

Making Disability Rights Real Whakatūturu Ngā Tika Hauātanga

Third report of the Independent Monitoring Mechanism of the Convention on the Rights of Persons with Disabilities

Aotearoa | New Zealand 2014-2019



Making Disability Rights Real 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.
Cover image: Tim Fairhall is smiling widely as he holds out a world globe to his side. Tim, with his mother Joan, challenged the Government to change the KiwiSaver rules. Now people with life-shortening conditions can use their KiwiSaver funds before the usual retirement age of 65 years. Photo courtesy of Attitude Pictures Ltd. www.attitudepictures.com.
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Caption: A young man talks in New Zealand Sign Language (NZSL) to friends at a NZSL signing flash mob to celebrate NZSL Week. Photo courtesy of Deaf Aotearoa.

Introduction

New Zealand's Independent Monitoring Mechanism (IMM) is pleased to present our third *Making Disability Rights Real report*. We are reporting on the status of implementation of the United Nations Convention on the Rights of Persons with Disabilities (Disability Convention) in New Zealand.

Designated under Article 33(2) of the Disability Convention, New Zealand's IMM partners are the Disabled People's Organisations' (DPO) Coalition, the Ombudsman, and the New Zealand Human Rights Commission. Our role is to provide independent evaluation of the extent to which disabled New Zealanders are enjoying their universal human rights set out in the Disability Convention.

The IMM identified six key themes in the lead-up to this report.

- Education
- Housing
- Seclusion and restraint
- Data
- Access to information and communication
- Employment

These key themes are indicative of wider disparate outcomes between disabled people and their non-disabled peers. Improvements in these areas will have significant positive effects on disabled people's lives.

The IMM conveyed these and other major concerns to the United Nations Committee on the Rights of Persons with Disabilities (Disability Committee) in December 2017, to assist the Disability Committee in forming the *List of Issues* for the New Zealand Government to address in its combined second and third report on the Disability Convention.

Making Disability Rights Real responds to the List of Issues but also extends beyond it, to reflect disabled people's experiences in New Zealand. Included is a priority focus on indigenous (Māori) disabled people and Pacific disabled peoples. A lack of disaggregated data makes it difficult to report the experiences of disabled Māori and Pacific peoples in relation to each individual article of the Disability Convention. For this reason, a global snapshot of the experiences of disabled Māori and Pacific peoples is presented at the beginning of the report. The IMM conducted a survey of disabled people and their supporters, and held public consultation hui (meetings), to inform our report. The nationwide survey was available online, in a range of accessible formats and languages, including te reo Māori, New Zealand Sign Language, Easy Read and braille. Hui were held in five locations around the country, all of which were well attended.

The IMM acknowledges change can take time. Positive progress has been made in the years since previous reports. In particular, we commend greater cross-government collaboration and improved participation of disabled people in the development of government policy.

Some system reviews are also underway that may provide benefits for disabled people. However, the primary comment of the IMM must be on current lived realities of disabled New Zealanders. There is still a great deal of work to do. Disabled people remain far from enjoying the full range of human rights and fundamental freedoms reaffirmed in the Disability Convention. Many disabled people are experiencing poverty, exclusion and lack of autonomy.

Eliminating these huge disparities requires a quantum leap. We need to move from compensating for an inaccessible society—founded on notions of disability as a deficit—to recognising disabled people as equal rights holders, by actively working to create fully accessible communities. The IMM urges the Government to mandate a systemic approach to explicitly integrating the Disability Convention into domestic law, and to apply the appropriate resource in order to make this a reality.

The recommendations in this report provide clear navigation to some critical starting points. We trust that they will serve as a springboard to accelerate meaningful advances for all disabled New Zealanders.

Peter Boshier

Chief Ombudsman Office of the Ombudsman Tari o te Kaitiaki Mana Tangata **Leo McIntyre**

Chair

Disabled People's

Organisations' Coalition

Paula Tesoriero MNZM

Disability Rights Commissioner | Kaihautū Tika Hauātanga New Zealand Human Rights Commission | Te Kāhui Tika Tangata

The Making Disability Rights Real report relates to the period up until December 2019. Production of the report was being finalised at the beginning of 2020, which coincided with the unfolding of the global Covid-19 crisis. These unprecedented circumstances circumvented what was business as usual, delaying the report's launch. It is recognised that this pandemic has affected many lives throughout the world and, of course, here in New Zealand. The repercussions of such an event are felt more keenly by disabled people and vulnerable groups. It is with this in mind, that the decision was made by the IMM not to include New Zealand's pandemic response in this report or as an addendum in Article 11. Instead it was decided that Covid-19 needed a specifically themed report based on disabled people's experiences and the Government's response to disability communities' needs during this time. Work on this report is underway.

Report format

The report starts with a brief outline of the Disability Convention, Optional Protocol and the IMM. It then provides an executive summary including priority recommendations, reference to the experiences of disabled Māori and Pacific peoples and a summary of the six key themes. The remainder of the report provides a detailed analysis of progress in the implementation of specific articles of the Disability Convention.

Terminology

Many words and terms can be used to identify disability. For some, the term 'disabled people' is a source of pride, identity and recognition that disabling barriers exist within society and not within individuals. For others, the term 'people with disabilities' has the same meaning and is important to those who want to be recognised as a person before their disability. The Disability Convention uses the term 'persons with disabilities'. In te ao Māori (the Māori world), 'tāngata whaikaha' may be used to refer to a disabled person.¹

The current consensus in New Zealand, based on the advice of the Disability Strategy Revision Reference Group, is to use the term 'disabled people'. We have used this terminology throughout our report. We acknowledge that members of the disabled community may wish to refer to themselves differently. The most important guiding principle is to remember to consider a person before considering their impairment.

The Disability Convention, Optional Protocol and the Independent Monitoring Mechanism

Government must uphold its end of the Disability Convention. Make New Zealand 100% inclusive and accessible.

Survey respondent

The Disability Convention

New Zealand signed the United Nations Convention on the Rights of Persons with Disabilities (Disability Convention) on 30 March 2007 and ratified it on 26 September 2008. The purpose of the Disability Convention is to promote, protect, and ensure universal human rights and fundamental freedoms for disabled people, and promote respect for their dignity. It recognises the right of disabled people to make free and informed decisions about their own lives. It sets out in practical terms how the rights of disabled people can be realised.

The Disability Convention places particular emphasis on reasonable accommodation: the concept of making appropriate changes or modifications to ensure disabled people have equal opportunities and rights. It also advocates universal design: the concept of designing products, environments, programmes, and services so they are usable by all people.

The principles of the Disability Convention, as specified in Article 3 are:

- respect for inherent dignity, individual autonomy, and independence of persons;
- non-discrimination:
- full and effective participation and inclusion in society;
- respect for difference and acceptance of disabled people as part of human diversity and humanity;

- equality of opportunity;
- accessibility;
- equality between men and women; and
- respect for the evolving capacities of disabled children and respect for the rights of disabled children to preserve their identities.

Six months after New Zealand signed the Disability Convention, the United Nations General Assembly adopted the Declaration on the Rights of Indigenous Peoples (UNDRIP).³ New Zealand expressed its support for UNDRIP in April 2010. While the declaration itself is not binding, many of the provisions reflect obligations set out in ratified conventions or covenants. In March 2019, Cabinet gave its approval for the Minister of Māori Development to lead a process to develop a national plan of action on New Zealand's progress towards the objectives of UNDRIP.

The Disability Convention shares some common underlying human rights principles with both Te Tiriti o Waitangi (Treaty of Waitangi) and UNDRIP. These include the importance of partnership, autonomy, close consultation, and full and effective participation. In monitoring the Disability Convention in New Zealand, we must also consider these intersecting rights and other relevant international conventions.⁴

The Optional Protocol

On 4 November 2016, New Zealand ratified the Optional Protocol to the Disability Convention (the Optional Protocol). This gives disabled people who believe their rights have been denied a way to make a complaint directly to the Disability Committee. In support of this, the IMM has published *Making Complaints to the United Nations Disability Committee: A Guide for New Zealanders.*⁵

Independent Monitoring Mechanism (IMM)

Article 33 of the Disability Convention requires governments to establish an independent mechanism to promote, protect and monitor its implementation. The structure of New Zealand's IMM reflects the partnership approach underpinning the Disability Convention. The IMM partners are the Disabled People's Organisations' (DPO) Coalition (a body reflecting the voice of disabled people in the monitoring process), the Ombudsman, and the Human Rights Commission.

The Human Rights Commission and the Ombudsman are established by statute.

The purpose of the Human Rights Commission is to promote and protect the human rights of all New Zealanders.

The role of the Ombudsman includes:

- investigating the administrative conduct of public sector agencies;
- reviewing their decisions relating to requests for official information;
- acting as a National Preventive Mechanism 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.

The DPO Coalition is made up of seven organisations.

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

This arrangement reflects Article 4(3) of the Disability Convention, which provides that all decision-making processes relating to disabled people shall actively involve disabled people through their representative organisations—effectively encompassing the expression 'Nothing about us without us'.

The IMM has published two earlier *Making Disability Rights Real* reports, which are available in a number of accessible formats.⁶



Caption: Bridget Ferguson reads a book in New Zealand Sign Language to her Deaf son, Carter. Photo courtesy of Deaf Aotearoa.

Executive summary

New Zealand has a mixed record when it comes to the rights of disabled people. Although we do some things well, there is still a great deal of work required to remove barriers stopping disabled people from participating in society on an equal basis.

The IMM have identified six key themes that must be prioritised to ensure the realisation of the fundamental rights set out in the Disability Convention in New Zealand. It is also important that we highlight the experience of disabled Māori and Pacific peoples in our report. We have ranked the six key themes in order to make clear where the most urgent action is needed by the Government.

Red: For immediate attention

Amber: Needs significant attention over the next 6 months

Yellow: Needs attention over the next 12 months

The IMM believes that **education**, **housing** and **seclusion and restraint** are the most pressing issues for disabled people that the Government must take urgent action on.

In education, a generation of disabled people is being significantly negatively impacted and set up for poor lifelong outcomes. This is despite recent years of reform, which unfortunately has not been co-designed effectively with disabled people, nor has it addressed systemic concerns for inclusivity.

Accessible housing is critical for disabled people to be healthy, safe and secure and to participate in their communities. There are simply not enough suitable homes available for the people who need them.

Seclusion and restraint continue to be used in secure health and disability facilities. While fewer people are affected by these practices than by inequities in housing and education, it continues to cause significant harm. Of particular concern is the disproportionate use of seclusion and restraint for Māori.

While the other key themes are also vital, we urge the Government to immediately address the severe inequalities created by the current education and housing system, and the ongoing use of seclusion and restraint.

Education

Key recommendation: introduce an enforceable right to inclusive education as a key element of the legislative framework, and ensures resource to attain equitable access.

Key recommendation: build co-design into every stage of the education reform process.

Housing

Key recommendation: implement legislation requiring all newly built housing to conform to universal design standards (refer also Article 9).

Seclusion and restraint

Key recommendation: strengthen the commitment to reduction of rates of restraint of persons with disabilities, and the rapid reduction, towards elimination, of use of seclusion in secure health and disability facilities, through robust, achievable and time-bound policies.

• Data

Key recommendation: restart the Disability Survey following each Census, commencing with the 2023 Census.

Access to information and communication

Key recommendation: enable disabled people to communicate more effectively with government agencies by increasing the number of accessible formats available so that disabled people can express their views in New Zealand Sign Language, and use braille, Easy Read and audio formats to engage fully.

Employment

Key recommendation: develop a comprehensive rights-based national disability employment strategy.

The IMM expects the response from the Government to the six priority areas to recognise the unique needs of marginalised groups, including disabled Māori and Pacific peoples.

Further examination of the key themes and a full list of recommendations are set out in the following sections.

Key themes

Māori

It is the IMM's view that the human rights of Māori, New Zealand's indigenous people, are not being fully realised as set out in the Disability Convention, United Nations Declaration of the Rights of Indigenous Peoples (UNDRIP), and New Zealand's founding constitutional document, Te Tiriti o Waitangi (Treaty of Waitangi). Compared to non-Māori, Māori have higher rates of disability, poverty, suicide and unemployment, and they have lower life expectancy. Tāngata whaikaha (disabled Māori) are further marginalised, faring worse than their non-disabled Māori peers, with lower labour force participation and lower rates of educational achievement. The IMM is concerned that barriers to full citizenship are still in place, which need to be removed in order to address these inequities.

Māori need to be able to access the right resources to allow self-determined solutions to address historical and persistent inequalities, and to be involved in decision- and policy-making processes. There are some initiatives in place to tackle entrenched inequities, including:

• Whāia Te Ao Mārama 2018 to 2022: the Māori Disability Action Plan – one of its aims is to increase tāngata whaikaha participation in the development of health and

disability services and increase provision of disability support services that are responsive to te ao Māori.

 Wai 2575 Health Services and Outcomes Kaupapa Inquiry (Wai 2575) has also highlighted the lack of robust data around Māori disability issues by the claims lodged with the Waitangi Tribunal.

In order to monitor outcomes of tāngata whaikaha effectively, the IMM needs quality disaggregated data to ensure tāngata whaikaha can enjoy their human rights on an equal basis with others.

Pacific peoples

The IMM is aware that Pacific disabled peoples share many experiences with tangata whaikaha. Cultural differences and language barriers can preclude Pacific disabled people and their families from being able to navigate often complex processes to access appropriate health and support services. Low cultural competence in many service providers also affects the ability of Pacific disabled peoples to fully participate in community and public life on an equal basis with others.

