 of the CRPD. They should be framed in such a way that it promotes choices other than segregation.

Currently, under these Acts people are either competent or not.

However, in Canada for example, when a person has a support network in place to facilitate supported decision making, the courts interpret that as evidence of competency.

Thus people who would be unable to choose for themselves have the legal backing to make their own decisions via their support networks. It works more effectively with a network of ten to twelve people not just one or two.

Health and rehabilitation

Q. To your understanding, and from your time at the CCDHB, what further steps have been taken by that organisation (and other DHBs) to provide the same level of health care to all disabled people as is available for the non-disabled population? Has the Commission any plans to monitor this issue?

There aren’t many initiatives to ensure disabled people get equity in health. Sometimes the Ministry of Health is forced to initiate such programmes. The HRC will be monitoring this.

Mid Central DHB has employed a specialist nurse to facilitate the health journey of people with learning disabilities. These nurses are widely used overseas.

Q. To the best of your knowledge, have access to health service issues improved since I interviewed you in May 2010? What further work has been done at your old employer, the CCDHB around this?

Yes it has improved.

Q. When I spoke to you in May 2010, there were some initiatives that were in development around improving disability awareness training for medical and general health staff at the CCDHB. Have these advanced since then and in what way? Is there any hope that these might be adopted as best practise nationally?

CCDHB have employed a Disability awareness trainer.

Q. To the best of your knowledge, has access to mental health services for people who also experience physical impairment improved since I last spoke to you in 2010? I recall you and Maurice Priestley citing the case of a mental health service user who had written to the CCDHB and the action they took around the complaint.

Access to mental health for people with physical impairments has improved somewhat. However, in other areas they are going backwards. The Deaf mental health service was shut down.

Another area of concern is the newborn screening programme. It should be compulsory for doctors who detect hearing loss to encourage the parents and child to learn sign language.

Some audiologists do this already but it’s usually not their first option.

Transport

Q. What monitoring has been undertaken and what monitoring is planned around accessible transport access issues by the Human Rights Commission?

HRC wants to do more work in response to the Accessible Journey. Hamilton is making good progress because it has a talented, motivated disabled person leading the way. However, we can’t just rely on finding such people as when they go the project falters.

Q. Where monitoring has been undertaken, what improvements have been noticed by the Commission, if any, in public transport access across all platforms?

HRC expects that as buses including Intercity buses are replaced that the replacement buses are accessible as part of reasonable accommodation. HRC also is talking to NZ transport about its national programme and will report back to government.

Work

Q. Any comments on HR departments who require job applicants to hold a drivers license for office jobs?

I was looking at a position as the Assistant Deputy Children's Commissioner. Iit stated that applicants had to have a clean driver's license. The advert specified a number or key requirements/skills for the position but driving wasn't one of them. It is discriminatory.

It would be appropriate to request a clean license say for a truck driver where driving is an essential part of the job, but not where it isn't.

Q. Once the person actually gets a job, employers refuse to acknowledge good performance or that the person has the capability for promotion to a more senior role. Is there a glass ceiling for disabled employees?

I've never heard it described like that before but income statistics, showed that 45% of disabled people were in the lowest income decile. Statistically we should only expect 10% of disabled people to be in that decile. You could interpret that as evidence of a glass ceiling.

Media

Q. Is HRC planning any media campaigns around portrayal of disability and the capabilities of disabled people?

HRC is planning to work with MSD on their awareness campaigns and with the Be. Leadership group. We are also interested in doing some work with social media.

We would like to do media work around celebrating and acknowledging disabled people's achievements. There also needs to be acknowledgement of Kimberly Centre policies and addressing that we got it badly wrong.

Q. Any other comments or observations?

The Domestic Violence Act is inconsistent with the CRPD. Disabled people living in group homes/residential care don't enjoy the same protections that other people do.

The Education Act needs a bit more work to comply with the CRPD.

A big area of concern is the institutionalisation of older disabled people. There is some evidence of older disabled people being coerced into institutions. Also the PPPR act is concerning.

Interview with Wendi Wicks — National Policy Researcher, Disabled Persons Assembly (NZ) Incorporated

1. What impact do you think that the Government's increased prescription charges will have on disabled people?

Potentially negative effects on disabled people who are predominately in the lower income groups. Wendi/DPA has queries in on this issue, but as yet there has been no response. No tangible details have been released on whether there will be increases on subsidised medicines and/or any increases to unsubsidised medicines.

