



Disability Rights: How is New Zealand doing?

Ngā Motika Hauātanga: Kei te pēhea a Aotearoa?

An update report about the state of disability rights in New Zealand

Aotearoa | New Zealand

Hereturikōkā | August 2022



Disability Rights: How is New Zealand doing? Ngā Motika Hauātanga: Kei te pēhea a Aotearoa? is available in alternate and summarised formats, including an accessible online Word version, braille, audio, te reo Māori, Easy Read and NZSL. Use your internet connected device, such as your mobile phone to activate the QR code on the cover. This will allow you to access these other formats.

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Cover image: Two young women – Angelica Woolley and Libby Hunsdale – lean on a fence looking at Angelica's phone. Libby smiles as she points to the screen.

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Introduction

Progress on disability rights in Aotearoa New Zealand was last reviewed by the United Nations Committee on the Rights of Persons with Disabilities (the Committee) in September 2014. Since then, the New Zealand Independent Monitoring Mechanism (IMM) under the United Nations Convention on the Rights of Persons with Disabilities (the Disability Convention) has published two further monitoring reports on the implementation of the Disability Convention:

- *Making Disability Rights Real 2014-2019*;¹ and
- *Making Disability Rights Real in a Pandemic*.²

This summary report updates the Committee, and the New Zealand Parliament and public, with more recent information on the priority areas that prevent disabled people in New Zealand from realising their full suite of human rights as set out in the Disability Convention. The report notes some areas where the government considers progress has been made toward the realisation of the Disability Convention, and the IMM's assessment of where further commitment is needed.

In March and April 2022, the IMM held a series of interactive dialogues (fora) between disabled people in New Zealand alongside government to review the implementation of the Disability Convention in Aotearoa. These fora examined the key issues raised in the IMM's two most recent monitoring reports on implementation of the Disability Convention. These discussions are reflected in the themes covered in this report.

The information provided to the IMM by the government during the fora allowed a more contemporary assessment of Aotearoa's progress in protecting the rights of disabled people under the Disability Convention.

There was extensive engagement from government with over 70 officials involved in the fora. This was coordinated by the Office for Disability Issues as the agency with the Disability Convention as its focal point. There was considerable work undertaken by government to prepare responses and the IMM welcomed the government's acknowledgement of inequities and work to do to progress disabled people's rights during the fora. The IMM acknowledged encouraging progress was reported in some areas; however, much more work is required to ensure disabled people in New Zealand can participate fully in all areas of life. For example, it was disappointing

to hear about generic work that may be of benefit to disabled people but that was not designed with disabled people and tāngata whaikaha Māori, or with them specifically in mind.

The Disability Convention

The purpose of the Disability Convention is to make sure disabled people are treated with dignity and respect and have the same rights as everybody else. The New Zealand Government signed the Disability Convention on 30 March 2007, ratifying it on 26 September 2008. It does not establish new rights, but sets out what governments need to do to ensure their disabled citizens can enjoy their human rights as provided by all the relevant United Nations human rights instruments. Under the Disability Convention, governments have a duty to work towards a more inclusive society by aligning policies and laws with this convention. To give effect to the Disability Convention and the *'Nothing about us without us'* mantra of the disability community, the government must ensure disabled people are actively involved in all matters affecting them.

Independent Monitoring Mechanism (IMM)

Aotearoa has set up an IMM, as required by Article 33(2) of the Disability Convention. The IMM independently monitors how the Disability Convention is implemented. The establishment of the IMM, and the three partners, was formally designated by Cabinet in 2011. The IMM partners are the DPO Coalition, the Ombudsman, and the Human Rights Commission. In addition to whole-of-IMM work, IMM partners have autonomous roles to promote, protect and monitor disability rights in Aotearoa. The IMM make-up reflects Article 4(3) of the Disability Convention, which provides that decision making processes affecting disabled people should actively include them.

Terminology

Many words and terms can be used to identify disability, and we recognise and acknowledge that different people prefer different terms. The Disability Convention uses the term 'persons with disabilities'. In this report, we use the term 'disabled people', based on the advice of the Disabled People's Organisations (DPO) Coalition and to reflect a social model of disability.

Te reo Māori is the language of Māori, our indigenous people, and one of three official languages in Aotearoa. Te reo Māori terms have been used throughout this report, with English definitions provided in the Glossary. In te ao Māori (the Māori world), 'tāngata whaikaha Māori' may be used to refer to disabled Māori.

The New Zealand Disability Strategy³ (NZDS) guides the work of government agencies on disability issues. It can also be used by individuals or organisations wanting to learn more about, and make the best decisions on, things important to disabled people.

Methodology

To identify the priority areas that the fora would focus dialogue with the government on and subsequently inform this report, the IMM:

- asked for written responses from the government on the *IMM Making Disability Rights Real* reports and recommendations, and reviewed these to evaluate progress;
- identified thematic areas of focus and developed questions on those themes which were submitted in advance to the government. These themes were drawn from concerns arrived at where the IMM considered government had not responded adequately, and from issues raised by disabled people and their representative organisations; and
- held a series of online fora with government officials to receive responses to the prepared questions, from which supplementary questions arose. Where responses were not able to be given at the fora, the government was given a further three weeks for written responses. Live viewing of the fora was available for the public, with opportunities for public participation by submitting questions to inform the IMM's supplementary questions during the sessions.

The drafting of the fora questions was informed using intersectional frames, supporting the prioritising of the issues. Frames included:

- Equal recognition before the law (Article 12)
- Participation, decision making, and visibility (Articles 4, 30, 8, 29)
- Intersectionality with other demographic groups (Articles 5, 6, 7)

The six thematic areas of focus were:

1. Obligations under Te Tiriti o Waitangi/The Treaty of Waitangi (Te Tiriti)⁴ (Article 5)
2. Poverty (Articles 27, 28, 25)
3. Equity and access during humanitarian crises (Articles 11, 5, 9)
4. Integrity of the person (Articles 10, 14, 15, 16, 17, 25)
5. Equality, non-discrimination and access to justice (Articles 5, 12, 13)
6. Accessibility and independence (Articles 23, 22, 21, 9, 19, 24, 25, 20, 26, 28)

Cross-cutting issues across all themes

Lacking and inconsistent data collection and use across agencies prevents momentum

The IMM acknowledges the government has made significant progress on data collection in recent years. Despite this, the enduring inconsistency and lack of data collection across agencies is preventing agencies from identifying, and resolving, the issues disabled people face. Where data and evidence is available, agencies are not consistently using this to inform disabled people's needs or changes in policy development, work programmes or service evaluation methodologies. Article 31 requires the government to collect and use data and statistical information to give effect to the Disability Convention. Such data should be disaggregated to assist in determining how Aotearoa is fulfilling the obligations under the Disability Convention, and to identify and address barriers faced by disabled people.