However, progress is being made, including the updating of the *Faiva Ora 2016–2021 National Pasifika Disability Plan*. It is hoped that this plan will enhance engagement with Pacific disabled peoples and enable people to access the services they need to realise their human rights.

Lack of disaggregated data continues to be an area of concern for the IMM, as in its absence it is difficult to monitor progress of the realisation of the rights of Pacific disabled peoples.

Education—refer Article 24

An enforceable right to inclusive education for students with disabilities is a key priority for the IMM.

The Education Act 1989 protects the right of all people to enrol and receive education at any school. However, the current legislative framework does not explicitly incorporate inclusive education or reasonable accommodation principles. There are a number of challenges including a lack of appropriate legislation, teacher training, data collection and funding.

Many disabled people and advocates are disillusioned with the lack of practical action regarding inclusivity in education. Small-scale interventions, such as better coordination of existing services and supports, additional support staff, and spending on existing property are positive steps but do not go far enough. Multiple aspects of the modern teaching and learning environment in New Zealand must be addressed so that all students can shine.

Housing—refer Article 19

It is crucial for disabled people to be able to live where they choose and have the support they need.

While there is nothing in New Zealand law preventing disabled people from living in a place of their choosing, the IMM is concerned that there are affordability, accessibility, and support issues that often create significant barriers to disabled people being able to realise this right.

There is also a long waiting list for government-owned housing stock, much of which will not meet the needs of disabled residents. Private landlords are often unwilling to have modifications made to their properties.

Seclusion⁷ and restraint—refer Articles 15, 24 and 25

The IMM is concerned at the continued use of seclusion and restraint practices in New Zealand prisons and healthcare facilities. Although there are often alternative options available to manage challenging behaviour, seclusion and restraint are not always used only as a last resort.

We have particular concerns about prisoners in Intervention and Support Units (ISU – previously known as At Risk Units), where prisoners are essentially held in solitary confinement, alone in their cell for up to 22–24 hours a day, watched on camera, including when toileting. The physical and material conditions in these units, where vulnerable prisoners are housed, are identical to those in segregation units and breach international standards. Mandela Rule 45(2) explicitly prohibits the placement of prisoners with physical or mental disabilities in solitary confinement.⁸

Seclusion and restraint are sometimes used in health and disability places of detention. The Health Quality & Safety Commission is working with Te Pou o te Whakaaro Nui⁹ and district health boards to reduce the use of seclusion and restraint with its initiative *Zero seclusion: Towards eliminating seclusion by 2020*. This project sets an aspirational target that is unlikely to be achieved in its set timeframe.

Data—refer Article 31

The IMM is aware that there are significant gaps in disaggregated disability data in New Zealand, including in housing, education, employment, and intersectional issues. This is compounded by the lack of a commonly accepted definition of 'disability' by public and private interests, making it difficult to do any kind of comparison between services. The absence of useful data has a negative impact on the quality of government policy and decision-making, and the ability of service providers to target services for disabled people. It also makes it difficult to accurately measure New Zealand's progress in implementing the rights in the Disability Convention.

The Government has committed to working with agencies and experts to collect data for all 29 measures identified in the *New Zealand Disability Strategy 2016–2026*. The Disability Data and Evidence Working Group was set up in 2015, with a focus on gathering data and evidence in order to develop effective policy and services to meet the identified needs of disabled people.

Access to information and communication—refer Articles 9 and 21

Disabled people have the right to express their opinions, and to seek, receive, and share information in forms that they can understand and use. Missing out on information, and being unable to express opinions, prevent disabled people from participating fully as citizens and limit their ability to interact with both government and wider society independently.

It is the IMM's view that a whole-of-government approach and legislation are required to ensure accessibility in the two-way flow of information, including government information and information in the broader public arena.

The Government has indicated that it hopes the introduction of its Accessibility Charter will provide increased access to information, with a focus on increasing provision of government information in Easy Read, braille, New Zealand Sign Language, and audio formats. It is also working with stakeholders to consider the possibility of introducing accessibility legislation to improve access to information.

Employment—refer Article 27

That IMM is concerned that disabled people experience significant inequities in labour force participation, employment rates and income. This is due to factors such as employer bias, inaccessibility, and inflexible support policies. Being unemployed or underemployed constrains other life choices and impacts on the right to an adequate standard of living.

Employment not only has a positive impact on disabled people's lives, but there would be a fiscal benefit of \$1.45 billion per year if the participation of disabled people in the labour market was equalised.¹⁰ However, investment in labour market strategies in New Zealand remains low.

There are positive initiatives underway in the public sector, such as internships for disabled people, an emphasis on consistent collection of data, and toolkits to build employer knowledge and confidence, and there is also some interest from the private sector. However, current initiatives are yet to yield significant or reliably durable shifts in employment outcomes, indicating the need to maintain focus on and resources for improving employment opportunities. Serious consideration to instituting temporary special measures or affirmative actions is also warranted.

The IMM supports the creation of a disability employment strategy to bring coherence across the actions of many stakeholders in employment.

Other areas of concern

It is not feasible to present all the areas of progress in disability rights in New Zealand in this report. Nor can this report comprehensively document each and every one of the many barriers that continue to prevent disabled people living full and barrier-free lives in New Zealand.

In addition to the IMM's six key areas of concerns, there are a number of other issues consistently raised regarding the implementation and full realisation of the Disability Convention in New Zealand.

To capture this and give the opportunity for disabled people to voice their concerns and issues, the IMM held a series of hui around New Zealand in 2019. We also conducted an online survey. This feedback has helped inform the present report.

Full list of recommendations

Māori

The IMM recommends that the Government:

- 1. Take immediate steps to progress a mechanism, by which the voice of tāngata whaikaha, can be formally included in all disability-related policy and legislative development, and any Crown–Māori partnership initiatives. This recommendation reflects and supports recommendation 11 of the IMM UNDRIP's report regarding the implementation of the UN Declaration on the Rights of Indigenous Peoples in Aotearoa New Zealand, June 2018.¹¹
- 2. Act to implement recommendations 3 and 6 of the IMM UNDRIP's report regarding the implementation of the UN Declaration on the Rights of Indigenous Peoples in Aotearoa New Zealand, June 2018.¹²
- 3. In addressing poorer socioeconomic outcomes for Māori, specifically identify and address the disproportionate impacts of these inequities on tāngata whaikaha.

Pacific Peoples

- 4. In addressing poorer socioeconomic outcomes for Pacific peoples, specifically identify and address the disproportionate impacts of these inequities on Pacific disabled peoples.
- 5. Continue to support the implementation of *Faiva Ora 2016–2021 National Pasifika Disability Plan* and the role of the Faiva Ora Leadership Group.
- 6. Support and resource the further development of an autonomous Pacific disabled peoples–led organisation, through which their voice can be formally included in all disability-related policy and legislative development, and in the co-design of an extended range and choice of support options.

Article 4: General obligations

The IMM recommends that the Government:

- 7. Include reference to the Disability Convention in all relevant future legislation, to promote awareness and understanding of the Disability Convention, and ensure that legislation is fully compliant with the obligations set out in the Disability Convention.
- 8. Work with disabled people to codify structures, timeframes, processes and resources that would enact genuine partnership with disabled people and to facilitate co-governance (including co-design, co-production, and co-evaluation) with disabled people of all legislation, policies, procedures and other decision-making processes affecting disabled people.
- 9. Take all necessary steps to ensure adequate resource availability for a diverse range of disabled people's representative organisations.¹³

Article 5: Equality and non-discrimination

- 10. Amend the Human Rights Act 1993, with a view to strengthening disabled people's right to non-discrimination, including:
 - a. removing or reducing disability related exemptions;
 - b. introducing an explicit definition of reasonable accommodation consistent with the meaning provided in Article 2 of the Disability Convention and General Comment 6 on Article 5;14 and
 - c. creating an explicit duty of reasonable accommodation.
- 11. As a matter of urgency, conduct an audit of existing legislation for conformity with the Disability Convention, specifically the right to non-discrimination and equality before the law, and report its findings publicly, specifically highlighting non-compliant legislation.
- 12. Develop, with disabled people, a disability discrimination impact assessment tool/framework and apply this whenever new legislation is developed or current legislation amended, to ensure systemic processes for harmonising all legislation with the Disability Convention and eliminating any discriminatory provisions.

Article 6: Women with disabilities

The IMM recommends that the Government:

- 13. Actively consult disabled women (and girls where appropriate) in legislative and policy development, decision-making, programme monitoring, and violence prevention measures.
- 14. Strengthen intersectional approaches that integrate disability perspectives within gender equity initiatives and gender perspectives within disability initiatives, including the collection and analysis of data.
- 15. In partnership with disabled women, conduct accessibility audits of violence prevention and response services (including those provided by third parties) to ensure that they are inclusive and accessible, and staff have access to appropriate training.
- 16. Ensure that all women's health and sexual and reproductive services (including those provided by third parties) are provided in accessible facilities and information on these services is provided in accessible formats.
- 17. Institute temporary special measures (affirmative action) aimed at accelerating equitable participation of disabled women in employment.

Article 7: Children with disabilities

The IMM recommends that the Government:

- 18. Collect more comprehensive disaggregated data for disabled young people to inform effective early intervention, especially in the fields of education, care and protection, and youth justice.
- 19. Continue to focus on putting mechanisms in place to put the child's voice at the centre of policy development.

Article 8: Awareness-raising

The IMM recommends that the Government:

20. Initiate a co-designed nationwide campaign that:

- a. promotes disabled people's rights and dignity, including profiling the value of diversity;
- b. counters negative perceptions about the value of disabled people's lives that have been highlighted (promulgated) through debates relating to the End of Life Choice Act 2019 and antenatal screening; and
- c. urgently and specifically counteracts public perceptions associating psychosocial disability and violence.
- 21. Include disabled people–developed disability inclusion content in school curricula and tertiary level training, particularly (but not limited to) mandatory training for all teachers and others in professions that work directly with disabled people.
- 22. Provide additional resources to ensure that anti-bullying prevention campaigns fully involve, and meet the needs of, disabled people.
- 23. Ensure that, in considering the introduction of expanded hate speech or new hate crime legislation, disability-related hate speech or crime is included.
- 24. Provide disabled people–led training, through the State Services Commission, on the Disability Convention for government personnel.

Article 9: Accessibility

- 25. Develop and agree on comprehensive definitions of universal design and accessibility and use these definitions consistently.
- 26. Update New Zealand Standard NZS4121:2001 and develop a comprehensive range of compatible accessibility standards to cover all aspects of community and civic access.
- 27. Ensure accessibility and universal design be implemented in all:
 - a. new housing developments;
 - b. public spaces;
 - c. transportation and ticketing systems;
 - d. shared-use spaces; and
 - e. technologies and communications.

- 28. Implement robust strategies and timelines to upgrade existing public infrastructure to meet best practice accessible design standards.
- 29. Implement systems to require regular monitoring and/or auditing against minimum standards of accessibility of all publicly accessible buildings, workplaces, civic or recreational areas, and public services.
- 30. Co-design accessible systems with disabled people, taking particular account of marginalised groups such as children.

Article 10: Right to life

The IMM recommends that the Government:

- 31. Ensure the potential negative impact that any legislation permitting assisted dying may have on disabled people is taken into consideration.
- 32. Ensure through effective monitoring that, should the End of Life Choice Act 2019 come into force, it does not have a disproportionate impact on the right to life for disabled people.

Article 11: Situations of risk and humanitarian emergencies

The IMM recommends that the Government:

- 33. Continue to work with the DPO Coalition on Disability Inclusive Disaster Risk Reduction (DIDRR) and that the work should expand to provide a comprehensive response to a range of humanitarian risk and natural disasters.
- 34. Develop and promote schemes that proactively support increasing resilience for disabled individuals, families, groups, and communities to mitigate the risks and impacts of natural disasters or other humanitarian emergencies.

Article 12: Equal recognition before the law

The IMM recommends that the Government:

35. Repeal and replace any legislation allowing forced interventions that are based on and, reinforce negative or deficient notions of disabled people, and permit compulsory 'treatment' interventions, including:

- a. Mental Health (Compulsory Assessment and Treatment) Act 1992 (noting that this is already committed to in the Disability Action Plan);
- b. Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003;
- c. Substance Addiction (Compulsory Assessment and Treatment) Act 2017; and
- d. any sections of the Oranga Tamariki Act 1989 Children's and Young People's Well-being Act 1989 that enable arbitrary detention, solitary confinement, restraint, or actions that may constitute cruel, inhuman or degrading treatment or punishment.
- 36. Request that the Law Commission's review of 'adults with impaired decision-making capacity':
 - a. is co-designed with disabled people;
 - is informed by a human rights approach that recognises universal legal rights to access support to make decisions, and that maximises participation;
 - c. reflects an understanding of substitute decision-making as an option only of last resort after all supported decision-making options are exhausted, and that any substitute decision should be based on the best interpretation of the person's rights, will and preference;
 - d. enshrines the importance of regular reviews and robust monitoring mechanisms; and
 - e. considers a unified framework that could be applied irrespective of the reason for (temporary or longer-term) decision-making substitution.
- 37. Ensure disabled people and their representative organisations have sustainable resources to lead the development of supported decision-making capability for disabled people, whānau, and duty bearers such as the health and disability workforce, legal profession, and financial institutions.