2. What impact do you think that the Government's increased spend on disability support in the Budget will have on those accessing Ministry of Health funded Disability Support Services and in particular accessing equipment for habilitation and rehabilitation purposes?

Increased funding in Budget 2012 is in Vote Health and for services already in existence. It is not for new services Further, aspects that have not been considered are that:

a. there will be more people needing funding/services;

b. more people wanting equipment;

c. it is unconvincing that the funding projections and current funding will keep up with an increased demand that is indicated by demographics.

d. more people as lower priority on the list that will be waiting for equipment, which may lead to greater disability in the long term, as their needs are not addressed. Who is going to go without what with the priorities in spending.

e. Disability Support Services budget will become increasingly stretched with an aging population.

f. those on low income will be greater effected.

g. rehabilitation might be on Vote ACC.

3. **You recently mentioned in a DPA Facebook page posting that there had been issues around disabled women accessing cervical screening and other screening services (e.g. breast screening). To the best of your knowledge, are there continuing access issues and what initiatives, if any, are you aware of to address them on the part of the Ministry of Health and DHBs?**

There are still access issues. Factors are where the facilities are located and how examinations are conducted. For example, not all facilities are accessible and rural women generally only have access to mobile Breast Screening units which are not accessible. There has been no action to make these more accessible. Access is possible when a woman can access a base hospital where breast screening facilities are accessible. But machines used to test for cancer may not be wheelchair accessible. There has been some work to make GP practices more accessible.

However it's not just getting into the premises. Equipment such as

adjustable-height examining tables that can be used for cervical screeningis rare. The lack of data collection on disabled women utilising cervical screening programmes renders disability issues invisible.

However, there is no consistent strategy. Disabled women are not seen asa priority. The situation borders on systemic discrimination–discrimination by omission. Health information is often available in PDFonly, which is not universally accessible. There are good Governmentguidelines for core government departments, but it's not enforced so the policy has no "teeth" to it.

4. **On the issue of collating health related statistics relating to disabled people (which is something you have also Facebooked on), is this still an ongoing issue? What initiatives, if any, have been undertaken to correct this on the part of the Ministry of Health, DHBs, and other public health agencies?**

Statistics — an ongoing issue and not just in regards to health.

a. There is a problem with the focus on medical definitions of disability, and a preoccupation with how to define disability. There is a need to not get hung up on definitions; use of self definition is an easier way to measure disability and its impacts.

b. Health — National minimum datasets seem to have nothing about disability.

c. Attached is a copy of extracts from the report to Parliament from the Abortion Supervisory Committee. The data it contains is fairly general and does not tell us if disabled people's lives are being devalued.

d. Post Census survey — it is based on functional impairment and only tells information for funding and planning purposes.

e. The definition of unmet need is generic and it is not possible to break down the stats into different areas, eg "geographic areas" or "access to equipment".

f. Could consider how the data will be used. Personal opinion that it is in the "too hard" area to add to work streams. It was posed to organisers of the census to add a disability question and they asked "how do you define it?". Self-definition was not accepted because they were very concerned to protect the reliability and validity of the data

5. Have there been any recent documents, in the past five years, that you know of that raise awareness of the Convention itself?

Parliamentarians Handbook explained the CRPD and how to implement it and outlined responsibilities for Parliament and MPs.

http://www.un.org/disabilities/default.asp?id=150

Inclusion International — good information on intellectual disability

a. Office of the High Commission of Human Rights

b. DPI have some good stuff

c. International Disability Alliance

d. Troika — produced a pamphlet on roles of respective independent monitoring entities (for CRPD).

e. ODI.

6. **Are there appropriate communication channels for circulating information to the public about educating towards a non-disabling society?**

It's in its infancy and largely led by disability sector, but the influence of disability sector on the rest of society is not great. Disability stuff not seen as applicable to the rest of society, eg, work, education etc. Britain more knowledgeable about disability rights combined with a rise in disability activism. Disabled people there are angry and demanding more from their government. New Zealand needs to get more assertive.

7. **What is the legislation that encourages and/or enforces standards in broadcasting contributing to the education and public awareness of the rights and positive depictions of people with disabilities?**

a. Complaints can be made via the Broadcasting Standards Authority and Advertising Standards Authority. This use of complaints has the potential to encourage positive depictions of disabled people and promote disability rights.

b. The Retirement Commission is educating on financial literacy. (As an aside, beneficiaries who retire are better off financially than other beneficiaries). There could be potential partnering with Retirement Commission (plus other agencies) to do something around disability rights and finances.