Concerns remain about participation of disabled people in decision making

The IMM acknowledges that the government has consulted more widely with the disability community in recent years.⁵ However, many concerns remain about a lack of genuine partnership with disabled people in legislative and policy design across government. The IMM considers that full participation of disabled people in government decision making is crucial to the implementation and progressive realisation of all IMM recommendations. Article 4(3) of the Disability Convention describes the obligations of governments to consult and actively involve disabled people through their representative organisations.

Lack of cross-agency cohesion and ownership of the Disability Convention is a persistent barrier

Notwithstanding the active focal point in the Office for Disability Issues and a cross-agency *Disability Action Plan*,⁶ activity to progress disability rights is largely siloed within individual agencies. The government's plan to establish a Ministry for Disabled People to progress disability rights is promising, but it must be resourced adequately and promulgate cross-agency efforts. The IMM found a lack of government collaboration and ownership as key contributors to persistent barriers for disabled people across all sectors. The IMM fora promoted collaborative discussions between agencies, and officials acknowledged the value of this in their

reflections on the fora. Fundamentally, equality requires the recognition of disabled people's right to equal citizenship with others. Citizenship includes every aspect of a person's life. The human rights model of disability recognises that human rights are interdependent, interrelated, and indivisible.⁷ The World Health Organization has recognised that factors such as employment status, housing and education can have direct and indirect impacts on health.⁸ This concept, 'the social determinants of health', is just one example that signposts the interdependence of the themes in this report. Therefore, making disability rights real in Aotearoa requires cross-agency collaboration and ownership of disability rights.

Obligations under Te Tiriti

*Me mahi tahi tātou mō te oranga o te katoa.
We must work together for the wellbeing of everyone.*

Articles 4, 5, 6, 7, 21, 30(1, 4), 31(2)

Te Tiriti and the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) are both strongly aligned with the human rights principles reflected in the Disability Convention. These include the importance of partnership, autonomy, close consultation, and full and effective participation. Article 3 of the Disability Convention affirms disabled people's inherent dignity, and right to be treated as equal citizens in all aspects of their lives. The IMM is concerned barriers to equal citizenship remain in place for tāngata whaikaha Māori and need to be removed in order to address persistent inequities. The observed inequities for Māori are amplified for tāngata whaikaha Māori as they are often worse off than non-Māori disabled people.

Disabled people are entitled, on an equal basis with others, to recognition and support of their specific cultural and linguistic identity, including sign languages and Deaf culture. Tāngata whaikaha Māori have experienced alienation from their culture and language, including the loss of stories of leadership by tāngata whaikaha Māori.

What is required to ensure tāngata whaikaha Māori rights are upheld?

- Obligations under Te Tiriti to tāngata whaikaha Māori need to be considered in the appropriate cultural context at all levels of decision making, planning and policy making.
- Tāngata whaikaha Māori and their representative organisations require adequate funding and resourcing in order to have full engagement and representation in decision making, planning and policy making. This will ensure efforts to improve disability rights are culturally inclusive and have fair and equitable outcomes for tāngata whaikaha Māori.

What has changed for tāngata whaikaha Māori since the IMM's last report?

Disparities demonstrate that the human rights of tāngata whaikaha Māori are not being fully realised as set out in the Disability Convention, UNDRIP, and Te Tiriti.

Statistically, Māori experience higher rates of disability and because Māori are a younger population, impairment rates are less likely to be linked with age related conditions.

Compared to non-Māori, Māori have higher rates of disability, poverty, suicide and unemployment, and have a lower life expectancy than other population groups. Tāngata whaikaha Māori are further marginalised, faring worse than their non-disabled Māori peers, with lower labour force participation and lower rates of educational achievement.

Government's summary of key progress

The government outlined a range of initiatives designed to improve health and wellbeing outcomes for Māori, which could indirectly benefit tāngata whaikaha Māori:

- *Whakamaua: Māori Health Action Plan 2020-2025*⁹ sets out the foundations of a commitment to Māori health and equitable outcomes. These include:
 - iwi, hapū, whānau and Māori communities can exercise their authority to improve their health and wellbeing;
 - the health and disability system is fair and sustainable and delivers more equitable outcomes for Māori;
 - the health and disability system addresses racism and discrimination in all its forms; and
 - the inclusion and protection of mātauranga Māori throughout the health and disability system.
- The Pae Ora (Healthy Futures) Bill which targets policies for disabled people, tāngata whaikaha Māori, and Pacific peoples.
- The announcement of the Enabling Good Lives (EGL)¹⁰ approach to be nationally rolled out after its successful trial. This approach is based on supporting disabled people's access to everyday life in everyday places, rather than focusing on 'special' places or activities for disabled people. The regional roll-outs of EGL have demonstrated good practice examples of genuine partnerships with Māori.

Where the government needs to show further commitment

These initiatives are in the early stages of development and the government must establish and meet timelines to report on measurable progress throughout implementation.