Article 13: Access to justice

The IMM recommends that the Government:

38. Undertake a strategic review of the justice system to ensure that it is accessible and fit for purpose for disabled people to ensure equal access. Recommended actions include, but are not limited to:

- a. improving data collection by the Ministry of Justice and the courts;
- b. undertaking mandatory and funded 'accessibility audits' of all courts and Ministry of Justice and Department of Corrections facilities;
- c. ensuring information about the justice sector is fully accessible, both in terms of its individual components and the various journeys that an individual may take through the justice system as a whole;
- d. providing further training on disability rights and accessibility within the justice sector, including the effects of multiple discrimination;
- e. encouraging and funding a significant increase in legal expertise on disability and human rights;
- f. establishing and funding an independent advocacy service for disabled people;
- g. reviewing any barriers that affect lawyers in private practice responding to disabled clients;
- h. increasing resources for community law providers that provide disability-related legal interventions; and
- i. increasing an understanding of 'neurodisability' within the justice system and developing specific cognitive and communication responses to people with neurological impairments.

Article 14: Liberty and security of person

- 39. Implement the formal recommendation, made in the Inquiry into Mental Health and Addiction, to repeal and replace the Mental Health (Compulsory Assessment and Treatment) Act 1992, in partnership with people with experience of mental distress, including wide consultation with tangata whaikaha, without delay.
- 40. Action paragraphs 33 and 34 of the Disability Committee's *Concluding Observations*, to eliminate detention in medical facilities on the basis of (actual or perceived) disability, provide treatment only on the basis of free and informed consent, and eliminate the use of seclusion and restraint in medical facilities.
- 41. Ensure that the review required by section 120 of the Substance Addiction (Compulsory Assessment and Treatment) Act 2017 is implemented comprehensively.

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

The IMM recommends that the Government:

- 42. Strengthens its commitment to reduction of rates of restraint of persons with disabilities, and the rapid reduction, towards elimination, of use of seclusion in secure health and disability facilities, through robust, achievable and timebound policies.
- 43. Pending elimination of these practices, require district health boards to regularly release annual statistics indicating performance against these policies, including reporting comprehensive data relating to long-term stays in seclusion.

Article 16: Freedom from exploitation, violence and abuse

- 44. Develop a range of initiatives to ensure that disabled people experience the same protection from domestic and other forms of violence as non-disabled people, and that 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 accessible material for disabled people;
 - b. increasing awareness of abuse experienced by disabled people and of the mechanisms to address it, and providing sustainable funding for disabled people–led organisations working in this area;
 - c. increasing resourcing for disabled people–led initiatives to ensure there are better systems of recognition, prevention and rapid response to abuse;
 - d. ensuring that data collection by the Police enables disaggregated data to be collected to allow for accurate recording and analysis of violence and abuse towards disabled people; and
 - e. ensuring people subject to compulsory detention on the basis of disability have ready access to trained advocates free of charge, and ensuring advocates cannot be prevented from visiting clients on demand to act as witnesses to situations and conditions.

Article 17: Protecting the integrity of the person

The IMM recommends that the Government:

- 45. Enact legislation to prohibit the use of sterilisation or any other non-therapeutic medical procedure on disabled children and disabled adults without their prior, fully informed, and free consent.
- 46. Improve methods of collecting and reporting on statistics on sterilisation and other non-therapeutic medical procedures in New Zealand, whilst ensuring all data collection is anonymised in such a way to prevent identification.

Article 18: Liberty of movement and nationality

The IMM recommends that the Government:

- 47. Review relevant legislation and policy to ensure that disabled people do not experience additional barriers over and above others when applying for entry into New Zealand, including but not limited to:
 - a. ensuring that immigration officers have regard to the Disability Convention when making decisions under the Immigration Act; and
 - b. repealing section 392 of the Immigration Act to enable the Human Rights Commission to receive complaints about immigration matters.
- 48. Work with disabled people to create immigration instructions that fulfil the Government's obligations under the Disability Convention and the Disability Strategy.

Article 19: Living independently and being included in the community

The IMM recommends that the Government:

49. Implement legislation requiring all newly built housing to conform to universal design standards (refer also Article 9).

- 50. Require Kāinga Ora—Homes and Communities to:
 - a. adopt a comprehensive definition of universal design;
 - commit immediately to a policy of implementing universal design in all new housing builds across all housing types;
 - c. commit to replacing or retrofitting all existing housing stock to universal design standards over ten years;
 - d. design a range of accessible specifications for each housing type available (that is, consistent with NZS4121:2001 design standards);
 - e. implement a comprehensive accessibility audit of its housing stock;
 - f. commit to ensuring that a representative proportion of their housing stock is retrofitted to meet accessibility standards (that is, per the accessible specifications developed above), as opposed to solely bespoke customisations. The proportion of accessible houses should, at minimum, be the proportion of Kāinga Ora tenants with an impairment; and
 - g. increase the tenure for any disabled tenants requiring bespoke modifications to ensure they can stay in homes that have been modified to their specifications.
- 51. Revise and/or expand all disability-related equipment and vehicle funding schemes to ensure that disabled people have access to the equipment they need to live independently and access their community.
- 52. Fully implement the recommendations of the 2008 Social Services Select Committee report (*Inquiry into the quality of care and service provision for people with disabilities*)¹⁵ to reduce the number of disabled people forced to live in rest homes.
- 53. Introduce accessibility legislation requiring all community services and facilities to be accessible by disabled people, and explicitly stating what is expected of all service providers.
- 54. As a matter of urgency, develop sustainable and equitable funding models so that all disabled people, irrespective of cause, can access flexible and integrated supports that facilitate independent living and full participation in the community;
- 55. Ensure that central government, local government, and any other housing providers determine the numbers and types of accessible housing in such a way that they can be assessed against the community's need.

56. Put more emphasis on the need for housing to be designed and built with accessibility in mind, and ensure disabled people have increased and quick access to sufficient housing modification funds to allow them to move about their own homes safely.

Article 20: Personal mobility

The IMM recommends that the Government:

- 57. Urgently review and extend investment in subsidised taxi and other travel schemes for disabled people unable to access public transport so they can secure consistent and transferable 24/7 access to a range of transport options nationwide.
- 58. Urge local government to embed accessibility requirements within its procurement processes for public transport to ensure that disabled people have equitable access to public transport.
- 59. Require that all taxi fleets must have all, or at least a substantial proportion of, vehicles that are wheelchair accessible, and ensure those vehicles are available in proportion to the general fleet.
- 60. Set expectation and implementation targets for territorial authorities to ensure that their roads, transport infrastructure, and pedestrian routes are constructed, retrofitted, and maintained to meet accessibility standards.
- 61. Equalise the funding for mobility training and equipment for all disabled people, regardless of the cause of impairment, thus removing the difference between Ministry of Health and Accident Compensation Corporation (ACC) clients.
- 62. Provide additional investment into research and development of mobility aids, and to develop or import innovative mobility aids.

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

The IMM recommends that the Government:

63. Expand the Accessibility Charter to include local authorities and district health boards.

- 64. Pass accessibility legislation requiring private providers of information, websites, and mass media to include accessibility.
- 65. Enable disabled people to communicate more effectively with government agencies by increasing the number of accessible formats available so that disabled people can express their views in New Zealand Sign Language, and use braille, Easy Read and audio formats to engage fully.
- 66. Increase access to information and communication for disabled Māori, including increased provision of interpreting, captioning, audio description, and Easy Read in te reo Māori.

Article 22: Respect for privacy

- 67. Conduct an audit and/or situational analysis of disabled people's experiences with privacy and information sharing.
- 68. Instruct all public sector agencies to ensure that any personal information they gather or hold about disabled people is secure, accessible and constitutes the least amount of intrusion necessary.
- 69. Ensure public sector agencies and service providers understand their responsibilities under the Privacy Act 1993 and the Health Information Privacy Code, and be required to demonstrate they have robust training and privacy policies in place in order to receive government funding—particularly in cases where services are outsourced to third parties. This should include improved complaints procedures, and assurances that information provided to complainants will be sent in accessible formats.
- 70. Instruct public sector agencies to provide all official documents in accessible formats, with the option to complete them online, using New Zealand Sign Language, or with the assistance of appropriately trained staff.
- 71. Ensure that the amount of medical data that disabled people are required to provide in order to access services and supports is reviewed and reconciled with a view to reducing repetition, only obtaining necessary information, and ensuring secure data-sharing mechanisms are in place.

Article 23: Respect for home and the family

The IMM recommends that the Government:

- 72. Ensure disabled people's whānau receive financial and other supports necessary to care for their children—including, but not limited to, assistance at home, accessible parenting courses, and access to communication support such as New Zealand Sign Language interpreters.
- 73. Ensure disabled children's right to remain in the family home is protected through the provision of financial and other support to their families.
- 74. Provide to the IMM evidence that confirms no children are being uplifted from a home situation solely on the basis of disability of any member of the family or whānau, or because of inadequate support.
- 75. Review the Adoption Act 1955 to ensure conformity with the Disability Convention. In particular, act without delay on earlier IMM recommendations to review sections 8 and 11 of the Adoption Act to prohibit adoptions being made on the basis of disability alone or without consent of the parent.
- 76. Ensure that court personnel and those furnishing reports to them are provided with training about disability rights and the Disability Convention, to ensure a human rights approach is adhered to.

Article 24: Education

- 77. Urgently introduce an enforceable right to inclusive education as a key element of the legislative framework, and ensures resource to attain equitable access.
- 78. Build co-design into every stage of the education reform process.
- 79. Establish a reference group, including disabled people via their representative organisations and reporting directly to the Minister(s) of Education, to work on key education initiatives.
- 80. Review, as a priority, existing learner support funding models to ensure they provide meaningful support to enable all disabled students to participate equitably in education.
- 81. Ensure that the implementation of proposed complaint and dispute resolution panels include co-design with disabled people and whānau to ensure there

- will be timely and effective responses where there is a lack of reasonable accommodation, as well as timely and effective remedy and redress.
- 82. Ensure there is safe and secure data and information sharing from a rights-based perspective.
- 83. Introduce and bolster meaningful training, development and progression for teachers and education leaders to ensure they are welcoming and inclusive of diverse children, including those with neurodisabilities or invisible disabilities.

Article 25: Health

- 84. Reform the Public Health and Disability Act 2000 to introduce provisions to ensure disabled people are meaningfully represented in governance roles across the health and disability system.
- 85. Advance innovative models of funding for integrated and flexible disability support, and provide adequate resourcing of those models, so that disabled people are able to enjoy the highest attainable standard of health; including but not limited to accelerating equitable access nationally to an *Enabling Good Lives* approach.
- 86. Take definitive action to clarify the expectation on district health boards to provide disability-related supports, particularly in relation to section 22(1)(c) and (d) of the Public Health and Disability Act 2000.
- 87. Implement earlier recommendations of the IMM to address inequities in life expectancy for disabled people, particularly people with intellectual/learning and psychosocial disabilities. Work with disabled people and their representative organisations to establish a comprehensive health improvement and monitoring programme.
- 88. Act on the outcomes of Phase 1 and upcoming hearings of the *Wai 2575 Health Services and Outcomes Kaupapa Inquiry*.
- 89. Ensure that the development of initiatives targeting equitable health service access for disabled people are co-designed with disabled people.
- 90. Ensure a co-design process with people with psychosocial experiences in the implementation of the recommendations of the *He Ara Oranga: Report of the Government Inquiry into Mental Health and Addiction*, and ensure that they are appropriately resourced to carry out this work.

Article 26: Habilitation and rehabilitation

The IMM recommends that the Government:

- 91. Act on earlier IMM recommendations to address disparities between habilitation and rehabilitation services funded by ACC and those services funded by other government agencies, to eliminate inequities in level and standard of services. Particular consideration should be given to disabled people born with an impairment, and those who acquired an impairment without an accident.
- 92. Ensure all disabled people have access to high-quality habilitation services and other preventive measures to proactively address and mitigate progression of impairments with a view to maintaining maximum independence, inclusion and participation in all aspects of life.
- 93. Broaden access to, and adequately resource, a comprehensive range of habilitation and rehabilitation services to enable disabled people to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.

Article 27: Work and employment

- 94. Consider the development of a more comprehensive rights-based national disability specific employment strategy that:
 - a. provides for solutions by tāngata whaikaha for tāngata whaikaha;
 - b. proactively addresses disabled people's inequitable employment outcomes;
 - c. is co-designed by disabled people and employers;
 - d. facilitates local innovation and ownership;
 - e. lifts investment; and
 - f. includes time-specific milestones, measurable actions and a monitoring framework.
- 95. Pending the fuller review referred to in recommendation 10, consider an immediate amendment of the Human Rights Act 1993 to explicitly define reasonable accommodation in an employment context, create a positive duty for

its provision and provide guidance for interpretation of undue burden, informed by Article 2 of the Disability Convention and *General Comment 6* on equality and non-discrimination.

- 96. Initiate affirmative actions or temporary special measures to increase the employment of disabled people within the public service. This could include establishing a quota or target, but could also include the following actions:
 - a. undertake to short-list and interview all appropriately qualified disabled applicants;
 - b. explore ways to incentivise investment by employers in universal design and accessible infrastructures—for example, tax rebates or concessions; and
 - c. consider how government procurement processes, or investments such as the Provincial Growth Fund, could positively contribute to disabled people's employment by requiring vendors or recipients to explicitly demonstrate how their initiative is inclusive of, and accessible to, disabled people.
- 97. Implement the 2014 recommendation to amend the Minimum Wage Act 1983 to eliminate minimum wage exemption permits.

