

Making disability rights real

Whakatūturu ngā tika hauātanga



Summary Report

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

Aotearoa | New Zealand
July 2012 – December 2013



Human Rights Commission

0800 496 877 (toll free)

infoline@hrc.co.nz

PO Box 6751, Wellesley Street,
Auckland 1141

Fax 09 377 3593 (attn: InfoLine)

TXT 0210 236 4253

www.hrc.co.nz

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The New Zealand Convention Coalition

C/- Disabled Persons Assembly
(New Zealand) Incorporated
PO Box 27524, Wellington 6141
convention.coalition@dpa.org.nz

Ombudsman

Fairness for all

Ombudsman

0800 802 602 (toll free)
www.ombudsman.parliament.nz
info@ombudsman.parliament.nz
PO Box 10152, Wellington 6143
Fax: 04 471 2254

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Cover image: Logan Mennie meets Auckland Zoo's elephant, Burma, during Blind Week in 2012.
Photo: NZ Herald/B Phibbs. Thank you too, to Logan.

Introduction

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

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

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

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

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

Developments such as the increasing engagement between Disabled People’s Organisations (DPOs) and government agencies are to be applauded. Moves towards the introduction of people driven service models are also encouraging. However, there is still a long way to go and some changes are occurring too slowly.

The second report of the Disability Convention Independent Monitoring Mechanism (IMM) details some of the experiences disabled people in New

Zealand encounter each day. It highlights barriers that prevent the full realisation of the rights set out in the Disability Convention. The report also recommends steps that need to be taken to better respect, protect and fulfil those rights. The five key overarching issues the IMM has identified during the current reporting period are:

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

The first part of the report also highlights four more specific matters of concern. These include the passing of the New Zealand Public Health and Disability Amendment Act 2013. This legislation means people are no longer able to pursue complaints of unlawful discrimination in relation to the Government's family care policy. The other three issues are the reliance on substituted decision-making, serious health outcomes for disabled people and the impact of sections of the Children Young Persons and Their Families Act 1989 on the rights of disabled children. The IMM partners trust the report will act as a powerful catalyst for change that will

lead to further improvements in the daily lives of people with disabilities.

This summary version describes the Disability Convention monitoring process and sets out the IMM's conclusions and its key recommendations. It also lists all the recommendations contained in the full report.



Paul Gibson
Disability Rights Commissioner
Human Rights Commission



Dame Beverley Wakem DNZM, CBE
Chief Ombudsman
Office of the Ombudsman



Mary Schnackenberg CNZM
Chair
New Zealand Convention
Coalition Monitoring Group

This summary and the full report are available to download from the Human Rights Commission's website at: www.hrc.co.nz/makingdisabilityrightsreal

**He aha te mea nui o te ao? He tangata, he tangata, he tangata.
What is the most important thing in the world? It is people,
it is people, it is people.**

The Disability Convention and the Independent Monitoring Mechanism

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

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

Six months after New Zealand signed the Disability Convention, the United Nations General Assembly adopted the Declaration on the Rights of Indigenous Peoples (UNDRIP). New Zealand expressed



Victoria Manning, the Hon. Ruth Dyson, the Hon. Tariana Turia and Disability Commissioner Paul Gibson at the launch of the New Zealand Sign Language inquiry report in 2013. Photo: C McDiarmid.

its support for UNDRIP in April 2010. While the declaration itself is not binding, many of the provisions reflect obligations set out in ratified conventions or covenants. The Disability Convention shares some common underlying human rights principles with both the Treaty of Waitangi and UNDRIP. These include the importance of partnership, autonomy, close consultation and full and effective participation.

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

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

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

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

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

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

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

The approach

In its first report published in December 2012, the IMM focused on developing a baseline picture of the state of disabled people's rights in New Zealand. The report contained seven key recommendations, pulling together the main priorities from a full list of 44 recommendations. It recommended that the Ministerial Committee on Disability Issues should ensure that action on those recommendations was completed by the end of 2014.



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

The second report assesses what progress has been made since June 2012.

This summary report highlights and discusses some key issues identified by the IMM during the reporting period, including its priority recommendations.