The IMM also believes that the government needs more intentionally targeted and co-designed initiatives within general strategies to eliminate the disparities tāngata whaikaha Māori experience:

- The government needs to co-design with tāngata whaikaha Māori, policies specifically targeted at addressing the added disparities tāngata whaikaha Māori experience compared with non-Māori disabled people.
- The government needs to demonstrate commitment to inclusion and self-determination for tāngata whaikaha Māori. To do this, the government must support and resource participation to ensure tāngata whaikaha Māori perspectives are reflected in the development of all legislation, policies, and decision-making processes. For example, no member of the interim Māori Health Authority Board identifies as tāngata whaikaha Māori.
- The government must support and resource the establishment of a self-determined monitoring mechanism for tāngata whaikaha Māori. The absence of a self-determined mechanism is a barrier to reflecting tāngata whaikaha Māori perspectives in disability-related policy and legislative development, and any Crown-Māori partnership initiatives.
- The intersectionality of ableism, racism, discrimination, and poverty results in long-lasting, poor outcomes for tāngata whaikaha Māori. Action needs to take the form of commitment to addressing recommendations made in the Welfare Expert Advisory Group (WEAG) report¹¹ relating directly to tāngata whaikaha Māori to bridge gaps in equity with regard to current inequitable socio-economic outcomes.

Poverty

Articles 27, 28

All disabled people have the right to adequate standards of living as affirmed in Article 28 of the Disability Convention. However, the over-representation of disabled people in poverty-related statistics in Aotearoa indicates that disabled people's rights are not being upheld. Disabled people are more likely to experience poverty, with many unable to meet everyday costs.

Disabled people on average have significantly lower incomes than non-disabled people, alongside increased disability-related costs, including but not limited to health and support costs. Furthermore, means testing and low thresholds for some support funding means that some disabled people in employment must use their income to meet these extra costs, increasing income disparity with non-disabled people. Digital inequities are key barriers to participation in society, including employment, for many disabled people. These digital inequities are often a product of poverty, which further perpetuates cycles of poverty, exclusion and unemployment.

What is required to eliminate poverty and inequality for disabled people?

- Mechanisms for measuring and meeting support and welfare assistance criteria must ensure an adequate standard of living for disabled people.
- Sufficient, flexible employment services need to be acceptable and available to both disabled people and employers throughout the employment cycle. These employment services must promote accessible workplaces, support disabled employees, create greater understanding and implement reasonable accommodation.
- Disabled people should have access to affordable, appropriate and accessible housing options.

What has changed for disabled people's standards of living since the IMM's last report?

Disabled people are over-represented in all aspects of poverty-related statistics, including income and material hardship. Evidence shows that poverty affects many areas of a person's life including housing, access to food, access to energy, information or communication, access to healthcare, transportation, safety, and participation.

There is no new data from Statistics New Zealand since the IMM's report *Making Disability Rights Real 2014-2019*, which highlighted several poverty measures regarding disabled people, and indicated that:¹²

- disabled people of working age (15-64 years old) had a median personal income of \$353 per week in 2018, less than half that of non-disabled people in the same age group (\$806);
- disabled people in employment had a median weekly income of \$144 less than non-disabled people in employment; and
- tāngata whaikaha Māori adults are three times as likely as non-disabled Māori adults to indicate they do not have enough money to meet everyday needs.

Recent employment data from the Welfare Expert Advisory Group and Ministry of Social Development suggests that over 50 percent of people on main benefits are disabled¹³ and 72 percent of unemployed disabled people want to work.¹⁴

Government's summary of progress

- Main benefits have been indexed to annual wage growth since 2020. In 2022, the Ministry of Social Development increased the rate of the main disability benefit (Supported Living Payment) to the level suggested by their Welfare Expert Advisory Group (WEAG) report¹⁵ in 2019. The increase was significant, although it met the suggested 2019 level, and was not adjusted to an equivalent 2022 cost of living.
- There is ongoing review of welfare, the Ministry of Social Development's Te Tiriti responsibilities framework, and services for disabled people planned.
- The government has proposed an income insurance scheme, to support short-term loss of work capacity, including due to disability and health conditions.
- Establishment of a Ministry for Disabled People to progress the rights of disabled people.
- Commitment from Kāinga Ora for a target of 15 percent of new public housing builds to meet universal design standards, with re-evaluation of the target over time.
- Establishment of a COVID-19 recovery '*Working Matters*' disability employment action plan,¹⁶ with the view to ensure disabled people can participate in employment on an equal basis with others.

Where the government needs to show further commitment

- The government should ensure that an adequate standard of living for disabled people is prioritised throughout the welfare overhaul. This work must have disabled people leading key discussions, decision making, and providing policy review around support for disabled people.
- Reviewing and improving guidelines and thresholds for disability-related financial support, including as living costs increase, so they meet the needs of disabled people.
- The government, through an agreed action plan, has agreed to remove the law that allows for the Minimum Wage Exemption (MWE) scheme.¹⁷ However, despite some progress, the MWE still remains in place. A moratorium should be put in place immediately on any new MWEs, and work to change the law should be completed within a specified period of time, in order to eliminate discrimination and exploitation of disabled people in employment.
- Sufficient, flexible employment supports should be available to all employees and employers throughout the employment cycle to support accessible work, and promote greater understanding and implementation of reasonable accommodation for disabled people.
- Ensuring the public sector is an exemplar of best practice for the employment of disabled people, including assurance that policies and processes within the public sector are accessible.
- Kāinga Ora should assess and respond to the current need for universally designed housing, significantly increase the 15 percent target of universally designed new build public housing, and support other affordable and accessible housing options.
- Mechanisms for identifying, measuring and meeting support and welfare assistance must align with the needs of disabled people in an equitable way. Disabled people who incur disability-related costs and/or are unable to work or otherwise earn sufficient income, on a short, medium or long-term basis, must be supported to enjoy a reasonable standard of living.
- Increasing employment support and revising eligibility criteria to ensure it is accessible to all disabled people seeking employment support.

Equity and access during a humanitarian crisis

Articles 5, 9, 11

Aotearoa experiences numerous emergency situations, including flooding and earthquake events, often specific to a region. The global COVID-19 pandemic has exposed many inequities for disabled people, including those present before the pandemic and exacerbated during the emerging response. Disabled people are more likely than non-disabled people to have support needs requiring close contact with caregivers or support workers, increasing the risk of transmission.

The IMM heard of disabled people's essential services, such as personal care and community support, being cut without due notice. Panic buying cleared supermarket shelves of essential items and online shopping was over-subscribed. Without physical support or means to access food online, many disabled people were unable to access food through the usual channels and needed to rely on their own social supports. Some people reported not being able to do this and going without food.