Article 28: Adequate standard of living and social protection

- 98. Adopt the disability-related recommendations of *Whakamana Tāngata*, the report of the Welfare Expert Advisory Group. The IMM endorses the report's stated purpose for a welfare system and encourages the holistic implementation of all recommendations as a matter of urgency, but specifically the following recommendations relating to housing availability and affordability, and income adequacy:¹⁷
 - a. Increase, as soon as possible, overall income support to levels adequate for meaningful participation in the community, as defined by the minimum income standard (which reflects different family circumstances, for example, children, disabilities and regional area) and maintain this level of support through appropriate indexation.
 - b. Urgently expand and accelerate Government efforts to substantially increase public housing on an industrial scale and continue urgent efforts to end homelessness.
 - c. Increase the range of home ownership and tenure options for people on low and low–middle incomes.

- d. Increase the capacity of third-sector community-based housing providers.
- e. Develop and enact laws and regulations to ensure healthy homes and housing security, decent standards of housing quality, universal design, and accessibility.
- f. Subsidise housing costs for people on low incomes (in addition to raising main benefit rates to provide an adequate income) and ensure the combination of changes to housing support and abatement rates make households better off.
- g. Improve access to affordable, suitable housing support for people on low and low–middle incomes, including a range of affordable home-ownership products and papakāinga housing.
- h. Improve the health and wellbeing of people with health conditions and disabilities, along with carers of people with health conditions and disabilities who interact with the welfare system by:
 - providing financial support that is adequate to live a life with dignity and is equitable across the social sector
 - implementing evidence-based approaches to support engagement in good, suitable work and the community where this is possible
 - implementing strategies to prevent work-limiting health conditions and disabilities.
- i. Include in the scope of the New Zealand Health and Disability System Review the relationship between the health and disability system and the accident compensation scheme and how the relationship between these and the welfare system could be changed to improve outcomes for people with health conditions and disabilities and carers.

Article 29: Participation in political and public life

- 99. Review the parameters for disqualification of voters subject to the Mental Health (Compulsory Assessment and Treatment) Act 1992 and the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 to ensure conformity with the Disability Convention.
- 100. Implement legislation and other measures to increase accessibility of election processes for disabled people, co-designed with disabled people.

- 101. Work closely with disabled people and the Electoral Commission to ensure that information about local and general elections can be provided in accessible formats, and that the necessary supports are in place to ensure that there is not a disproportionate exclusion from voting of people with an intellectual impairment.
- 102. Review the support for disabled candidates and electoral processes; and resource and provide reasonable accommodations at both local and central government levels.

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

- 103. Take steps to mandate that publicly funded sporting and cultural initiatives and facilities, including those provided in partnership with local government, are made accessible as a requirement of standard procurement procedures and existing facilities to best practice accessibility standards.
- 104. Ensure that all tourist facilities, hotels and other accommodation providers, public attractions, and sporting and cultural facilities are required to provide detailed information on their websites outlining the accessibility features of the venue and/or service.
- 105. Require all sporting, cultural, entertainment and/or recreational facilities to make provision for accessibility features proportionate to the prevalence of those access needs in the community.
- 106. Introduce a discount scheme for disabled people's companion tickets to enable disabled people to take a support carer to events and performances at a reduced cost.
- 107. Provide increased funding to train and employ trilingual interpreters and audio describers, and to make their services available at civic and cultural events. This will require developing a strategy to build a pool of trilingual personnel.
- 108. Introduce legislation to require an increase in the amount of captioning and audio description on New Zealand television, including the provision of captions and audio description for OnDemand content, including content provided in te reo Māori.
- 109. Require sporting events to provide a live commentary for blind patrons—either generated from within the stadium or via standard radio stations—which must be live and not delayed.

- 110. Introduce new legislation requiring film distributors and producers to include accessibility features, including captions and audio description—particularly when these have been made available in other parts of the world.
- 111. Increase funding for sporting bodies to make their activities and facilities fully inclusive of disabled sportspeople.

Article 31: Statistics and data collection

The IMM recommends that the Government:

- 112. From 2023, re-start the Disability Survey following each Census, commencing with the 2023 Census.
- 113. Continue to introduce disability data collection in all general household surveys conducted by Statistics New Zealand.
- 114. Continue to promote the benefits and advise on the limitations of the Washington Group Short Set of Questions on Disability in order to encourage the creation of a consistent cross-agency data set.
- 115. Continue work with disabled people and representative organisations to ensure that Census completion is barrier-free for disabled people, so they can engage as they choose, with independence, confidence, and dignity.

Article 32: International cooperation

- 116. Continue its commitment to, and consolidate its partnership with, the Pacific Disability Forum.
- 117. Fund disabled people's participation in initiatives of international cooperation, including significant international disability events such as the Global Disability Summits, the annual Conference of State Parties, and at the United Nations when New Zealand is reviewed against the Disability Convention by the Disability Committee.
- 118. Build New Zealand's Pacific aid programmes and initiatives so they are accessible to, and inclusive of, the needs of the disabled people in the region.

Article 33: National implementation and monitoring

- 119. Create a transparent mechanism to demonstrate that it makes substantive and meaningful changes in response to IMM recommendations.
- 120. Work with the IMM to explore how to formalise increased diversity to reflect the groups detailed in *General Comment 7.*¹⁸



Caption: Kiringāua Cassidy wields his pouwhenua in front of Tamatea at Ōtākou Marae. Kiringāua is carving a role for himself as an orator in both te reo Māori and English, a singer, and a teacher of Kapa Haka in Dunedin. Photo courtesy of Attitude Pictures Ltd.

The experience of Māori

Māori must be able to support Māori: Kotahitanga, Manaakitanga, Rangatiratanga, Whānaungatanga.

Hui participant

Pākehā voice should not dominate everything.

Hui participant

We need a Māori DPO—and to be a member of the DPO Coalition.

Hui participant

The human rights of Māori, the indigenous people of New Zealand, are not being fully realised in Aotearoa New Zealand. Evidence, as set out below, shows that positive life outcomes for Māori are comparatively lower than for other population groups.

Tāngata whaikaha (disabled Māori) are further compromised, and are even further from realising the rights set out in the Disability Convention.

Many disabled Māori see themselves as Māori first. Understanding the experience of tāngata whaikaha can only happen within the cultural and human rights context of Māori as tāngata whenua (people of the land) and partners in Te Tiriti o Waitangi (Treaty of Waitangi).

Signed in 1840 by Māori rangitira (chiefs) and representatives of the British Crown, Te Tiriti is regarded as a founding document of government in New Zealand. Its articles set out the principles of full participation, self-determination, equality and non-discrimination. These rights are also set out in the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP).

During public consultation held by the IMM, some participants asked why the rights of indigenous people are not explicitly provided for in the Disability Convention. In answer, it was noted that the Disability Convention can be viewed through an 'UNDRIP lens', which offers an indigenous perspective. For example, Article 18 of UNDRIP states:

Indigenous peoples have the right to participate in decision-making in matters which would affect their rights, through representatives chosen by themselves in accordance with their own procedures, as well as to maintain and develop their own indigenous decision-making institutions.

The commitments set out in Te Tiriti and the UNDRIP have not been upheld, resulting in systemic cultural and economic impoverishment for Māori. Māori have a higher rate of disability than the wider population, and tāngata whaikaha fare worse than non-disabled Māori in many social and economic indicators. In comparison to non-Māori, Māori have a lower median income,¹⁹ higher rates of poverty, lower life expectancy,²⁰ higher rates of suicide,²¹ and disproportionate rates of child removal by Oranga Tamariki—Ministry for Children.²² Tāngata whaikaha have lower labour force participation, lower income, higher unemployment, greater likelihood of inadequate, damp, cold housing, higher rates of discrimination, and lower rates for self-assessed health status of excellent or very good.²³ Tāngata whaikaha are also subject to disproportionate rates of compulsory treatment under both the Mental Health (Compulsory Assessment and Treatment) Act 1992 and the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003.²⁴ Historically, Māori have not been given the right and resources needed to implement self-determined solutions to address these inequalities.

In 2018, the IMM UNDRIP invited the Expert Mechanism on the Rights of Indigenous Peoples to New Zealand. During this visit, community members raised the following concerns.^{25, 26}

- Māori self-determination is not adequately protected by legal or constitutional arrangements and there is a lack of true partnerships in decision-making, with the balance of power, resources, authority, and world views tipped towards the State.
- Information in Te Reo (Māori language) is lacking, and there is only a very small pool of trilingual New Zealand Sign Language interpreters, which impedes participation by Māori Deaf in cultural events, hui, and discussions.
- The impact of institutionalisation, and removal from whānau (family) which Māori continue to experience at higher rates than non-Māori, are enduring, including the loss of opportunity for tāngata whaikaha to grow up in whānau, hapū (sub-tribe), and iwi (tribe), and within their culture. This is currently the subject of a wider health services claim to the Waitangi Tribunal.²⁷
- Māori now have one of the highest per population suicide rates among comparable countries.²⁸ Rates are particularly high among Māori youth, specifically young Māori men. The latest statistics show that rates for women and older Māori have increased.
- There are entrenched inequalities in education, housing, justice, health, employment and income.
- The disability system transformation has not implemented a Whānau Ora (integrated and self-determined family approach to wellbeing) approach.²⁹
- The Whānau Ora Interface Group have been talking to Te Pūtahitanga o Te Waipounamu about aligning system transformation with the Whānau Ora approach.

Dr Paula Thérèse King authored a report on the health status of tāngata whaikaha in preparation for Stage 2 of the Waitangi Tribunal *Wai 2575 Health Services and Outcomes Kaupapa Inquiry* (disability). In its conclusion, she states:³⁰

This report has demonstrated that significant inequities exist for Māori with lived experience of disability in health outcomes – in terms of exposure to the determinants of health and well-being, access to health and disability services, and the quality of health and disability care received (including health and disability system responsiveness). There is clear evidence of multiple systemic and structural barriers affecting these health outcomes for Māori with lived experience of disability. These systemic barriers have been created, maintained, and reinforced by the strategies of the Crown. The resulting effects include redistributing resources, preventing meaningful involvement, and a failure to monitor outcomes or respond appropriately to inequities that have emerged. In other words, the significant inequities which impact on Māori with lived experience of disability have not occurred through happenstance.

. . .

Māori with lived experience of disability are not actively prevented from participating in policy and legislative developments, but neither is the opportunity to participate guaranteed, or actively sought by the Crown. Nor is there evidence that reasonable accommodations and supports are put in place by Crown organisations to support participation of Māori with lived experience of disability. This amounts to something close to the exclusion of Māori with lived experience of disability from health and disability sector decision-making.

During consultation hui to inform this report, both tāngata whaikaha and non-Māori expressed concerns about:

- the lack of and pressing need for the voice of tangata whalkaha to be included in decision-making, perhaps through a formalised structure such as a panimpairment indigenous disabled people's organisation;
- a need to build knowledge of and commitment to Te Tiriti-based practice among disabled people's organisations and the DPO Coalition;
- the dominance of medical or 'western' models in, for example, psychiatry, neurology and paediatrics;
- the lack of respect for, funding of and access to, kaupapa Māori (Māori customary practice) practitioners' services; and
- a lack of cultural competency among support staff.

These outcomes suggest a failure to uphold Article 30 of the Disability Convention, Right to participation in cultural life:

Persons with disabilities shall be entitled, on an equal basis with others, to recognition and support of their specific cultural and linguistic identity, including sign languages and deaf culture.

Māori with disabilities have experienced alienation from their culture and language, including the loss of stories of leadership by tāngata whaikaha. The following excerpt from Dr Paula Thérèse King's report to the Waitangi Tribunal illustrates this:³¹

...it appears that Māori in the ancient world who had impairment were people with god-like power and god-like status. They were known for the talents that they possessed, not for what they didn't have. As time progressed, this notion appeared to change...

The need to remove barriers to full citizenship is recognised and addressed, to an extent, in the tāngata whaikaha leadership group's Māori disability action plan, *Whāia Te Ao Mārama*.³² This plan's key aim is to achieve full participation by tāngata whaikaha in te ao Māori (the Māori world), including access to culturally appropriate supports and building cultural competency within non-Māori disability support services. There is no agency specifically contracted to support its implementation. In contrast, the Ministry of Health has contracted with a non-government agency to implement *Faiva Ora*, a Pacific disability action plan.

It is hoped that increased investment, as a result of the 2019 Wellbeing Budget, will improve Māori mental health and wellbeing, including lowering the rate of suicide. As part of the response to the report of the 2018 Mental Health and Addiction Inquiry, *He Ara Oranga*,³³ the Ministry of Health signalled that work with Māori leaders will be key to the suicide prevention strategy, with one-third of funding to be dedicated to Māorispecific initiatives. Māori have expressed mixed views on the extent to which the *He Ara Oranga* report and suicide prevention strategy reflect Te Tiriti rights or respond adequately to the unequal wellbeing outcomes.

The IMM needs more quality disaggregated data to properly monitor outcomes for tāngata whaikaha. Evidenced inequalities show that disabled Māori are far from enjoying universal human rights on an equal basis with others, and even further from fully realising their rights as indigenous people.

Bishop Manuhuia 'Manu' Bennett saw Te Tiriti as 'the promise of two peoples to take the best possible care of each other'.³⁴ Available statistics and the day-to-day lives of many tangata whaikaha suggest this promise is yet to be fulfilled.