As recognised in the first report, monitoring the Disability Convention presents some unique challenges. These include the breadth of issues covered by the Convention and the lack of disability data and research in important areas. In addition, environmental and attitudinal barriers hinder disabled people's full participation

in society on an equal basis with others. Collectively these factors can make the effective measurement and assessment of progress difficult.

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

Key issues

The IMM has identified five broad areas that require particular attention in order to promote greater realisation of the rights set out in the Disability Convention. While promising progress has been achieved in some of these areas during this latest reporting period, much more work is still required. These five key areas are:

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

Data

The dearth of statistics and information relating to disabled people in New Zealand was noted in the first IMM report. But there is a continued absence of quality data based on consistent definitions across a range of indicators. This makes it difficult to obtain an accurate view of many issues that have an impact on the lives of disabled people. It also hinders the measurement of progress and the recognition of improvements that have been made.

Statistics New Zealand expects to release the 2013 *Disability Survey* results in

mid-2014. These should provide further valuable information about the experiences of disabled people, their needs and the barriers they encounter. However, ongoing work is required in this area to ensure that robust, timely and useful data are regularly collected across a range of sectors. This data can then be used to make practical changes that will improve the daily experiences of people with disabilities.

Accessibility

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

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

The Disability Access Review was announced on 20 October 2013. It will be undertaken jointly by the Ministry of Business, Innovation and Employment and

the Office for Disability Issues. The review will consider whether the current building regulatory system meets the needs of people with disabilities. This is an important step towards improving the physical accessibility of buildings.

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

Building a people-driven system

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

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

The implementation of a comprehensive people driven model must remain a priority for the Government. The IMM recognises that there has been progress in this area

since the last report and that building a people driven system can take time. Significant changes cannot occur overnight. However, the IMM remains concerned that the roll-out of policies and practice is too slow. Many current projects do not include representatives from DPOs; neither do they have disabled people or their family members in leadership roles.

Violence and abuse

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

There is increasing awareness of the prevalence of violence and abuse within society generally. However, the specific forms of abuse disabled people face require particular attention. These include situations where people may have limited ability to verbalise or communicate what is happening to them, or where they may be reliant on the abuser for day-to-day support and assistance.

Further work is required to prevent abuse against disabled people in all environments. If abuse does occur, there need to be systems in place to detect it quickly and to respond effectively and in a manner appropriate to the needs of the disabled person concerned.

Education

The IMM supports initiatives that have been taken to make schools more inclusive. Since the last monitoring report, the Education Review Office (ERO) has undertaken a number of evaluations and surveys. These indicate that good progress has been made towards schools and early childhood centres becoming more inclusive. However, the IMM shares ERO's concern about the way schools report on their inclusiveness. This reporting focuses predominantly on activities and strategies and much less on the outcomes that are achieved for disabled students. The IHC has questioned the methodology used by ERO and the statistical significance of some of its findings.

Exclusion, isolation and bullying remain significant issues for children and youth. Education-related complaints continue to make up a large proportion of disability complaints to the Human Rights Commission. It is essential more work is done to ensure that disabled children are able to fully realise their education rights, and that this occurs in partnership with DPOs.

The IMM remains concerned that there is a gap between the legal right to education and the ability to ensure that this right is realised at a practical level for individual students. There is still no enforceable right to inclusive education in New Zealand.

Other matters of concern

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

Reliance on substituted decision-making

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

Removal of remedies for unlawful discrimination in relation to family caregivers

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

Serious health outcomes

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

Right to family life

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

Key recommendations

The key recommendations from the IMM for the current period largely replicate those from 2011/12. This reflects the importance of these key issues and the fact that ongoing work is required in these areas, even though some progress has been made.