At the beginning of the pandemic in 2020, there was misinformation about the use of personal protective equipment (PPE). This was coupled with a lack of understanding by carers and disabled people themselves on how to use PPE safely and effectively. Also of concern at the beginning of the pandemic was the lack of PPE availability. The government improved PPE training, guidance and resourcing throughout the course of the pandemic.

As Aotearoa continues to negotiate the COVID-19 response, disabled people continue to face barriers and challenges that the non-disabled population do not experience. The government must ensure adequate resources and processes are in place to protect disabled people. Doing this will work to inform how to navigate and support disabled people and mitigate barriers during any future humanitarian crisis.

What is required to ensure disabled people's rights are upheld during a humanitarian crisis?

- In the event of a national emergency, the National Emergency Management Agency¹⁸ (NEMA) should specifically consult with the DPO Coalition and other key groups (DPOs, Iwi, whānau groups, service providers) on Disability Inclusive Disaster Risk Reduction (DIDRR). Similarly, local government should involve

disabled people in their local emergency planning. It is important to ensure that disabled people and their allies are involved in all stages of planning – before, during the emergency itself and in the recovery phase. Disabled people need to have equitable access to information during all phases of an emergency situation.

- Obligations under Te Tiriti to tāngata whaikaha Māori in all planning and responses during all stages of emergency planning and execution are met.
- In preparation for, and during, a humanitarian crisis, the government should take an intersectional approach as it connects with key representative community groups to ensure that disabled people’s services are maintained, resourced, and not put at further risk during an emergency response. An intersectional approach acknowledges that certain individuals and communities face a variety of barriers, and therefore it is important to work collaboratively to achieve equitable outcomes.
- Resource disabled people’s organisations, service providers, and community groups in the event of an emergency situation to support the wellbeing of their members, clients and community members.

What has changed for disabled people since the IMM’s last report?

- A key finding in the *Making Disability Rights Real in a Pandemic*¹⁹ report was that disabled people experienced delays receiving accessible information and communications relating to the emergency response. This prevented many from being able to make informed decisions about their safety and health during this time, heightening both fear and anxiety.
- The recent easing of restrictions to contain the COVID-19 Omicron outbreak has further highlighted the inequities disabled people continue to face. Disabled people’s voices continued to be excluded from the consideration of new frameworks and eased public health restrictions. At the time the fora were held, there were issues around the COVID-19 vaccination roll-out, for example, some disabled people did not have the support they needed to get to a vaccination site.
- Disabled people need to be informed during an emergency, so they can make decisions about their own health and safety in real time. During emergency situations, disabled people face more challenges and barriers than the non-disabled population. This puts them at serious risk, and these risks need to be managed to ensure equitable outcomes. The government must prioritise the protection of disabled people in the face of the current pandemic.

Government's summary of progress

- NEMA has processes in place to engage with disabled people and is increasing its alternate information output especially in New Zealand Sign Language.
- Many agencies have improved their provision of information in alternate formats through a cross-agency process set up prior to the COVID-19 emergency.

Where the government needs to show further commitment

- Learn from disabled people's experiences through improved accessible consultation processes.
- Provide accessible information in real time. The IMM acknowledges the complexities and the initial chaos due to the amount of information needed in different communication formats. A great deal of pressure was put on DPOs to provide re-formatting services, when DPOs were also supporting their members and navigating their own experiences of the pandemic.
- Understand the digital divide and its many facets and consolidate systems to produce alternate communication formats and printed material in a timely way. In turn, distribute this through appropriate networks to ensure full reach to the disability community.
- Consult with disabled people about the removal of public health measures. This has put many disabled people who are more likely to experience poor outcomes when contracting Omicron at risk. In light of this, the Disability Rights Commissioner initiated an inquiry under the Human Rights Act 1993 into the impacts of the government response to the pandemic on disabled people and tāngata whaikaha Māori.²⁰
- Ensure and enable engagement with grass roots communities, such as Iwi and community health hubs, in planning and executing public health measures and emergency responses. This supports disabled people to engage and work with groups they trust and is especially relevant for tāngata whaikaha Māori and Pacific peoples.
- Ensure contracted service providers understand their responsibilities to continue to provide essential services for disabled people during emergency situations and be aware of consequences if this does not happen.
- Ensure consistent responses and information across all government agencies – there were many inconsistencies with regard to the release of information.

Integrity of the person

Articles 10, 14, 15, 16, 17, 25

Disabled people have the right to be respected for who they are and treated on an equal basis with all others. Disabled people should be supported to make decisions about matters that affect their health, wellbeing and integrity. Unfortunately, some disabled people in New Zealand are still denied the opportunity to have control over their wellbeing and integrity due to substitute decision making practices still prevalent in Aotearoa. Disabled people want Aotearoa to move to a supported decision-making approach, where they have increased control over their own destiny and integrity. The impacts of substitute decision-making approaches are discussed further in the next section.

The Disability Rights Commissioner has described violence and abuse of disabled people in Aotearoa as *'epidemic'*.²¹ Disabled adults' experience of violence and abuse is disproportionately higher than rates of violence experienced by non-disabled people. Disabled adults are more likely than other adults to be subject to sexual assault.²² New Zealand Health Survey Data 2020/2021 shows that disabled adults are less likely to report 'good', 'very good', or 'excellent' health compared with non-disabled adults.²³ Disabled adults are over six times as likely as non-disabled adults to have experienced psychological distress.²⁴

What is required to ensure disabled people are treated on an equal basis with all others?

- Respect for inherent dignity, individual autonomy and integrity including the freedom for disabled people to make their own choices and be independent.
- Disabled people should have their freedoms protected by law on an equal basis with all others. Any deprivation of liberty must be in conformity with the law, and the existence of disability should not justify a denial of human rights.

What has changed for disabled people since the IMM's last report?

The IMM remains concerned at the ongoing use of seclusion and restraint practices in Aotearoa's prisons and healthcare facilities and believes these outdated practices need to be removed. Although there are often alternative options available to manage challenging behaviour, seclusion and restraint are not always used as a

last resort. There is an urgent need to promote alternative options, and make them available, to manage challenging behaviour and examine why these alternatives are not always being used.