Recommendations

The following recommendations alone cannot address these systemic inequities. All recommendations within this report carry the expectation that they will be implemented in ways that give effect to indigenous rights to self-determination and full participation.

With that in mind, the IMM recommends that the Government:

1. Take immediate steps to progress a mechanism, by which the voice of tāngata whaikaha, can be formally included in all disability-related policy and legislative development, and any Crown–Māori partnership initiatives. This recommendation reflects and supports recommendation 11 of the IMM UNDRIP's report regarding the implementation of the UN Declaration on the Rights of Indigenous Peoples in Aotearoa New Zealand, June 2018.³⁵

- 2. Act to implement recommendations 3 and 6 of the IMM UNDRIP's report regarding the implementation of the UN Declaration on the Rights of Indigenous Peoples in Aotearoa New Zealand, June 2018.³⁶
- 3. In addressing poorer socioeconomic outcomes for Māori, specifically identify and address the disproportionate impacts of these inequities on tāngata whaikaha.



Caption: "Fofola e fala kae talanoa e kāinga" The fala (mat) is a common space for talanoa (dialogue) with family and friends. A group of five friends sit on a mat chatting. Le Va has produced organisational guidelines for disability support services to enable culturally intelligent care for Pasifika families. Photo courtesy of Le Va–www.leva.co.nz.

Pacific peoples

Pasifika DPO should be a member of the DPO Coalition.

Hui participant

Gap much bigger than realised.

Hui participant

Disparity between Māori/Pasifika which is further heightened when disability factored in. Many disabled Māori/Pasifika are left behind because it is difficult to access and use complaint mechanisms. People need to know their rights and not face further stigma/extra hurdles to realise these.

Survey respondent

As one of the non-indigenous minority populations in New Zealand, the IMM is of the view that Pacific disabled peoples share some parallel experiences with tangata whaikaha in that their day-to-day realities reside within the broader cultural context and social outcomes for Pacific communities.

Like Māori, Pacific peoples also have a higher rate of disability after adjusting for differences in ethnic population age profiles.³⁷ Visibility and representation of Pacific disabled peoples within Pacific populations, as well as the broader population of disabled people, is generally low. Pacific disabled peoples have formed a panimpairment network, but this is not part of the DPO Coalition. Their voices are therefore not formally represented in government engagement.

Poor outcomes for disabled Pacific peoples are evident across most social indicators, including healthcare access and treatment, employment and housing.³⁸ These poor outcomes are often compounded when intersected with other characteristics, particularly for Pacific women, who have lower rates of labour force participation and pay.³⁹

A significant factor affecting visibility is the lack of regularly collected and disaggregated data articulating the experiences of Pacific disabled peoples. The consequences are compounded for Pacific communities whose voices and worldviews are already underrepresented.

Cultural differences, language barriers, and low cultural competence within disability services have significant effects on engagement between Pacific communities, disability services and Pacific disabled peoples. Systems are complex and hard to navigate, and they potentially discourage Pacific disabled peoples and their families from seeking or receiving entitlements and assistance. During the consultation hui informing this report, Pacific disabled peoples indicated that the formality of language for many government processes—for example, the Census—impeded Pacific peoples' participation in many areas of public life.

There are few Pacific community-owned or operated service providers for Pacific disabled peoples. This produces a lack of culturally grounded services for Pacific disabled peoples, and Pacific peoples have relatively low levels of contact with services overall, although this is increasing.⁴⁰

Some progress is being made to improve the lives of Pacific disabled peoples, the most significant being the newly refreshed *Faiva Ora 2016–2021 National Pasifika Disability Plan.*⁴¹

The Faiva Ora Plan has three major focuses:

- involving and encouraging better engagement with disabled people within Pacific communities;
- · enabling people to access the right support; and
- building Pacific cultural competencies and partnerships with service providers to better meet needs.

The implementation of the plan is supported by Le Va, a Pacific organisation fostering health and wellbeing for Pacific communities, and the Faiva Ora Leadership Group of Pacific peoples with lived experience of disability. The groups act in a governance-role, amplifying Pacific disabled peoples' voices and providing advice to the Ministry of Health.

Recommendations

- 4. In addressing poorer socioeconomic outcomes for Pacific peoples, specifically identify and address the disproportionate impacts of these inequities on Pacific disabled peoples.
- 5. Continue to support the implementation of *Faiva Ora 2016–2021 National Pasifika Disability Plan* and the role of the Faiva Ora Leadership Group.
- 6. Support and resource the further development of an autonomous Pacific disabled peoples—led organisation, through which their voice can be formally included in all disability-related policy and legislative development, and in the co-design of an extended range and choice of support options.

Article 4: General obligations

Adequate funding and resources for disabled people. Listen to disabled people themselves. Make sure that teachers and other education professionals are not perpetuating ableism. Disabled people deserve the same opportunities as non-disabled people.

Survey respondent

Many of the voices on what disabled people need in New Zealand are from non-disabled people.

Survey respondent

General bias and stigma toward disabled people. Particularly non-disabled people's voices being prioritised in conversations around disability issues.

Survey respondent

Know our rights, use our rights, have courage to make complaints.

Survey respondent

Article 4(1) outlines the general obligations of the Disability Convention, and requires governments to ensure and promote the full realisation of all human rights and fundamental freedoms for disabled people. It calls for governments to adopt legislative and administrative measures to ensure the rights in the Disability Convention are implemented. Article 4(1) also calls for governments to refrain from engaging in practices inconsistent with the Disability Convention, and to ensure that public authorities and institutions act in conformity with the Disability Convention. Article 4(3) provides that all decision-making relating to disabled people shall actively involve disabled people, including children.

Although there are few examples in New Zealand of legislation that is directly contrary to the wording of the Disability Convention,⁴² the IMM is concerned that some laws do not fully reflect contemporary thinking about the intent and purpose of

the Disability Convention. A key example is the Human Rights Act 1993: the principal legislative instrument intended to safeguard the rights of disabled people in New Zealand. Although this Act defines disability as one of the prohibited grounds for discrimination, it significantly erodes this right through a series of exemptions based on whether, across a broad range of activities, it is considered 'reasonable' to make accommodations.

A further example of laws not reflecting the intent of the Disability Convention is the Substance Addiction (Compulsory Assessment and Treatment) Act 2017. The IMM is concerned at the way in which this legislation undermines disabled people's rights. This is explored later in *Article 14*. The IMM is also concerned that noncompliance with the Disability Convention at a policy or practice level is even more widespread than the legislative frameworks may suggest.

In terms of Article 4(3), it is the IMM's view that in recent years the Government has consulted more widely and actively with the disability community. The Government is to be recognised for these improvements to its consultative processes with disabled people and an increasing number of co-design initiatives. A positive example of implementation of Article 4(3) in legislation is section 5(1)(b)(i) of the Oranga Tamariki Act 1989 which requires children's rights to be taken into account in the exercise of powers under that Act. Development of the *New Zealand Disability Strategy 2016–2026* and *Disability Action Plan 2019–2023* involved co-design with disabled people and their organisations.

However, some concerns still remain about the lack of genuine partnership in legislative and policy design, with 'consultation' being the predominant modality, with an unequal balance of power, voice, and resources limiting disabled peoples' opportunities and capacity to meaningfully engage. Examples include the often very tight timeframes for consultation, poor resourcing for disabled people's organisations, and key information not being provided in accessible formats. Most recently, disabled people raised concerns about the very short timeframe to provide feedback on the Government's consultation document as part of the Mental Health Act reform. The Government should set realistic consultation periods, and have independent consultation mechanisms in place to ensure the disability community can provide feedback in a meaningful and comprehensive way. The Government should resource disabled people's organisations to create such independent consultation mechanisms.

Recommendations

- 7. Include reference to the Disability Convention in all relevant future legislation, to promote awareness and understanding of the Disability Convention, and ensure that legislation is fully compliant with the obligations set out in the Disability Convention.
- 8. Work with disabled people to codify structures, timeframes, processes and resources that would enact genuine partnership with disabled people and to facilitate co-governance (including co-design, co-production, and co-evaluation) with disabled people of all legislation, policies, procedures and other decision-making processes affecting disabled people.
- 9. Take all necessary steps to ensure adequate resource availability for a diverse range of disabled people's representative organisations.⁴³

Article 5: Equality and non-discrimination

Make sure everyone gets the same opportunities and does not have to fight for them.

Hui participant

Having to go to the 'side door' if you have mobility issues—reinforcing the 'additional needs' philosophy.

Survey respondent

Introduction

Article 5 affirms that all disabled people shall be given equal recognition and protection by the law. It prohibits discrimination on the grounds of disability and requires the implementation of effective legal protections against discrimination and the provision of reasonable accommodation.

General comment

Non-discrimination is a fundamental principle for ensuring disabled people's enjoyment of universal rights. This is reflected by its inclusion as both a principle (Article 3(b)), and a distinct article in the Disability Convention. Social inequality and discrimination drove the development of the Disability Convention. Where differential treatment or outcomes persist, even in the context of positive progress, this is a signal that further and ongoing work is needed.

Importance of Article 5 to disabled people in New Zealand

Discrimination is still present in many different forms and has immense consequences for disabled people and their families. It marginalises the contributions disabled New Zealanders can, and wish to, make.

Better understanding and promotion of reasonable accommodation, including recognition that its denial constitutes discrimination, is key to achieving non-discrimination in New Zealand. At its core, non-discrimination is about the dignity of equal participation.

For all disabled people to be free from discrimination, intersections between disability, indigeneity, ethnicity, sexuality, gender or gender identity, and age must be recognised. Communities subject to multiple and cumulative impacts must be prioritised. A recently released report, *Counting Ourselves* (based on the results of the survey of the same name)—about the health and wellbeing of trans and non-binary people in New Zealand—demonstrates that disabled trans and non-binary respondents were more likely to have experienced discrimination than their non-disabled peers and were more likely to have experienced sexual violence.⁴⁴

Current place of Article 5 in New Zealand law and practice

There are some contradictions in the legislative framework with regard to non-discrimination on the basis of disability, with discrimination being both prohibited and, in some cases, legitimised.

Disability is one of the grounds of discrimination prohibited under New Zealand's Human Rights Act 1993. The prohibition extends to actions of both the state and private sectors. ⁴⁵ The Human Rights Commission (HRC) receives enquiries about and complaints of discrimination on the ground of disability, and offers a free mediation service aimed at settling disputes. If mediation is unsuccessful, a complainant can approach the Human Rights Review Tribunal (either directly or through the Office of Human Rights Proceedings).

The Human Rights Review Tribunal hears claims relating to breaches of the Human Rights Act and can determine if discrimination has taken place. Currently, complainants can experience considerable wait times to have their case heard by the Tribunal, or to receive a decision. The average waiting time for a hearing is more than two years, and just under two years for a decision—an average of four years in total.⁴⁶ The Tribunal recently received an increase in resources, which may help to reduce waiting times.⁴⁷

Principles of non-discrimination are also enshrined in other parts of New Zealand law—for example, the New Zealand Bill of Rights Act 1990, and section 8 of the Education Act 1989, which describes the (non-enforceable) right of disabled children and students to access education.⁴⁸

However, there are a number of Acts that seemingly contravene the right to equality before the law and permit non-consented interventions and substituted decision-making for disabled people.⁴⁹ The burden of inequality before the law is likely to fall disproportionately on people with psychosocial or cognitive impairment, thereby creating further disparities between disabled people, and leaving some disabled people even further behind.

Committee's previous dialogue with the State on Article 5

During New Zealand's last review in 2014, the Disability Committee made three recommendations in relation to non-discrimination.⁵⁰

The first recommended that the Government reconsider Funded Family Care to:

...ensure that all family members who are carers are paid on the same basis as other carers are and recommends that family members who are carers be entitled to make complaints of unlawful discrimination in respect of the State Party's family care policy.

There has been positive progress on this recommendation, with the Government agreeing to:

- repeal the discriminatory Part 4A of the Public Health and Disability Act 2000 which deals with family care;
- remove the prohibition on partners as paid family carers; and
- pay family members on the same basis as other people providing support to disabled people.

These changes will take effect in 2020.51

The second recommended that the Human Rights Act be:

...amended to include a definition of reasonable accommodation, in conformity with the definition of reasonable accommodation in article 2 of the Convention.

The Government has indicated to the IMM that there are no plans to amend the Human Rights Act, as it considers that the Court has confirmed that the Human Rights Act is consistent with the definition of reasonable accommodation in Article 2 of the Disability Convention.⁵² In the IMM's view, the Human Rights Act should nevertheless be amended to include an explicit definition of reasonable accommodation, strongly aligned with the guidance contained in the Disability Committee's *General Comment 6, Article 5: Equality and Non-discrimination.*⁵³

Concerned about the lack of understanding of reasonable accommodation, the Disability Committee recommended that guidelines for reasonable accommodation '...be promptly completed in line with provisions of the Convention and distributed'. In light of this recommendation, the IMM produced the guide Reasonable accommodation of persons with disabilities in New Zealand in 2016.⁵⁴

Comment on the realisation of Article 5 in New Zealand

Structural discrimination remains a part of both government and societal arrangements in New Zealand. Disabled people are still frequently positioned as

'other', as having special or additional needs, and in some cases, limited decision-making capability. Aspects of the legislative framework reflect and reinforce these notions, contrary to a social model of disability. These issues have not been assigned priority attention, nor do they routinely inform policy design.