8. **Are there any recent developments on a national public awareness campaign?**

a. Budget money was given for a national awareness campaign but it did not use a partnership approach.MSD control how the campaign runs and do not involve DPOs as partners. Perception that money could have been better spent- it was used on many small projects with limited influence. It was also variable: some good initiatives have got funding, others have missed out. Money should go to DPO, eg, "Hearing Voices" who do great work but they got no funding.

b. National awareness campaigns need to be thought out carefully, for example, "Like Minds" is national campaign to feature ordinary people. Original campaign lost momentum and starting up again hasn't recaptured the momentum of the earlier campaign.

9. **Would you be able to tell us the current status of the following**:

10. **Personal mobility assistance**

a. Personal mobility assistance guide dogs, equipment not enough funding.

b. ABC would be in favor of more coherent legislation for companion animals. Guide dogs and hearing dogs covered, but not mobility dogs.

c. Lots of shop keepers, taxi drivers "can't take that dog'.

d. Dogs may not be allowed on a marae. Iwi and marae need to discuss companion animals on marae.

e. Motorised chair funding criteria states you can only use the chair inside which restricts mobility.

f. Increased demand on capped or restricted budget criteria becomes tougher and people miss out. The budget has not kept up with the demographic demand. Lower level needs miss out which can result in higher level needs in future. Private industry get wealthy supplying disability devices, eg, chairs, cochlear implants.

11. ACC legislation

ACC original legislation was good yet current practice has no reflection of the original purpose. ACC are the gatekeepers.

ACC Futures are a campaign/ consortium resisting privatization and commodification of ACC.

ACC rehabilitation/habilitation, not very consistent.

In Australia a National Disability Scheme is starting up that looks like what ACC was originally meant to look like in the *Woodhouse Report* (1967).

12. Total Mobility Scheme

Total Mobility always changing-constant tinkering with scope and eligibility.

Legislation it derives from is assistance based, not rights based. Also it does not address equity.

Land Transport and other authorities do not see transport as a right, disabled people are problems, haven't addressed demand, funding and equity, based on a charity model.

13. **What if any positives had you seen in the development of disability policies, programmes or legislation over the last 5 years?**

    a. Engagement with business — legal and appearance on boards

       Changes to the building act, inconsistencies to the National Interest Analysis, Special Education Review, Social Welfare Reforms following Future Focus. Less than what is needed and constitutes "tinkering" rather than planned and strategic approach.

    b. Convention could it be more powerful as a piece of legislation, needs proper collaborative work, what next? What are the tools that can be used next, and how to get this actioned?

    c. Government not acting in line with a paradigm shift, need for DPOs to have direct relationship to the Ministerial committee.

14. **Do politicians have enough disability awareness to develop disability policy, programmes or legislation that is consistent with the CRPD?**

    No, they should have more disability awareness.

15. **Do you think that the government / government departments assign enough money to implement their disability policies and programmes?**

    No.

16 At the Disabled Peoples' forum you mentioned the Ministry of Health would engage in a seemingly endless cycle of reviewing disability policy without implementing any changes. 1. Does this happen in other Government departments? 2.What is needed to stop this from happening?

1 Yes. 2. Proceeds from mindset; needs mindset changes then behaviour. The shift won't come on its own and it needs to be informed by attitude change.

17. Any other comments or observations about systemic issues for disabled people?

Gains have been small for amount of effort that needs to happen. If we keep on the case, something will happen- cannot work on an individual approach, it needs disabled people to work as a group.

Appendix Four — Submissions

Call for Submissions to the 2012 Convention on the Rights of Persons with Disabilities (CRPD): Monitoring Report

This is our chance to give feedback on how well we are doing with the CRPD.

We want to hear from disabled New Zealanders about their authentic experiences in six key areas to be highlighted in a report being submitted to the New Zealand Government. We want your input so please have your say!

The areas we want feedback on are:

- Social inclusion

- Health
- Work
- The way disability support services are run
- Barriers to making complaints
- Lack of disability awareness

Submissions can be about any or all of the six areas listed above.