For disabled people, it is fundamental that they have the same protection from violence and abuse as non-disabled people, and that agencies are positioned to prevent, and respond to the abuse disabled people experience. Monitoring frameworks and audit systems to report violence and abuse need to be accessible and fit-for-purpose.

Disabled people in New Zealand continue to experience inequities in life expectancy, particularly those with learning disabilities. People with learning disabilities have overall poorer health outcomes compared to people without learning disabilities, despite higher-than-average use of health services. There are significant differences in life expectancy—people with learning disabilities can expect their lives to be shorter by an estimated 17-24 years compared to the general population.²⁵ There is concern that the deaths of some people with learning disabilities may be premature or avoidable. Like everyone, disabled people want to live good and long lives.

Concern also remains that there is no legislation in place to prohibit sterilisation (or any other non-therapeutic medical procedure) on disabled children and adults. Disabled people want their lives to be valued on an equal basis with all others, and be meaningfully represented in decisions that affect their lives.

Government's summary of progress

- The government has acknowledged that the Mental Health Act 1992 is outdated and does not adhere to contemporary mental health philosophy. Repealing and replacing the Mental Health Act is underway but careful consideration still needs to be given to ensuring the voices of tāngata whaikaha Māori are involved in this work programme. Moreover, new legislation needs to effectively enable a supported decision-making approach.

Where the government needs to show further commitment

The government must take urgent steps to ensure that disabled people are afforded the right to make decisions about their own lives and have control over their wellbeing and integrity, by:

- Reassessing its performance in relation to reducing and then eliminating seclusion and restraint practices in Aotearoa. It is clear that the *'Zero Seclusion:*

Safety and dignity for all' by 2020 project²⁶ commissioned by the Health Quality and Safety Commission has not achieved the goals it set. Further, tāngata whaikaha Māori continue to be secluded at higher rates than the general population.

- Initiatives to address involuntary sterilisation and other non-therapeutic medical procedures on disabled people have stalled despite a project focusing on protecting bodily integrity being explicitly listed in Aotearoa's current *Disability Action Plan*.²⁷ Until legislation is enacted prohibiting involuntary sterilisation or other non-therapeutic medical procedures, a moratorium should be placed on these discriminatory practices in Aotearoa.
- Ensuring disabled people are not negatively affected by the End of Life Choice Act, and that data is collected to ensure disabled people are not impacted by a lack of safeguards against coercion, feelings of being a potential burden to family, devalued identity, and a lack of even or equal choices in the absence of properly resourced support and palliative care options.

Equality, non-discrimination and access to justice

Articles 5, 12, 13

Disabled people continue to face widespread discrimination in Aotearoa. Disabled people die earlier, have twice the unemployment rate of non-disabled people, are more likely to report inadequate housing conditions, have insufficient money for basic necessities or healthcare, and are overrepresented in the care and protection, youth justice, and corrections populations.

What is required to ensure equality, non-discrimination and access to justice for disabled people?

Having control over their own lives and circumstances ensures disabled people are valued as equal citizens. The requirements for this include:

- All measures must be taken to respect a disabled person's rights, will and preferences, and to prevent abuses, conflicts of interest or undue influence over the exercise of legal capacity.
- Access to sufficient, diverse, and guaranteed systems of supported decision making is critically important for disabled people in New Zealand to participate in decisions affecting them.
- Those responsible for developing and implementing law and policy must ensure disabled people's participation in this work.

What has changed for disabled people since the IMM's last report?

Disabled people continue to experience barriers preventing them having equal access to resources and opportunities. This leaves disabled people feeling that their rights of full participation are less important than perceived costs for government, business or organisations.

Laws still exist in Aotearoa permitting people's rights to be limited because of disability. These laws reflect a view that disabled people lack capacity, which in turn reinforces this way of thinking. The Mental Health (Compulsory Assessment and Treatment) Act and the Protection of Personal Property Rights Act for example, are laws that can mean disabled people lose the right to determine what happens to them. Compulsory treatment is disproportionately applied to tāngata whaikaha

Māori. Disabled people have told the IMM that loss of control undermines their value as equal citizens and creates trauma.

Government's summary of progress

The IMM acknowledge there has been some progress on legal reform. Key areas of progress include:

- The government has committed to repealing and replacing the current Mental Health (Compulsory Assessment and Treatment) (MHCAT) Act.
- There is work underway by the Law Commission²⁸ to review adult decision-making legislation (non-criminal).
- There has been significantly increased investment in communication assistance within the court system.
- A range of initiatives to improve data collection and information accessibility within the court systems has been put in place.
- The Ministry of Justice is trialling a range of court system and justice reforms to make processes more accessible, and more solution focused.
- Some work has been undertaken on a high-level audit of laws inconsistent with the Disability Convention.

Where the government needs to show further commitment

Despite some positive progress, considerable work remains to uphold the mana of disabled people's right to be treated equally before the law and to exercise legal agency:

- The government needs to show a greater commitment to understanding and implementing a legal framework that protects disabled people's rights to make decisions about their own lives. Those responsible for developing and implementing law and policy in the justice sector must work with disabled people and embed the Disability Convention in legislation to ensure the realisation of Article 12.
- The government needs to ensure that any new mental health legislation is compliant with Article 12 of the Disability Convention. The Mental Health (Compulsory Assessment and Treatment) Act repeal consultation document²⁹ included considerations inconsistent with the Disability Convention within (such as whether and when compulsion and seclusion could be permitted). While the IMM understands that policy consultation processes need to canvas a range of views and that public consultation cannot pre-empt the

outcomes of policy development, the IMM believes this can occur in a manner consistent with the Disability Convention.