There has been significant improvement in the engagement between government agencies and the DPO Coalition. Nevertheless, critical sectors like education, health, justice, and housing all maintain structures and policies that fail to provide equal and non-discriminatory access for disabled New Zealanders. For example, disabled children do not have an enforceable right to inclusive education, health services can be provided without consent, and there is overrepresentation of people with mental health and neurodiverse conditions in the youth and adult criminal justice systems.⁵⁵

Alleged discrimination on the basis of disability has consistently been within the top three bases on which complaints are received by the HRC, which comprise approximately one-third of all complaints received annually. In the five-year period ending 30 June 2019, the HRC received 2082 enquiries and complaints of alleged unlawful discrimination on the ground of disability under the Human Rights Act.

The following table provides an analysis of disability discrimination complaints received by the HRC in the five years since New Zealand's previous review by the UN Disability Committee in 2014.

Table 1: Yearly distribution of disability discrimination complaints (excluding complaints related to more than one area)

Areas	2014	2015	2016	2017	2018	2019	Total
Government activity	159	137	146	105	110	104	761
Employment	79	86	101	100	107	108	581
Provision of goods and services	58	58	63	55	71	78	383
Educational establishments	20	13	30	29	22	30	144
Land, housing and accommodation	18	15	14	22	14	11	94
Places, facilities, vehicles	6	8	5	5	3	16	43
Qualifying bodies		1	1		2	0	4
Vocational training bodies			1			1	2
Advertisements					1	1	2
Grand Total	340	318	361	316	330	349	2014

Formal complaints are likely to represent only a small proportion of disabled people's discriminatory experiences, and it is reasonable to suppose there is a link between the high number of employment-related complaints received and the disparate employment outcomes disabled people experience. For example, there is a 47 percent gap in the labour force participation rates of disabled and non-disabled people of working age (26 percent versus 73 percent).⁵⁶

Engagement with the mediation service offered by the HRC is voluntary, but agreed resolutions can extend to systemic improvements, as illustrated in the following examples.

- Providers of services and public places improved the accessibility and safety of sites, including those of significant national importance.
- An accommodation provider recognised the role of disability assist dogs and sought to increase awareness throughout the industry.
- An electricity company changed its policy for customers with a medical dependency on an uninterrupted electricity supply.

Further examples are set out in **Appendix 2**.

The right to make complaints and seek redress for discrimination is vital. A more proactive approach by the Government to ensuring equality and reasonable accommodations in all areas of public life would reduce the need for disabled people to secure the right to non-discrimination through individual and potentially multiple complaints.

Recommendations

- 10. Amend the Human Rights Act 1993, with a view to strengthening disabled people's right to non-discrimination, including:
 - a. removing or reducing disability related exemptions;
 - b. introducing an explicit definition of reasonable accommodation consistent with the meaning provided in Article 2 of the Disability Convention and General Comment 6 on Article 5;⁵⁷ and
 - c. creating an explicit duty of reasonable accommodation.

- 11. As a matter of urgency, conduct an audit of existing legislation for conformity with the Disability Convention, specifically the right to non-discrimination and equality before the law, and report its findings publicly, specifically highlighting non-compliant legislation.
- 12. Develop, with disabled people, a disability discrimination impact assessment tool/framework and apply this whenever new legislation is developed or current legislation amended, to ensure systemic processes for harmonising all legislation with the Disability Convention and eliminating any discriminatory provisions.

Article 6: Women with disabilities

I am the parent of a young woman with a severe disability. We find getting caregivers to work in our home extremely difficult and finding programmes that are meaningful for her to attend is really hard.

Survey respondent

Introduction

Article 6 recognises that disabled women and girls can be subject to discrimination on the basis of both gender and disability, resulting in cumulative disadvantage. Ensuring equitable exercise of rights and freedoms therefore requires active measures for the advancement of disabled women and girls.

General comment

A whole of government and intersectional approach is necessary to secure full and equal participation for all disabled women and girls in society. Disabled women, including indigenous disabled women, must be involved in all matters affecting them, particularly in gender equity initiatives.

The Disability Committee notes that globally, women and girls with disabilities face barriers in most areas of life.⁵⁸ Of particular concern is the greater risk of disabled women and girls experiencing violence.⁵⁹ Although there is little local research on disabled women and girls in general, or their experiences of violence specifically, combining global evidence with this country's high levels of family violence,⁶⁰ it is highly likely that disabled women in New Zealand face these same elevated risks.

Importance of Article 6 to disabled people in New Zealand

Disabled women and girls in New Zealand want, and expect, to have their voice and concerns heard by decision-makers, but indicate it is a struggle to have their concerns acknowledged or acted upon. As indicated in the Government's response to the Disability Committee's *List of Issues for New Zealand*, disabled women leaders have been included in some national reference, governance and advisory groups in recent years.

Disabled women in New Zealand face a range of inequities. Violence towards disabled women was the top concern expressed during consultations with disabled women held by the Human Rights Commission in 2018 to inform their submission for the Seventh Periodic Review of New Zealand under the Convention on the Elimination of Discrimination Against Women.⁶¹

As part of the right to health, disabled women should have equal access to mainstream sexual and reproductive services, violence reduction initiatives, and health screening and specialist services, when required. A recent report by the YWCA (previously Young Women's Christian Association) confirms that in New Zealand this is not universally the case, with disabled women still encountering inaccessible products, services, and communication channels.⁶²

For disabled women in New Zealand to achieve an adequate standard of living, targeted and tailored programmes, including temporary special measures (affirmative action),⁶³ need to be in place to address the disparate employment outcomes disabled women face, compared to both non-disabled men and women and disabled male peers. If disabled women are not an integral part of the design and development of initiatives to address gender-based disadvantages, there is a risk of leaving disabled women behind.

Current place of Article 6 in law and practice

There is little recognition in the New Zealand legislative or policy framework of the intersectional discrimination and cumulative risk that disabled women may face. As noted in the Government's response to the Disability Committee's List of Issues, some Cabinet papers are required to consider disability impacts. However, there is no requirement for disability perspectives to include an intersection with gender or any other characteristic, such as recognising indigenous peoples.

The only legislation particular to disabled women is that constraining rights to bodily autonomy. In the Contraception Sterilisation and Abortion Act 1977, contraception (section 4) or termination (section 34) are permitted without the person's consent. Sections of the Adoption Act 1955 are likely to disproportionately impact disabled women as primary caregivers. For example, section 8(1)(b) allows for children of disabled parents to be removed for adoption without parental agreement in certain circumstances. In 2016, a number of aspects of this legislation were found to be discriminatory by the Human Rights Review Tribunal.⁶⁴ The Government has not yet made any amendments to this law. The Ministry of Justice has indicated to the IMM that reform of adoption law is on its work programme, and that the Human Rights Review Tribunal decision will be taken into account.

In July 2019, the Family Violence Act 2018 came into effect, replacing the Domestic Violence Act 1995. Of potential benefit to disabled women was the clarification that a carer relationship can be a type of 'family relationship' for the purposes of invoking the protective elements of the Act—for example, protection orders.

In May 2019, the Government announced a \$320 million investment in family and sexual violence services.⁶⁵ Included in expanded prevention programmes is \$2 million to research or better understand the needs of particular communities. Disability is included in this work stream, alongside youth, elderly, new migrants and LGBTQIA+ communities (lesbian, gay, bisexual, transgender, queer, intersex, asexual, +).

The New Zealand Police do not collect disaggregated statistics on sexual and other violent crime towards disabled women. There is currently only one generic code (1M, broadly referring to 'mental') to record attendance to incidents of concern, harm or crime towards disabled people. This makes it difficult to accurately assess, record and monitor disparate access or disproportionately poorer outcomes for disabled women.⁶⁶

As part of the State Services Commission's Diversity and Inclusion programme, the Ministry for Women developed a gender analysis policy tool called *Bringing Gender In.*⁶⁷ This tool guides the inclusion of gender issues and supports the policy development process. It reflects an intersectional approach, recognising the diversity of women and prompting policy makers to analyse different effects for different populations of women, including disabled women.

Committee's previous dialogue with the State on Article 6

The Disability Committee made two recommendations in its 2014 *Concluding Observations with regard to disabled women*: ⁶⁸

The Committee recommends that this work be continued and strengthened to assist women with disabilities in obtaining education and employment and in combating domestic violence. The Committee also recommends that organizations representing women and girls with disabilities be involved in these programmes.

In response, the Government noted that this work was in progress, with the work being 'integrated into the long-term work programme to improve employment outcomes and the Ministerial Group on Family Violence and Sexual Violence Work Programme.' 69

Comment on the realisation of Article 6 in New Zealand

Definitive analysis of disabled women's and girls' realities is challenging in the absence of robust intersectional data about disability and gender. Data gaps affect

the development of legislative, policy and service responses to the multiple forms of discrimination disabled women and girls may face.

Available evidence demonstrates that disabled women are marginalised in a range of outcomes, particularly in employment and parity in income. Disabled women:⁷⁰

- have lower labour force participation rates than non-disabled women (46 percent versus 71 percent), and disabled men (46 percent versus 54 percent);
- have higher unemployment rates than non-disabled women (10 percent versus 6
 percent) and disabled men and non-disabled men (8 percent versus 5 percent);
- are less likely to be in full-time employment than either non-disabled women or disabled men; and
- are more likely (66 percent) than disabled men (51 percent) to earn \$30,000 or less.

This results in disabled women bearing a disproportionate burden of poverty. This can be made worse by the costs of health, sexual, and reproductive services, which may be higher due to inaccessible infrastructure.⁷¹

An intersectional forum on disability and sexuality was held during the ILGA World Conference in New Zealand in March 2019. Women expressed and affirmed issues around disabled people frequently being regarded as asexual and needing to be shielded from relationships. These types of views lead to a lack of education about relationships, consent, and sex, which potentially places some disabled women at greater risk of exploitation and abuse—a situation reflected in the recent YWCA report.

Research suggests that women with intellectual disabilities do not access publicly funded breast or cervical screening programmes to the same degree as non-disabled women. The IMM acknowledges that the *New Zealand Disability Action Plan 2019–2023* refers to a work programme by the Ministry of Health to improve access to quality healthcare and health outcomes for disabled people generally. However, barriers arising from physical inaccessibility of facilities or equipment continue to prevent disabled women accessing these healthcare services. This lack of reasonable accommodation effectively constitutes discrimination.⁷²

Consultations conducted by the HRC in 2018 to inform its submission to the Committee on the Elimination of All Forms of Discrimination against Women showed violence and abuse as the highest priority concern for disabled women. Compounding this concern was the inaccessibility of some women's refuges (shelters) in terms of both physical access and staff knowledge or confidence in disability responsiveness. This means disabled women wishing to escape a violent situation

may have nowhere to go.⁷³ Further, as victims of sexual violence, people with disabilities face a disproportionate disadvantage at the point of disclosure, reporting that they are less likely to be believed and are often perceived as asexual.⁷⁴

In 2016, the Government family violence prevention programme, *It's Not Ok*, produced a resource for disabled people and carers called *Domestic Violence and Disabled People*. This resource recognises particular risks for disabled people in general, and disabled women in particular, and is designed to build disabled people's knowledge of their rights, and their recognition of behaviour that constitutes abuse.

In 2018, the Disability Rights Commissioner joined the Ministry of Social Development to convene the Family Violence Prevention Expert Advisory Group to ensure disability-inclusive responses. While some violence prevention initiatives have included recognition of disability, there is no nationwide strategy to address violence and abuse towards disabled women or girls. The perceived absence of priority attention to issues of concern for disabled women, including violence, was highlighted during the consultation hui and survey informing this report.

A disabled women's forum, supported by CCS Disability Action, is considering formalising its structure to fulfil the characteristics of a disabled people's organisation. The purpose of such a group would be to ensure the voices and issues of disabled women are included within decision-making systems. A recent report from the YWCA suggests that New Zealand is the only signatory to the Disability Convention that does not have a women's disabled people's organisation.⁷⁶

Recommendations

- 13. Actively consult disabled women (and girls where appropriate) in legislative and policy development, decision-making, programme monitoring, and violence prevention measures.
- 14. Strengthen intersectional approaches that integrate disability perspectives within gender equity initiatives and gender perspectives within disability initiatives, including the collection and analysis of data.
- 15. In partnership with disabled women, conduct accessibility audits of violence prevention and response services (including those provided by third parties) to ensure that they are inclusive and accessible, and staff have access to appropriate training.

- 16. Ensure that all women's health and sexual and reproductive services (including those provided by third parties) are provided in accessible facilities and information on these services is provided in accessible formats.
- 17. Institute temporary special measures (affirmative action) aimed at accelerating equitable participation of disabled women in employment.

Article 7: Children with disabilities

Real, active education support for children with disabilities. Massively more support for parents of kids with disabilities—we're on our own with this, and support is incredibly thinly spread and hard to access.

Survey respondent

Events have access for disabled but only with caregivers—our daughter comes with a family.

Survey respondent

To stop discriminating and ensure disabled persons' rights and dignity are upheld whether parent or child with disability.

Survey respondent

Introduction

Article 7 reaffirms that disabled children have equal rights as non-disabled children.

General comment

Disabled children often experience significant barriers to the full enjoyment of their rights. Ensuring the voices of disabled children are included in all decision-making processes that affect them, and creating safe and supportive environments, are essential to guarantee their full and effective participation in society.

The Disability Committee has not issued a General Comment on the theme of children. However, the Committee on the Rights of the Child has issued several General Comments.⁷⁷ Many of these relate to the need for children to have a voice, and to enjoy increasing decision-making capacity as they grow and develop.