Disabled people are invited to send submissions to the Project Coordinator, Pam MacNeill, either by sending:

- An e-mail to pmacneillconsulting@gmail.com
- A TXT to 0274 575461
- A voice recording on CD or tape; or
- A Braille document

Anyone assisting a disabled person to write a submission is asked to note this at the beginning of the submission.

All material being posted should be addressed to:

Pam MacNeill
CRPD Monitoring Report Project Coordinator
435 Fergusson Drive
Heretaunga
Upper Hutt 5018

Please note that submissions close on **Friday 8 June 2012**.

Submissions received

The following is a sample of submissions received by the project team. Although additional submissions were also received and the themes identified therein included in the report, the respective authors specifically requested that their submissions not be appended to the report.

Submission One

Seclusion in acute mental health services and prisons

Submission from The Phoenix Group

The Phoenix Group is a collective of people living in Wellington, New Zealand, who identify as having experience of mental distress, mental illness, or using mental health services.

Being aware of the Convention Coalition, and its responsibilities to report on New Zealand's performance in adhering to the United Nations Convention on the Rights of Persons with Disabilities, the Phoenix Group wishes to alert the Coalition to what we believe are abuses of those rights, in the use of seclusion in acute mental health services and prisons in New Zealand.

In particular, we believe that the use of involuntary seclusion (also known in prisons as detention in an “At Risk Unit”), ie, the isolation of individuals in a locked room without their consent, contravenes the rights of such persons under Article 15 — Freedom from torture or cruel, inhuman or degrading treatment or punishment. Specifically, we believe that:

1. The use of involuntary seclusion in any form amounts to cruel, inhuman or degrading treatment, and we are aware of anecdotal accounts of the use of seclusion as punishment.

2. The New Zealand Government, as States Party to the Convention, is failing in its duty to protect people who experience mental distress or mental illness, by its failure to "take all effective legislative, administrative, judicial or other measures to prevent persons with disabilities, on an equal basis with others, from being subjected to torture or cruel, inhuman or degrading treatment or punishment". The failure described occurs as a result of the States Party continuing to operate Mental Health, Police, and Justice services in accordance with the Mental Health (Compulsory Assessment and Treatment) Act 1992.

We believe the Mental Health (Compulsory Assessment and Treatment) Act 1992 should be amended as it discriminates against people who experience mental distress, by depriving them of their right under Article 14 — Liberty and security of the person — that “if persons with disabilities are deprived of their liberty through any process, they are, on an equal basis with others, entitled to guarantees in accordance with international human rights law and shall be treated in compliance with the objectives and principles of this Convention, including by provision of reasonable accommodation.”

The Mental Health (Compulsory Assessment and Treatment) Act 1992, by its very nature, allows for people subjected to its provisions not to be treated on an equal basis with others. The basis of this subjection is that of a clinical opinion that the person is “mentally disordered”. Therefore the deprivation of rights to be treated on an equal basis with others is enacted solely on the basis of the person's disability. We believe this constitutes a clear breach of Article 5 — Equality and non-discrimination, specifically,

"1. States Parties recognise that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law";and

“2. States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.", and a breach of Article 12 — Equal recognition before the law, specifically,

"4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person’s rights and interests."

While there are provisions under the Mental Health (Compulsory Assessment and Treatment) Act 1992 that provide safeguards as described in Article 12-4, we do not believe that those safeguards are sufficient, nor are they “proportional to the degree to which such measures affect the person’s rights and interests”. There is considerable research evidence internationally to support the view that seclusion is harmful, and that it can be avoided by adopting models of care that preclude its use, and provide for sufficient staffing and adequate facilities to protect the safety of all persons involved in the support of people enduring severe mental distress.

In our view, the additional damage and distress caused to people who are deprived of their liberty and the right to human contact and communication while enduring mental distress, is such that the New Zealand government should legislate to eliminate seclusion from all mental health-related detention facilities, including “At Risk Units” in prisons.

We believe that, as described above, the New Zealand Government is subjecting its citizens to breaches of the Rights guaranteed to them by the New Zealand Government as a States Party under the Convention. We believe that this is occurring on the basis of disability, that the relevant legislation itself contravenes the convention by its very nature, and that alternatives are available, but are not being provided because they would cost more than continuing with these abuses.

Sincerely

The Phoenix Group.

Submission Two

Submission to the New Zealand monitoring report: UN Convention on the Rights of Persons with Disabilities

Submitted by an anonymous contributor

I write as a health professional, a person with a disability and a member of the Auckland Council's Disability Strategy Advisory Group.