- Work on supported decision making needs to be accelerated and led by disabled people. Work to build capacity for supported decision-making practice, pending the outcome of the Law Commission's review of the legal framework for adult decision making, has been intermittent. This protracts the substitute decision-making norms that disabled people remain subject to.
- The government needs to expand on the work it has done to improve the responsiveness, accessibility and solution focus of the court, and ensure commensurate work on a collaborative plan to prevent disabled people coming into contact with the courts.
- Every legislative opportunity to explicitly embed the Disability Convention in legislation must be taken. This has not occurred in a range of significant recent legal reform (for example health and education). To date, the Disability Convention is only referenced in a single piece of legislation in Aotearoa (the Oranga Tamariki Act) and further work is needed to enshrine the Disability Convention in domestic legislation.
- The IMM understands implementation of IMM recommendations may need to be progressively realised. However, to date there has not been any plan developed to implement IMM recommendations for reform of the Human Rights Act to: harmonise with evolved definitions of reasonable accommodation; remove disability related exceptions; and allow the Human Rights Commission to receive immigration-related complaints. The government has rejected the IMM's recommendation to repeal Section 392 of the Immigration Act, which currently prohibits the Human Rights Commission to receive immigration-related complaints. This was rejected on the basis that immigration is inherently discriminatory. The Acceptable Standard of Health migrants have to meet serves as a proxy for discrimination on the basis of disability.
- The legal framework of Aotearoa needs to ensure that disabled people can achieve redress for legal or social inequities. Courts and complaints bodies must apply a social model of disability and ensure procedural or reasonable accommodations to facilitate access to justice. This is not universally the case in Aotearoa at present.
- The government needs to review the criminal justice system to ensure that criminal procedure is followed in accordance with all the safeguards and guarantees that are applicable to non-disabled persons, and that deprivation of liberty should be applied as a matter of last resort.

Accessibility and independence

Articles 8, 9, 19, 20, 21, 24, 29

Disabled people in New Zealand expect the Disability Convention to be implemented effectively to make their rights real. To make this happen, the government has an obligation to ensure all systems and structures such as public buildings, roads, transport, the education and judicial systems, schools, hospitals, and all government services including websites and information are accessible to disabled people.

Disabled people have the right to access information in a way they can understand, and access all aspects of public and community life. It is their right to live a good, independent life on an equal basis with others. The government can make this happen by consulting with disabled people, their whānau and support networks, to inform policy development and service delivery. Disabled people must not be left behind.

What is required to ensure disabled people's independence and accessibility?

- Improved and adequate resourcing of government agencies to meet the needs of disabled people to ensure equity is a business as usual activity.
- Ongoing engagement with disabled people through their representative organisation(s) as set out in Article 4.3 and *General Comment 7*³⁰ to inform all areas of work and understand what is required.
- Co-designing all systems and structures with disabled people.
- Government agencies and officials having an understanding and awareness of the concept of accessibility and inclusion, and its implications on the day-to-day lives of disabled people.
- Government collecting and analysing data and evidence to prove that it is closing the equity gaps that exist for disabled people.

What has changed for disabled people since the IMM's last report?

The government must keep working towards progressive realisation of disability rights to make it a reality for disabled people to live independently and participate fully in community and public life. In light of this, a Ministry for Disabled People is in the process of being set up, and accessibility legislation drafted. Disabled people see this as the government taking positive action to advance their rights. They are optimistic about the establishment of the new Ministry, and the roll-out of the

disability support system transformation across the country to encompass the Mana Whaikaha Enabling Good Lives principles and values.³¹ Disabled people in New Zealand look forward to seeing how these initiatives will work in practice and hope the outcomes will improve their daily lives.

However, the work to implement the Disability Convention must not be left to a single Ministry. All government agencies need to understand their responsibilities and fulfil their obligations to disabled people. Necessary steps must be taken to ensure that this new Ministry is well positioned to strengthen collaboration between central government agencies as well as with local government, to make accessibility a reality in Aotearoa by eliminating barriers disabled people face every day.

The IMM continue to hear of the many challenges disabled people have when accessing information and how this inhibits their independence. This was particularly relevant during the COVID-19 emergency and the various responses from the government (see [Equity and access during a humanitarian crisis](#)). It continues as the country negotiates Omicron and the public health measures to control this COVID-19 outbreak.

The IMM recognise there is some progress such as the Accessibility Charter³² which requires government agencies to commit to ensuring accessibility of their websites, information and services. There is increased awareness of the informational needs of disabled people, and recognition of their right to have information in a way they can understand. Accessible information includes language translations and alternate formats such as New Zealand Sign Language, Easy Read, braille, audio, and Large Print. The government's growing understanding is contributing to there being a significant increase in the amount of information available in alternate formats. However, the digital divide needs to be recognised and understood, in order to be overcome.

The education framework continues to exclude many disabled students at all levels of the system. Disabled learners continue to be disproportionately represented in separate learning environments, such as specialist schools, residential schools and satellite units. This creates significant barriers for disabled learners to realise their rights to education in line with Article 24 of the Disability Convention.

Government's summary of progress

- Understanding its obligations under the Disability Convention, by setting up the Ministry for Disabled People and creating accessibility legislation to advance the rights of disabled people.

- A growing commitment to providing accessible information by having a process for government agencies to follow when setting out to produce information and resources in alternate formats under the Accessibility Charter.
- Implementing the Mana Whaikaha Enabling Good Lives principles in the transformation of the health and disability services.³³ This should support disabled people to be independent as this approach is people centred and supports disabled people to make decisions about their own lives.

Where the government needs to show further commitment

- Involving disabled people in all aspects of the new Ministry for Disabled People and the drafting of accessibility legislation. This involvement needs to be explicit.
- Building government capability that includes a collective accountability and an understanding of the Disability Convention to ensure all government agencies are aware of and can meet their responsibilities to this Convention. This capability and accountability should not only be left to the new Ministry.
- Understanding the realities and regional differences (such as costs) when rolling out programmes such as Enabling Good Lives throughout the country, and ensuring all areas of life are addressed. This will support disabled people to live with dignity and have control and choice over their own lives.
- Ensuring disability support services are equitable from service-to-service, region-to-region and funded adequately. For this to happen, the government needs to have an understanding of individuals' needs and how these can be met, including where a disabled person wants to live, and with whom.
- Realising the Disability Committee's General Comment 4³⁴ and the Committee's 2014 concluding observations recommendation 49³⁵ by ensuring the education system is fully inclusive, including accelerating the implementation of education dispute resolution.
- Improving identification and reporting of actions that belie an inclusive education system, such as physical restraint incidents, suspensions and stand-downs.
- Resourcing the Office for Disability Issues (or its equivalent department within the new Ministry for Disabled People) to ensure its role to reinforce accessibility and ensure the independence of disabled people can be fully realised.