The IMM recommends:

- A That the Government continue to jointly develop the Disability Action Plan with DPOs (including disabled people, children and their families) and commit to its full implementation.
- B That Statistics New Zealand, in partnership with DPOs, lead a programme of work to ensure that key outcome and prevalence data are collected in a way that makes it possible to compare outcomes for disabled and non-disabled people. This work should include a common definition of disability and involve consultation with key stakeholders, government and international agencies.
- C That the Government integrate accessibility and universal design across all its work by:
 - 1 improving access to the built environment including through the review of NZS 4121:2001
 - 2 improving access to transportation services for disabled people, including development of national accessibility design standards for all aspects of public land transport
 - 3 providing accessible communications services, including websites, throughout all government agencies.
- D That the Department of Corrections and Ministry of Health work together, in consultation with the IMM, to ensure:
 - 1 the requirements of prisoners with disabilities are reasonably accommodated and
 - 2 best practice in the detention and treatment of people with an intellectual/learning disability or a mental illness.
- E That the Government:
 - 1 establish an enforceable right to inclusive education
 - 2 implement a whole of school anti-bullying programme to ensure that schools are safe and nurturing places for disabled students
 - 3 establish initiatives that promote the value of difference and affirm the identity of disabled students.

- F That the Government develop a range of initiatives to ensure that:
- 1 disabled people have the same protection from domestic and other forms of violence as non-disabled people and
 - 2 agencies identify and appropriately respond to abuse, neglect and violence directed at disabled people.
- G That the Government urgently address the specific matters of concern identified by the IMM in the introductory section of this report, by:
- 1 repealing the New Zealand Public Health and Disability Amendment Act 2013, particularly those sections which remove remedies for unlawful discrimination in relation to complaints by caregivers who are family members and limit when family members can be paid
 - 2 reviewing relevant laws, in particular mental health legislation, to ensure that the principles of supported decision-making are appropriately reflected and applied in accordance with Article 12 of the Disability Convention
 - 3 addressing significant disparities in health outcomes between disabled people and non-disabled people, particularly for people with an intellectual or learning disability
- 4 amending the Children, Young Persons and Their Families Act to ensure that disabled children have the same rights as other children when an out of home care arrangement is being considered, and have legal representation and protection when decisions are being made in relation to these matters.
- H That the Government provide the IMM with a progress report, as at the end of 2014, on implementing the recommendations of the IMM's 2011/12 report.

Monitoring programme for the next period

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

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

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

- 1 opportunities for disabled people's voices to impact on policy decisions about their lives
- 2 supported decision-making
- 3 issues relating to vulnerable children with disabilities, particularly those at risk of being parted from their families
- 4 reporting the experiences of Māori and Pacific disabled people
- 5 preventing violence, abuse and neglect within residential services, homes and public places
- 6 considering the compounding challenges experienced by people with disabilities as they age
- 7 accessibility of information, including government web standards
- 8 guidance provided by the Disability Convention in relation to bio-ethical issues such as pre-natal testing
- 9 support for people with experience of mental illness in prisons and other places of detention.



The Hon. Tariana Turia. Photo: C McDiarmid.

Recommendations in the body of the report

The full report tracks progress in meeting the obligations set out in various articles of the Disability Convention and recommends further actions needed. Those recommendations are listed below:

Recommendation 1

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

Recommendation 2

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

Recommendation 3

That Statistics New Zealand make it a high priority to:

- 1 produce a report from the 2013 *Disability Survey* comparing the human rights outcomes of disabled women and men with non-disabled women and men

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

Recommendation 4

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

Recommendation 5

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

Recommendation 6

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

Recommendation 7

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

Recommendation 8

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

Recommendation 9

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

Recommendation 10

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

Recommendation 11

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

Recommendation 12

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

Recommendation 13

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

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

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

Recommendation 14

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

Recommendation 15

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

Recommendation 16

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

Recommendation 17

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

information and communication requirements.

Recommendation 18

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

Recommendation 19

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

Recommendation 20

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

Recommendation 21

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

Recommendation 22

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

Recommendation 23

That the Government establish an enforceable right to inclusive education.

Recommendation 24

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

Recommendation 25

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

Recommendation 26

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

Recommendation 27

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

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

Recommendation 28

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

Recommendation 29

That the Ministry of Social Development:

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

Recommendation 30

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

Recommendation 31

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

Recommendation 32

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

Recommendation 33

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

Recommendation 34

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

Recommendation 35

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

Recommendation 36

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

disability and involve consultation with key stakeholders, government and international agencies.

Recommendation 37

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

Recommendation 38

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