Barriers to raising and maintaining standards consistent with progress in civil society.

There is no overall funded disability related forum or mechanism aimed at developing strategies that enable society to juggle the balance between affordability and the personal needs of people with disabilities and there rights as citizens.

While the New Zealand Human Rights Act makes it unlawful to discriminate against people with disabilities, in reality central Government and local authorities cling to budget constraints and minimum standards set by outdated legislation such as the Building Act 2004, the Resource Management Act 1991, NZ Standard 4121; regulations that are years behind best practice. People with disabilities should be able to carry out their everyday transactions with the same equity and dignity as everyone else.

More flexible but mandatory regulation is needed to ensure regulatory compliance does keep pace with modern standards of accessibility and service provision.

Complaints under the Human Rights Act are very slow to bring about the attitudinal and conceptual changes that are more progressive and obvious in jurisdictions that have discrimination against disability legislation.

Despite the Human Rights Act New Zealand is littered with buildings, modes of transport and hazardous traffic crossings that act as barriers to full participation and social inclusion. Current compliance, consents and standards as administered by many Councils and Government departments are not working for people with disabilities. The minimal standards that do exist are inadequate by today's best practice codes, are not well enforced, do not comply with the New Zealand Disability Strategy or the United Nations Convention on the Rights of Persons with Disabilities. Local Authority Council officers when faced with threats of legal appeals and limited budgets — the norm — have no legislative teeth to enforce best practice standards. This is despite the fact that good design that accommodates people with disabilities does benefit the whole community. Persistently poor access for blind and low vision people to Government and local authority websites illustrates the point.

There is little appreciation at central Government and local authority levels that, if financial and policy resources were made available to accommodate people with disabilities, everyone would benefit from more accessible buildings and transport. Mothers with strollers, tourists with trolley bags and older people with minor or temporary limitations gain from services and amenities that are designed for the convenience of all citizens. Accessibility is a philosophy of good inclusive design and best practice from which the whole community derives benefit. Inclusive design is a public good. “Do it once, do it right”. Avoid expensive retrofit. Inclusive design is the cheapest long-term strategy.

The quality of life of New Zealanders with disabilities would be improved immeasurably if major cities and towns were required to conform to urban design standards that made dignified access, participation and social inclusion a fundamental outcome.

A small country of only 4 million people should have contemporary national enforceable standards that are inclusive of all citizens regarding dignified access to buildings, transport and information services.

Health, prevention and rehabilitation service

A study, “*Clear focus: the economic impact of vision loss in New Zealand in 2009*”, showed that vision loss cost New Zealand society $2.8 billion in 2009, and this figure is increasing each year.

Most vision loss is correctable, preventable or treatable. By investing in prevention, the cost savings for New Zealand in the medium term would be millions of dollars.

Without further investment, direct health costs alone are projected to more than double to $523 million by 2020, compared with $198 million in 2009.

The Māori population is disproportionately affected by vision loss - for example, the overall prevalence of vision impairment and blindness in Māori aged 45 to 74 years is twice that of non-Māori.

There is need to focus attention on those communities which are most likely to miss out on care. These are frequently the same communities that suffer poor health in many other respects and have most difficulty accessing high quality and timely health care.

The above costs are not inevitable. Vision loss and blindness rehabilitation services are central to quality of life, access to education and employment, and to reducing barriers to full participation within the community. Better outcomes for health funders and consumers could be achieved by attention to risk reduction, enhanced early detection, workforce development and distribution of eye care professionals; and by more equitable access to low vision rehabilitationists. Better overall value would result from attention to equity of access to eye health and vision care services, improved systems for the delivery of eye care, and the gathering and dissemination of quality evidence.

This study quantifies the disabling effects of poor prevention and rehabilitation strategies in the field of eye health. Indications are that the management of hearing loss and child health is similarly compromised.

(see;www.vision2020.net.nz

or

www.rnzfb.org.nz)

General rehabilitation

A recent rehabilitation workforce service forecast, recognised that there is no comprehensive rehabilitation system in New Zealand. Provision of, and access to rehabilitation services is fragmented and varies greatly between regions. The main funders of rehabilitation - the Ministry of Health, Accident Compensation Corporation and District Health Boards, all purchase different components of rehabilitation leading to the provision of varied and often inequitable services and therefore, different outcomes for clients. Services are provided through public and private providers in in-patient, outpatient, community and home based settings. Again it is noted that, as a population, Māori have on average the poorest health status of any ethnic group in New Zealand.