Acknowledgements

The IMM would like to acknowledge and thank all those people who have contributed to this report, initially through involvement in *Making Disability Rights Real 2014-2019*; the subsequent *Making Disability Rights Real in a Pandemic* report; and in the recently held national fora. Thank you for your valuable insights and sharing of your experiences and time. You have ensured we focus on the issues which are important to disabled people in New Zealand. Moreover, the national fora and resulting report would not have been possible without the efforts of disabled people's organisations, which are integral to progressing the rights of disabled people in New Zealand.

IMM contact information

Aotearoa's IMM was formed in accordance with Article 33 of the Convention. Its three partners are New Zealand's Human Rights Commission, the Ombudsman, and the Disabled People's Organisations Coalition (a group of six disabled people's organisations).

Disabled People's Organisations Coalition (DPO Coalition)

DPO Coalition members:

- Association of Blind Citizens of New Zealand Incorporated
- Balance Aotearoa
- Deaf Aotearoa Tāngata Turi
- Disabled Persons Assembly New Zealand
- Muscular Dystrophy Association of New Zealand Incorporated
- People First New Zealand Ngā Tāngata Tuatahi

Email: us-dpo@groups.io

Human Rights Commission

Tel: 0800 496 877 (free phone)

Email: infoline@hrc.co.nz

Website: www.hrc.co.nz

Fax: 09 377 3593 (attn: InfoLine)

TXT: 0210 236 4253

PO Box 10424, The Terrace, Wellington 6143

Ombudsman

Tel: 0800 802 602 (free phone)

Email: info@ombudsman.parliament.nz

Website: www.ombudsman.parliament.nz

Fax: 04 471 2254

PO Box 10152, Wellington 6143

Glossary

Term / Agency	Definition / Explanation
Accessibility Charter	The Government's initiative to ensure communication, services and information provided by state sector agencies are available to everyone.
Aotearoa	Te Reo Māori name for New Zealand.
Declaration on the Rights of Indigenous Peoples	See <i>United Nations Declaration on the Rights of Indigenous Peoples</i> .
DIDRR	Disability-Inclusive Disaster Risk Reduction
Disability Action Plan	Provides a cross-government mechanism to progress action on the implementation of the <i>Disability Strategy</i> . The renewed 2019-2023 plan updates the previous Disability Action Plan, in consultation with the NZ disability community aligning its objectives with the Disability Committee's <i>List of Issues</i> .
Disability Committee	The Committee on the Rights of Persons with Disabilities (referred to as the Disability Committee in this report) is the body of independent experts which monitors implementation of the Disability Convention by the States Parties in the United Nations.
Disabled People's Organisations (DPOs)	Representative organisations of disabled people and which are recognised by Article 4(3) of the Disability Convention.
Hapū	Sub-tribe

Term / Agency	Definition / Explanation
Health Quality and Safety Commission	A Crown entity working with clinicians, providers and consumers to improve health and disability support services.
Human Rights Commission (HRC)	The national human rights institution for New Zealand. Formed in 1977, it functions under the mandate of the Human Rights Act 1993.
Independent Monitoring Mechanism (IMM)	The mechanism to monitor the Disability Convention/CRPD. In New Zealand, the IMM is made up of the Human Rights Commission, the Ombudsman and the Disabled People's Organisations Coalition.
Intersectional approach	Acknowledges that certain individuals and communities face a variety of barriers, and therefore it is important to work collaboratively to achieve equitable outcomes.
Iwi	Tribe
Kāinga Ora	The government agency that provides public housing, and related services, for people in New Zealand.
Law Commission	Reviews New Zealand law and makes recommendations to government to improve the law.
Mana Whaikaha/Enabling Good Lives	Prototype of the transformed disability support system, launched and trialled in mid-central New Zealand in October 2018.
Māori Health Authority	A new, statutory entity in the establishment phase will be responsible for ensuring the health system works well for Māori.

Term / Agency	Definition / Explanation
Mātauranga	Education, knowledge
Ministry of Social Development	<p>Helping to build successful individuals, and in turn build strong, healthy families and communities. It does this by providing:</p> <ul style="list-style-type: none"> • employment, income support and superannuation services; • funding to community service providers; • social policy and advice to government; • student allowances and loans; and • social housing.
National Emergency Management Agency (NEMA)	The Government steward for national emergency risk reduction, preparation, response and recovery.
New Zealand Disability Strategy	This guides the work of government agencies on disability issues from 2016 to 2026. It can also be used by individuals or organisations wanting to learn more about, and make the best decisions on, things important to disabled people.
New Zealand Sign Language (NZSL)	One of three official languages in Aotearoa/New Zealand.
Office for Disability Issues (ODI)	Key agency in government on disability issues. Working toward a vision of New Zealand being a non-disabling society.

Term / Agency	Definition / Explanation
Ombudsman	<p>An Ombudsman’s role includes:</p> <ul style="list-style-type: none"> • investigating the administrative conduct of public sector agencies; • reviewing their decisions relating to requests for official information; • acting as a National Preventive Mechanism to examine places of detention under the Crimes of Torture Act 1989; • recommending remedial action be taken where agencies have acted unfairly; • acting as an appropriate authority under the Protected Disclosures Act 2000; and • providing advice and guidance relating to all of the above.
Oranga Tamariki— Ministry for Children	Government agency charged with providing care and protection for children and young people.
Statistics New Zealand	Also known as Stats NZ, this New Zealand public service agency collects statistics related to the economy, population and society of New Zealand.
Tamariki	Children
Tāngata whaikaha	Disabled people
Tāngata whaikaha Māori	Disabled Māori
Te ao Māori	The Māori world.
Te reo Māori	The first language and an official language of New Zealand.