Current place of Article 7 in law and practice

In recent years, the role of children in decisions affecting them, particularly in care and protection and youth justice matters, has received extensive attention and has

been the subject of major legislation reform.⁷⁸ A pleasing part of this was the repeal of legislation that allowed disabled children to be removed from their families and put into state care in certain instances.⁷⁹

The Government launched the *Child and Youth Wellbeing Strategy* on 29 August 2019. The Strategy provides a unifying framework and a way of aligning work across government agencies to support all New Zealand children and young people to have a good life. It includes an aspirational vision, nine principles, and six wellbeing outcomes outlining what children and young people need for a good life.

The Strategy includes a Current Programme of Action, which sets out the policies, initiatives, programmes, and plans to help achieve its vision and outcomes. The programme brings together more than 75 actions and 49 supporting actions, led by 20 government agencies. These actions were backed by significant funding in the 2019 Budget. The Government will deliver on and add to these actions over the next one to five years.

There has been a recognition within the education system that children and young people with additional learning needs require better identification and, in turn, funding to meet these identified learning needs. The Government's *Learning Support Action Plan* is one example of this proposed approach.⁸⁰

Committee's previous dialogue with the State on Article 7

The Disability Committee has previously said that it was concerned some children with disabilities, especially Māori disabled children, have difficulty in accessing some government services, including health and education services.

The Government noted in its response that there was work in progress and it would consider the Disability Committee's recommendation when updating the *Disability Action Plan*.⁸¹

Comment on the realisation of Article 7 in New Zealand

The recognition in the *Child and Youth Wellbeing Strategy* of disabled children and young people is pleasing. The IMM notes that around 450 children and young people who self-identified as having a disability were consulted in its development. The IMM looks forward to the implementation of the actions that come out of the Strategy, and strongly encourages these actions being co-designed with disabled children and their families to the greatest extent possible.

Disabled children and young people can experience disparate outcomes in areas such as education. They also generally struggle to have their voices heard. The IMM has previously noted a lack of disaggregated data to inform policy and service delivery for disabled children. For example, Oranga Tamariki—Ministry for Children does not collect disaggregated data on disabled children entering care or protection. The Ministry of Education advised the IMM it does not collect enrolment, achievement, stand-down, suspension, expulsion or exclusion data disaggregated for disabled children and young people. Disabled children's experience may therefore still be invisible within agencies' service delivery systems. We need to be able to track the outcomes for disabled children and young people for the purposes of better service delivery.

The Oranga Tamariki (National Care Standards and Related Matters) Regulations 2018 give specific recognition to the communication needs of disabled children in state care. The Regulations also require reporting of disaggregated data on disabled children in state care to the Independent Children's Monitor. These are welcome developments.

Recommendations

- 18. Collect more comprehensive disaggregated data for disabled young people to inform effective early intervention, especially in the fields of education, care and protection, and youth justice.
- 19. Continue to focus on putting mechanisms in place to put the child's voice at the centre of policy development.

Article 8: Awareness raising

Public attitude is by far the biggest barrier I face. It's amazingly tiring constantly having to educate/appease/justify/fit in. It's the main reason why I often choose to remain secluded.

Survey respondent

General public lack of awareness of how many people have or are affected by disabilities.

Hui participant

Introduction

Article 8 states that governments should educate their citizens about the rights and dignity of disabled people, and acknowledge their achievements and skills. Governments should also take the appropriate measures to combat stereotypes, prejudice and any other activities that might harm disabled people.

To realise the rights set out in Article 8, long-term and comprehensive programmes guided by disabled people and their representative organisations need to be in place across all areas of society.

Importance of Article 8 to disabled people in New Zealand

This article provides the foundation by which all other rights set out in the Disability Convention can be realised. Unfortunately, there continue to be inaccurate and damaging stereotypes and prejudices about disability that preclude disabled people from being accepted for who they are and what they can do. Raising awareness of disability issues and acknowledging the barriers that exist to prevent the full participation of disabled people in everyday life, are vital for creating a non-disabling society.

Current place of Article 8 in New Zealand law and practice

There is nothing in New Zealand law that specifically requires or explicitly advocates for the systematic positive promotion of disability and the rights and dignity of disabled people. Although the Harmful Digital Communications Act 2015 aims to prevent cyberbullying and specifies disability as an area of focus.

Committee's previous dialogue with the State on Article 8

In its *List of Issues*, the Disability Committee requested the Government provide information on:⁸²

- a. Measures targeted at public and private actors undertaken to combat stigma, stereotypes, prejudices, negative attitudes, bullying, hate crime, hate speech and discriminatory language against persons with disabilities, in all spheres of life, including cyberspace;
- b. Involvement of the media in awareness-raising strategies, including campaigns;
- c. Measures taken to promote and sustain a greater understanding that the life of persons with disabilities is of equal value to that of others, and to eradicate and prevent attempts to disseminate ideas that life as a person with disabilities is 'not worth living'.

The Government responded by referencing *Think Differently* (2010–2015), *Like Minds, Like Mine* (1997–present), the *Disability Confident* campaign (2016–2017), New Zealand Sign Language (NZSL) Week and the Bullying Prevention Advisory Group. The Government also referred to a project by the HRC focused on addressing attitudes toward disability. It acknowledges that further work will be resource dependent, but to date the IMM has not understood it to have committed any resources.

Comment on the realisation of Article 8 in New Zealand

Awareness raising has been addressed in some areas, in particular long-running campaigns such as *Like Minds, Like Mine* that focus on mental health discrimination and stigma. Other campaigns with a pan-impairment focus, including *Think Differently* and *Disability Confident*, lacked the scope or longevity required to promote systemic attitudinal change.

Positive stories about disability do sometimes appear in the media, but there are still a large number of reports portraying disability and disabled people in an undesirable light, including frequent use of negative language such as 'wheelchair bound'. Despite 20 years of the Like Minds, Like Mine campaign, there is a persistent tendency for the media to associate mental illness with violence, contrary to evidence. In her 2019 report, at Part IV—Underlying causes of disability-specific forms of deprivation of liberty—Catalina Devandas-Aguilar, the United Nations Special Rapporteur on the rights of persons with disabilities, observed:⁸³

A central aspect of prejudice against persons with psychosocial disabilities is the baseless belief that they are prone to violence. This assumption has proven to be

wrong, in fact, evidence shows that they are actually more likely to be victims of violence.

Of particular concern have been the discussions around the End of Life Choice Act 2019 and new forms of antenatal testing for genetic conditions including Down Syndrome.⁸⁴ Discussion on both topics has included consideration about what constitutes a dignified life, and has been viewed by some members of the disability community as devaluing the lives of disabled people and promoting euthanasia and abortion ahead of the provision of an equal society.

There is an indication that digital harm is more prevalent among teens experiencing one or more disabilities and a recent survey showed that:⁸⁵

...respondents with a disability who answered the online survey also indicated that they experienced online hate at a higher rate compared to non-disabled participants. ...15% of these respondents were targeted with online hate compared to 10% of participants without impairments.

Many disabled people report a lack of awareness about disability among the people they are required to interact with in government departments and in the justice sector. During the consultation hui held to inform this report, participants also reported that social attitudes to disability continue to exclude disabled people from all areas of society and community life. One participant noted when talking about housing:

...applied for 100 rentals—and didn't get one. Landlords assume we'll need modifications and deny us as unsuitable. The issue here is assumptions, not inaccessibility.

Survey respondents raised issues with attitudes towards disabled people with these statements typifying responses on issues of attitudes and awareness raising:

My disability is not obvious, I cannot stand long, I cannot sit long, I need to use the lift, I cannot walk distances on pavement or hard surfaces. People comment I am lazy for taking the lift. I have to justify why I am not able to do some things ... it takes my focus off the job in hand and being professional to make everything personal about my needs.

I can take care of myself providing I have access and opportunity to approach my challenges. I don't need objectification, or praise for bravery, or pity. People's attitudes are the worst barrier.

Recommendations

- 20. Initiate a co-designed nationwide campaign that:
 - a. promotes disabled people's rights and dignity, including profiling the value of diversity;
 - b. counters negative perceptions about the value of disabled people's lives that have been highlighted (promulgated) through debates relating to the End of Life Choice Act 2019 and antenatal screening; and
 - c. urgently and specifically counteracts public perceptions associating psychosocial disability and violence.
- 21. Include disabled people–developed disability inclusion content in school curricula and tertiary level training, particularly (but not limited to) mandatory training for all teachers and others in professions that work directly with disabled people.
- 22. Provide additional resources to ensure that anti-bullying prevention campaigns fully involve, and meet the needs of, disabled people.
- 23. Ensure that, in considering the introduction of expanded hate speech or new hate crime legislation, disability-related hate speech or crime is included.
- 24. Provide disabled people–led training, through the State Services Commission, on the Disability Convention for government personnel.

Article 9: Accessibility

Digital inclusion often excludes people unable/unwilling to use technology.

Hui participant

A must—a blind-friendly route to transport stops. That is, no huge stretches of unsafe space without footpath, no super difficult roundabout crossings or other busy roads with no lights.

Survey respondent

My primary concern is about accessible information. I need alerts about changes in the neighbourhood. When the council digs up our footpaths, they put handwritten notes in our letterbox, which rarely get read. Some neighbours do alert us, but in fairness they all lead busy lives.

Survey respondent

Introduction

Governments should make it possible for disabled people to live independently and participate in their communities. This means that any place open to the public, including buildings, roads, schools and hospitals, must be accessible to disabled people.

General comment

The IMM recognises that some progress has been made in recent years to increase accessibility in certain areas of public life, but there is still a need for greater consistency in accessibility around the country.

Importance of Article 9 to disabled people in New Zealand

Accessibility is vital to ensure that disabled people can participate in public life, work, travel, and that they can receive information on an equal basis with others.



Caption: Four members of People First gather in front of the uncut ribbon at the opening of the Whakatāne Beach Mat Project. Photo courtesy of People First.

Current place of Article 9 in New Zealand law and practice

There are legislation and codes that govern accessibility in New Zealand.

- Building Act 2004 and Building Regulations 1992
- Local Government Act 2002
- Resource Management Act 1991
- New Zealand Urban Design Protocol 86
- The Guidelines for facilities for blind and vision impaired pedestrians 87
- The Pedestrian planning and design guide 88
- The Disability Strategy; the Accessibility Charter, and the related Accessibility Guide: Leading the way in accessible information 89
- New Zealand building standard (NZS 4121:2001 Design for access and mobility— Buildings and associated facilities)

The DPO Coalition worked with the Ministry for Business, Innovation and Employment to develop a guide for the practical application of universal design principles, in the resource *Buildings for everyone: Designing for access and usability.*⁹⁰

Committee's previous dialogue with the State on Article 9

In its *List of Issues*, the Disability Committee asked the Government to provide information on:

- measures taken to ensure that all public buildings are made fully accessible, independently audited, and verified;
- progress in the implementation of the Building Act 2004 and Building Code; including premises where fewer than 10 people are employed, which are currently exempted;
- measures taken for the provision of universal access to safe, inclusive, accessible, green, and public spaces, having regard to particular barriers faced by women, children, and older disabled people;
- steps to ensure that the wide application of the concept of universal design is endorsed by authorities at all levels of public service provision, including the number of wheelchair-accessible buses and taxis; and
- measures taken to ensure that electronic ticketing systems for public transport and journey/travel/timetable information are accessible.

The Government's response included information about the Building Act, which requires reasonable access and progressive upgrade of buildings. The Government confirmed there are no plans to amend the Building Act to remove the exemption for small factories and industrial buildings.⁹¹ There have been no explicit measures taken to ensure universal access to public spaces, most of which are local authority–controlled and regulated under the Local Government Act and the Resource Management Act.

Comment on the realisation of Article 9 in New Zealand

Some measures have been taken since by the Government, local government, and transport operators to improve accessibility.

The New Zealand Disability Strategy 2016–2026 promotes universal design. Kāinga Ora (formally Housing New Zealand Corporation) new builds are required to reflect the principles of universal design, and the Government is considering how to incorporate them into planning for KiwiBuild homes. Cabinet has agreed to 'commence the design of an approach to achieve a fully accessible NZ, in collaboration with stakeholders', which may include accessibility legislation.⁹²

The increased percentage of wheelchair-accessible buses is also welcomed. However, many disabled public transport users still experience challenges accessing transport, using inaccessible ticketing systems, and frustration at the regional variation in ticketing and discount systems. People in rural areas are particularly disadvantaged in their access to public transport.

There were 345 taxis with wheelchair hoists in New Zealand in 2018, down from 435 in 2017. There are 2361 wheelchair-accessible public transport buses, up from 2210 in 2017, and making up 94.5 percent of the total fleet in New Zealand.⁹³ At present, there is regional variation in the application of accessible concessions and electronic ticketing systems. The Government anticipates that, in the future, payment for public transport will be provided consistently across the country and ticketing will become more accessible.

However, there are significant concerns around the introduction of inaccessible electronic ticketing and self-service kiosks such as those used by Air New Zealand, the major air carrier in New Zealand. The Government is the majority shareholder in Air New Zealand and has a duty to ensure that its responsibility as a signatory to the Disability Convention is met in relation to accessibility of transport.

Private construction lags behind public buildings in recognising the need for accessibility to be included in the design phase, and in particular to ensure new homes follow universal design principles.

A common theme at consultation hui was that disabled people need accessible transport to get out and live life. Other issues raised included the need for accessible information, housing and public buildings and spaces. The high cost of accessible technology and the lack of people to provide training on such technology was also raised.