(see:http://bit.ly/JyrFmW)

Further inequities impacting on social inclusion

People sustaining injury and incapacity as a result of accident fare better in terms of service delivery, rehabilitation and care than do people who have sustained incapacity through illness or congenital disability. If a leg or sight is lost through diabetes, the overall outcomes are likely to be less favorable than if sight or a leg was lost as the result of an accident.

Again, inequities arise from wage rates in the disability and elder care sector being just above the minimum wage rate. Thus, care is variable and clients are more vulnerable to exploitation.

Submission Three

Submission on Disabilities (CRPD) Monitoring Report

From Carolyn Weston

The following are my observations and experiences:

1. Social Inclusion: I believe that there is an improvement in this area. I certainly see more disabled people around the streets and taking part in community activities. A few days ago I did hear a radio announcer on Radio Live saying that in his opinion he thought that people with mental illnesses should be placed into an institution and given shock treatment like they did fifty years ago to make them behave. I didn't expect anyone to have this view and he didn't like people with mental illnesses participating in the community. Having views like this expressed on the radio by an announcer is not helpful. May be he was trying to be radical to get people to ring but by the sound of his voice he sounded sincere.

2. Health: Over the past few years I have had first-hand experience with health services. From the 2005-2008 the Southland District Health board had a very active Disability Support Advisory Committee, comprising staff of the District Health board, disabled people, parents of disabled people and people working in the disability sector. This Committee met around 4 times a year and we developed a Disability Strategic Plan which consisted of goals such as having print information in accessible formats, health staff (especially nurses) receiving disability awareness training etc. In 2008 the Otago District Health board and the Southland District Health board combined into one entity and the new Board decided to have mainly Board members on this Committee with two people from the community appointed by the Board. I am not sure if there was two people from Otago and two people from Southland however Board members certainly hold the majority seats on this Committee. The Disability Strategic Plan appears to have disappeared and no one appears to be working on the goals anymore. The new Disability Support Advisory Committee do not even appear to be communicating with the disability community in Southland, (I do not know if they do in Otago). I believe that this is a backward step. When I was in hospital last year, it was obvious that some doctors and nurses were not aware of all the needs of blind people. Some were good and others were not. I have seen support staff bring in meals and put the meal on the patient's table but do not wake the patient or tell the patient who cannot move or see that their meal has arrived. Some elderly people have asked these staff to cut the meat for them or something but the staff say no you have to ask your nurse. The person who brought around the menus for the following day would not even read me the menu and I had to ask my nurse to read it. Sometimes I didn't even know the menu had been put near my bed and so I didn't ask my nurse to read it to me so I ended up getting what someone else chose for my meals the following day. I was really angry about this as I have enough wits about me to choose for myself. One time an elderly woman was given her lunch on her table, she was asleep and she woke up. She did not know her lunch was there but when the staff came back to clear away and her lunch was cold. They suggested she call her nurse but she didn't want a cold lunch. The nurse did offer to heat her lunch up but it

was food that would not be so nice heated up. This woman had memory loss and she had broken her hip. There certainly needs to be more work and research in how disabled people are treated in the health sector.

3. Work: I believe that it is still very difficult to obtain paid employment. With the number of unemployed rising, disabled people will find it harder to obtain work. I finish my paid work on the 30th June and other than voluntary work I do not expect to obtain new part-time work. I am not too worried about this but I feel that I am not quite ready for retirement yet. As I have served on Committees administrated by Government Ministries or Departments, it is interesting how they all treat disabled people differently. The Ministry of Health’s Administrator Manager of the Health and Disability Ethics Committees used to be very supportive, ensuring that there was some grass for my guide dog near our Meeting venues and even ensured that someone took my guide dog for a walk as I did not know the area. With a new Manager and limitations on the budget, I have found that the Ministry of Health is less supportive regarding my disability needs. For example, a couple of weeks ago I told the Ministry of Health staff that I would not be able to stay for the night at my son’s home. I would need accommodation. They know I have a guide dog. They usually booked me into the Brentwood Hotel. However I received notification that I and Tane had been booked into a hotel in town which had no grass nearby. I had to advocate strongly for this booking to be changed. Luckily my guide dog Tane and I are staying at the Brentwood Hotel. This should not have happened. When I was on the National Advisory Council for Employment of Women, the Labour Department were very supportive. They even paid for a carer as sometimes I was unable to walk. I think that all Government Ministries and Departments should have a policy which ensures that any disabled staff, disabled contractor or disabled committee member should receive the support they require to do their job.