Term / Agency	Definition / Explanation
Te Tiriti o Waitangi (Treaty of Waitangi)	New Zealand's founding document, signed on 6 February 1840. It is an agreement, in Māori and English, made between the British Crown and about 540 Māori rangatira (chiefs). The two texts have different meanings.
United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)	Also referred to as the CRPD, UNCRPD and the Disability Convention.
Welfare Expert Advisory Group (WEAG)	An independent advisory group established in May 2018 to advise government about options that could best give effect to its vision for the future direction of the social welfare system.
Whānau	Family

Endnotes

- 1 See *Making Disability Rights Real 2014-2019* <https://www.ombudsman.parliament.nz/resources/making-disability-rights-real-2014-2019-0>, accessed May 2022.
- 2 See *Making Disability Rights Real in a Pandemic*, <https://www.ombudsman.parliament.nz/resources/making-disability-rights-real-pandemic>, accessed May 2022.
- 3 See New Zealand Disability Strategy, <https://www.odi.govt.nz/nz-disability-strategy/>, accessed June 2022.
- 4 Te Tiriti o Waitangi / Treaty of Waitangi is New Zealand's founding document, signed on 6 February 1840. It is an agreement made between the British Crown and about 540 Māori rangatira (chiefs). There are two different texts (in te reo Māori and English), with different meanings.
- 5 See *Making Disability Rights Real 2014-2019*, <https://www.ombudsman.parliament.nz/resources/making-disability-rights-real-2014-2019-0>, accessed May 2022.
- 6 See *Disability Action Plan*, <https://www.odi.govt.nz/disability-action-plan-2/>, accessed May 2022.
- 7 United Nations Convention on the Rights of Persons with Disabilities, *General comment No. 6 (2018) on equality and non-discrimination*. See <https://www.ohchr.org/en/hrbodies/crpd/pages/gc.aspx>, accessed May 2022.
- 8 World Health Organization, *Rio Political Declaration on Social Determinants of Health*. See <https://www.who.int/publications/i/item/rio-political-declaration-on-social-determinants-of-health>, accessed May 2022.
- 9 *Whakamaua* is a Ministry of Health action plan that guides the Ministry, the whole health and disability system, and Government to give effect to a Māori Health Strategy that sets out to achieve the best health outcomes for Māori. See <https://www.health.govt.nz/publication/whakamaua-maori-health-action-plan-2020-2025>, accessed June 2022.
- 10 Enabling Good Lives (EGL) is a person-centred approach to support disabled people by offering greater choice over the supports they receive. See <https://www.enablinggoodlives.co.nz>, accessed May 2022.
- 11 See the Welfare Expert Advisory Group's report *Whakamana Tāngata*: <http://www.weag.govt.nz/weag-report/>, accessed May 2022.
- 12 Statistics NZ, Quick stats about income (2013). See <https://www.stats.govt.nz/reports/2013-census-quickstats-about-income>, accessed May 2022.
- 13 *Whakamana Tāngata*, page 29.
- 14 See Working Matters Disability Action Plan, <https://www.msd.govt.nz/what-we-can-do/disability-services/disability-employment-action-plan/index.html>, accessed June 2022.
- 15 *Whakamana Tāngata*, page 23.

- 16 See <https://www.msd.govt.nz/what-we-can-do/disability-services/disability-employment-action-plan/index.html>, accessed June 2022.
- 17 The Minimum Wage Exemption Scheme is a policy in place that allows some disabled people to be exempt from earning a minimum wage for paid work. See <https://www.employment.govt.nz/hours-and-wages/pay/minimum-wage/minimum-wage-exemptions/>, accessed May 2022.
- 18 The National Emergency Management Agency is a Government steward for national emergency risk reduction, preparation, response and recovery. See <https://www.civildefence.govt.nz/about/about-nema/>, accessed May 2022.
- 19 Above, n 2.
- 20 See <https://www.hrc.co.nz/our-work/people-disabilities/inquiry-support-disabled-people-during-omicron-outbreak/>, accessed May 2022.
- 21 See <https://www.1news.co.nz/2021/12/01/abuse-towards-disabled-kiwis-reaches-epidemic-proportions/>, accessed May 2022.
- 22 See <https://www.odi.govt.nz/whats-happening/violence-against-disabled-people-in-new-zealand-new-research/>, accessed May 2022.
- 23 See <https://www.health.govt.nz/publication/annual-update-key-results-2020-21-new-zealand-health-survey>, accessed May 2022.
- 24 Above, n 22.
- 25 See <https://www.ombudsman.parliament.nz/resources/off-the-record>, accessed May 2022.
- 26 See *Zero seclusion: Safety and dignity for all*. <https://www.hqsc.govt.nz/our-work/mental-health-and-addiction-quality-improvement/projects/zero-seclusion-safety-and-dignity-for-all/>, accessed June 2022.
- 27 See <https://www.odi.govt.nz/disability-action-plan-2/>, accessed May 2022.
- 28 See <https://www.lawcom.govt.nz/media-release/law-commission-review-law-relating-adult-decision-making-capacity>, accessed May 2022.
- 29 See <https://www.health.govt.nz/publication/transforming-our-mental-health-law-public-discussion-document>, accessed May 2022.
- 30 General Comment No. 7. See <https://www.ohchr.org/en/documents/general-comments-and-recommendations/general-comment-no7-article-43-and-333-participation>, accessed June 2022.
- 31 Above, n 10.
- 32 The Accessibility Charter is a commitment to working towards full information accessibility. The document has been signed by 37 Government Chief Executives. See: <https://www.odi.govt.nz/guidance-and-resources/the-accessibility-charter/>, accessed May 2022.
- 33 Above, n 10.

- 34 General Comment No. 4. See <https://www.ohchr.org/en/documents/general-comments-and-recommendations/general-comment-no-4-article-24-right-inclusive>, accessed May 2022.
- 35 United Nations Committee on the Rights of Persons with Disabilities, *Concluding Observations on the initial report of New Zealand 2014*. See <https://digitallibrary.un.org/record/791464?ln=en>, accessed June 2022.

**DPO
COALITION**

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