4. Way Disability Support Services are run: We will all have different experiences with service providers. I do know that the Royal New Zealand Foundation of the Blind have now developed more involvement from clients regarding Foundation’s services. I am one of three Royal New Zealand Foundation of the Blind members who sit on the Clients Service Committee and the Royal New Zealand Foundation of the Blind Board have agreed that a fourth member be appointed. Recently I met with groups of members in Dunedin and Wellington and discussed their views on how the Royal New Zealand Foundation of the Blind services meet their needs or where improvement is required. I have compiled a report to the Clients Service Committee. Whilst the Royal New Zealand Foundation of the Blind have used other methods of obtaining members’ input

into monitoring their service delivery.I do believe that more members will be involved in this new method. There were around 25 to 30 members at the meeting in Wellington. I know that the Disability Resource Centre Southland also have clients actively involved in monitoring their service performance. These two providers provide me with disability support services.

5. Barriers to Making Complaints: I think that the major barrier preventing disabled people making complaints is due to the following:

   - Information about complaint procedures are not in accessible formats such as Braille, CDs, Word Files, NZ Sign Language or in Simple English. If these Procedures were more available and in accessible formats more disabled people would have access to this information.

   - My observation is that many older people do not feel comfortable about making a complaint. If the Royal New Zealand Foundation of the Blind provides them with a service, they are usually grateful for that service or they are worried that if they complain about something they will not receive services from that agency again.

   - Disabled people from other cultures may feel uncomfortable about complaining because it is not culturally appropriate to do so or the Complaints Procedure appears to be not culturally sensitive to their culture. English as a second language may also be an issue for some people.

   - Whilst there are Health and Disability Advocates around the country, one wonders if there are enough of them, do disabled people and their families/whānau know how to contact these advocates? Should there be more resources available to provide more advocates? Do disabled people have skills in advocacy to advocate for themselves or on behalf of a friend?

6. Look at Disability Awareness: I do think that the public are more aware of disabled people living in the community however I do think New Zealand has a long way to travel before this issue is completely addressed. I agree with the current Minister of Disability Issues that the TV programme “Attitude” should be on TV at a more peak viewing time. Whilst this programme certainly fills a gap in

our TV programming, I feel that it ignores some groups of the disability community, especially disabled people over the age of 40 years. There appears to be dominance in sporting activities however disabled people can do many other things. It is probably better to have more than one Disability Awareness TV Programmes on our screens and there are certainly enough channels to cater for this. The main issue is that people can turn off their TV if they don't want to watch a programme or tune to another channel. Changing attitudes is not easy and the best way to do this is to start with children. When I worked with children in Playcentre they were very accepting of me and treated me like any other parent. Even the parents were surprised to find out after a few weeks that I was legally blind. Other parents had not told them and I did not say anything however they did see me using a white cane in town. I did not meet with any open opposition those years ago. However, with Health and Safety regulations it might be more difficult for a legally blind woman to work in early childhood education these days. All we can do is keep working at educating more people about the skills and abilities of disabled people.

7. Education: You have not mentioned education however I have a friend who works in Special Education and he is concerned about National Standards at schools and how many children with disabilities will cope in such a system. These National Standards this Government has introduced does not seem to have included the issues many disabled student faces when at school. Is there provision for these students? Will students with a learning disability always fail?

8. Parenting: One last issue recently came to my attention with Paula Bennett Minister of Social Development talking about either taking children off parents who have abused them or sterilising mothers who have abused their children. This is not a disability issue however such attitudes could present issues for disabled women in the future. If these policies were adopted who would decide who is going to be a fit parent? Who would decide who should be sterilised? Some women with an intellectual disability are already sterilised because their parents or carers do not want the problem of keeping them clean etc. when they have their period. We do not want to return to the 1920s and 1940s when disabled girls were sterilised without informed consent. If someone gets away with such a policy for one group of women then it would just be a step away to including other women such as disabled women. I think that these last two illustrations demonstrate individuals' attitudes towards people who are different from other people. (I do not approve of anyone abusing children but I would have thought that any mother who abused her child would be dealt with via the legal process and end up in prison). What about the men who abuse children?