There is a growing number of micro-vehicles and devices, such as e-scooters, many of which can be used on footpaths and which can cause safety issues for disabled pedestrians, including when parked.

Hui and survey participants gave a plethora of examples where accessibility requirements were either not addressed, or not addressed properly. One person noted, 'All very well to say there is a ramp to go into a building, but if the doors are weighted too heavily then you're stuffed'.

Recommendations

- 25. Develop and agree on comprehensive definitions of universal design and accessibility and use these definitions consistently.
- 26. Update New Zealand Standard NZS4121:2001 and develop a comprehensive range of compatible accessibility standards to cover all aspects of community and civic access.
- 27. Ensure accessibility and universal design be implemented in all:
 - a. new housing developments;
 - b. public spaces;
 - c. transportation and ticketing systems;
 - d. shared-use spaces; and
 - e. technologies and communications.
- 28. Implement robust strategies and timelines to upgrade existing public infrastructure to meet best practice accessible design standards.
- 29. Implement systems to require regular monitoring and/or auditing against minimum standards of accessibility of all publicly accessible buildings, workplaces, civic or recreational areas, and public services.
- 30. Co-design accessible systems with disabled people, taking particular account of marginalised groups such as children.

Article 10: Right to life

Sterilisation and hormone treatment of disabled children is still legal here. Records should be kept.

Survey respondent

Introduction

Article 10 states that every human being is born with the right to life. Governments must guarantee that this is equally true for people with and without disabilities.

General comment

This article is relevant to issues such as pre-natal testing, pregnancy termination, access to medical care, assisted suicide and euthanasia. It has particular significance to disabled New Zealanders at present as a result of proposed changes to pre-natal screening, and the passing of the End of Life Choice Act 2019.

Importance of Article 10 to disabled people in New Zealand

While the right to life is always of fundamental importance, the current debates around pre-natal screening and assisted dying have elevated the significance of this article in recent times.

Current place of Article 10 in New Zealand law and practice

The New Zealand Bill of Rights Act 1990, in particular section 8, protects the right of all New Zealanders not to be deprived of life.

The End of Life Choice Act 2019 may enable people to ask for assisted dying if they have a terminal illness that is likely to end their life within six months and if they meet other eligibility criteria. A person is not eligible for assisted dying solely on the grounds they have a disability, including a psychosocial disability, or is of advanced age. The Act will only come into force if passed by a majority of voters in a national referendum in late 2020.

Committee's previous dialogue with the State on Article 10

The Government's first report to the Disability Committee noted that the New Zealand Bill of Rights Act provides that no one shall be deprived of life—a right that

applies equally to all people. In its 2014 *Concluding Observations on New Zealand,* the Disability Committee did not address Article 10.

Comment on the realisation of Article 10 in New Zealand

There are a number of areas of concern that appear to undermine the right to life provided for in Article 10.

There is concern at the impact that the End of Life Choice Act 2019 may have on the right to life for people with medical and psychiatric conditions.⁹⁴ The Human Rights Commission's submission on this legislation highlighted issues such as: ⁹⁵

- lack of safeguards against coercion;
- feelings of being a burden in the environment; and
- devalued identity and a lack of even/equal choices for disabled people in the absence of properly resourced disability support and palliative options.

The figures comparing life expectancy of people with intellectual impairment to those of their non-disabled peers, published by the Ministry of Health in 2011, show a significant discrepancy between the life expectancy of non-disabled men (18 years more), and non-disabled women (23 years more) and that of their peers with intellectual impairments. A similar discrepancy exists for people with psychosocial disabilities.⁹⁶

The use of antenatal screening to detect genetic difference, in particular Down Syndrome, is an area of concern to disabled people and their organisations.⁹⁷ A recent report commissioned by the Law Foundation identified some key areas of concern around the need for effective genetic counselling for parents who choose to undergo testing, and to ensure that screening does not lead to eugenic outcomes.⁹⁸

Recommendations

- 31. Ensure the potential negative impact that any legislation permitting assisted dying may have on disabled people is taken into consideration.
- 32. Ensure through effective monitoring that, should the End of Life Choice Act 2019 come into force, it does not have a disproportionate impact on the right to life for disabled people.

Article 11: Situations of risk and humanitarian emergencies

...people still don't realise what deaf means to them because deaf is [an] invisible disability. The lack of New Zealand Sign Language interpreters in emergencies, warning disasters [is concerning].

Survey respondent

Introduction

Article 11 requires governments to take all necessary measures to protect and ensure the safety of disabled people during situations of risk including armed conflict, humanitarian emergencies and natural disasters.

As noted in the introduction, this report was largely finalised prior to the outbreak of the Covid-19 pandemic. The IMM acknowledges that this crisis has been keenly felt by disabled New Zealanders. Rather than delay release of the report, the decision was made to instead focus the IMM's efforts on a Covid-19 themed report based on disabled people's experiences and the Government's response to disability communities' needs during this time. Work on this report is underway.

General comment

The duty to protect and ensure the safety of disabled people during situations of risk must be carried out taking into account obligations under international law, including international humanitarian law and human rights law.

Importance of Article 11 to disabled people in New Zealand

The Canterbury earthquakes in 2010 and 2011, and the more recent mosque attacks in March 2019 brought into focus the importance of Article 11 for disabled New Zealanders. Disabled people need to get the same information as everyone else on what measures and precautions they need to take during an emergency situation, in a way that they can understand and at the same time as everybody else.

Current place of Article 11 in law and practice

Situations of risk and natural disasters exacerbate everyday difficulties for disabled people, including poorly designed or inaccessible public buildings, facilities and services.

Following the Canterbury earthquakes, the Kanohi ki te Kanohi consultancy⁹⁹ set up the Earthquake Disability Leadership Group. The original focus of this group was to ensure the Christchurch rebuild was inclusive of, and accessible to, disabled people. In 2016, the group was transformed into a charitable trust and took on a New Zealand—wide role.

The Office for Disability Issues published information for disaster preparedness for disabled people as part of New Zealand's 'Get ready' week.¹⁰⁰ In addition, the 'Get ready' website has information relating to disaster preparedness for people with a number of impairments.¹⁰¹

In September 2019, CBM NZ¹⁰² organised both a study tour and a Disability Inclusive Disaster Risk Reduction (DIDRR) roundtable. This roundtable brought together two disabled people–led organisations, the Pacific Disability forum, colleagues from the Philippines, and representatives from across the New Zealand Government. During the roundtable, a toolkit on DIDRR was shared with participants.¹⁰³

Committee's previous dialogue with the State on Article 11

The Disability Committee made no concluding observations on Article 11 in its 2014 *Concluding Observations on New Zealand*.

However, in its resolution 28/4,¹⁰⁴ the Human Rights Council requested the Office of the High Commissioner for Human Rights to prepare a study on Article 11 of the Disability Convention on situations of risk and humanitarian emergencies, in consultation with states and other relevant stakeholders.¹⁰⁵

Comment on the realisation of Article 11 in New Zealand

The Canterbury earthquakes of 2010 and 2011 have brought the issue of DIDRR more sharply into focus in New Zealand. Disabled New Zealanders face more challenges than non-disabled New Zealanders after a disaster and during the recovery phase, such as a lack of information in accessible formats, inaccessible facilities and services, and difficulty accessing appropriate support services. There is an international push to design and implement disability-inclusive 'disaster risk reduction and resilience practices' and this has been addressed in the National Disaster Resilience Strategy. The Human Rights Commission's Monitoring Human Rights in the Canterbury Earthquake Recovery report makes it clear that New Zealand needs to prioritise the needs of disabled people in DIDRR work.

Recommendations

- 33. Continue to work with the DPO Coalition on Disability Inclusive Disaster Risk Reduction (DIDRR) and that the work should expand to provide a comprehensive response to a range of humanitarian risk and natural disasters.
- 34. Develop and promote schemes that proactively support increasing resilience for disabled individuals, families, groups, and communities to mitigate the risks and impacts of natural disasters or other humanitarian emergencies.

Article 12: Equal recognition before the law

Article 12 of the UNCRPD [Disability Convention] gives disabled people the right to enjoy legal capacity on an equal basis with others. In Aotearoa New Zealand, there are many people subject to court orders under the Protection of Personal and Property Rights Act 1988 (PPPR Act) who do not enjoy this right...

Survey respondent

You are not equal before the law; you are drugged to conform.

Hui participant

Suppression of your will—who benefits?

Hui participant

Need to repeal the Protection of Personal and Property Rights law.

Hui participant

They don't listen, and family get overridden.

Hui participant

Introduction

This article requires states to recognise disabled people as persons before the law everywhere, and to provide access to support to exercise this legal capacity on an equal basis with others. All measures must be taken to respect a person's rights, will and preferences, and to prevent abuses, conflicts of interests or undue influence over the exercise of legal capacity. Any restrictions must be of the shortest possible duration, and be subject to independent and impartial review and oversight.

General comment

The IMM considers that genuine fulfilment of this article will require a transformational shift in New Zealand legislation and practice, from substitute decision-making to supported decision-making, fully respecting disabled people's autonomy, and the right to appropriate decision-making support. In recent years, analysis of this article has been provided by the Disability Committee *General Comment 1*,¹⁰⁸ and by the Special Rapporteur's 2018 report to the Human Rights Council.¹⁰⁹ Both were unequivocal that there are no circumstances in which laws permitting detention or forced treatment on the basis of disability would comply with the Disability Convention.

Importance of Article 12 to disabled people in New Zealand

The importance of this article cannot be overstated. Access to sufficient, diverse, and guaranteed systems of supported decision-making is critically important for all disabled New Zealanders to participate in decisions affecting them. This is particularly so for people with psychosocial, cognitive, learning or intellectual impairments who continue to be subject to detention in institutional settings, to treatment without consent, and to a lack of independent support and advocacy.

Current place of Article 12 in New Zealand law and practice

Discrimination on the basis of disability is prohibited by the Human Rights Act 1993. Freedom from discrimination, and the right to refuse medical treatment, are affirmed in the New Zealand Bill of Rights Act 1990.

Nevertheless, the following laws permitting differential treatment, including in certain circumstances, detention, forced treatment and substituted decision-making, are currently in place.

• The Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 provides for diversion from the justice system for persons with an intellectual disability (with assessed IQ of 70 or below) who have been charged with, or convicted of, an offence, to compulsory care and rehabilitation, including in secure facilities. This Act was not intended to cover individuals who have not committed a criminal office, because detention would be a breach of their human rights. However, the IMM is concerned that extensions to compulsory care orders, based on an assessment of ongoing risk, can lead to some people with intellectual disabilities being detained for periods of time exceeding the maximum length of sentence they would be liable to in the criminal justice system.

- The Mental Health (Compulsory Assessment and Treatment) Act 1992 provides for the compulsory assessment and treatment of people who are considered to have a mental disorder within the meaning of the Act. Compulsory treatment is an entry point into mental health services for people posing a serious risk of harm to themselves or others. The IMM is concerned that aspects of the Act are inconsistent with contemporary thinking about mental health and human rights. It incorporates a medical model approach to mental health, which in turn enables the use of compulsion.
- The Substance Addiction (Compulsory Assessment and Treatment) Act 2017 allows for compulsory treatment of individuals if their 'capacity to make informed decisions about treatment for [their] addiction is severely impaired' and other requirements are met. This legislation does not align with the Disability Convention or contemporary mental health philosophy. There is also a lack of robust scientific evidence to support the efficacy of compulsory treatment of those addicted to substances.
- Right 7 of the Code of Health and Disability Rights—the right to make an
 informed choice and give informed consent—includes an exception permitting
 a service provider to provide services without the consent of the recipient where
 they have reasonable grounds to believe the person is not competent to make
 their own decisions.

Each of these laws contain some safeguards, including requirements to ascertain, if possible, the views of the disabled person, external oversight, and specific review periods. However, these provisions do not reflect contemporary understanding of the right to access support to make decisions, or the shift to establishing a person's will and preferences rather than acting in a person's best interests. Conformity with the Disability Convention would be best served by repealing this framework of substitute decision-making in its entirety, although there is no current commitment to do so.

However, the Government agreed in the *New Zealand Disability Action Plan 2019–2023* to repeal and replace the Mental Health (Compulsory Assessment and Treatment) Act 1992 as one of the first three priority responses to the report of the inquiry into mental health and addiction, *He Ara Oranga*.¹¹⁰

The Minister of Justice has also more recently requested the Law Commission to review laws related to adults with impaired decision-making capacity.¹¹¹

Disabled people will need to be fully involved from the outset in this work, which will ideally develop a universal framework focused on fulfilling the right to adequate support and to participate fully in decision-making. In accordance with Article 12, mental capacity and legal agency must be recognised as separate concepts within any such framework.

Committee's previous dialogue with the State on Article 12

In its 2014 *Concluding Observations* on the initial report from New Zealand, the Disability Committee recommended that:¹¹²

...the State Party take immediate steps to revise the relevant laws and replace substituted decision-making with supported decision-making. This should provide a wide range of measures that respect the person's autonomy, will and preferences, and is in full conformity with article 12 of the Convention, including with respect to the individual's right, in his or her own capacity, to give and withdraw informed consent, in particular for medical treatment, to access justice, to marry, and to work...

The 2017 *List of Issues* sought a progress update on law reform measures and increased access to tailored supports for all disabled people to be able to exercise legal capacity and participate fully in managing their affairs.

Comment on the realisation of Article 12 in New Zealand

There have been some positive actions towards strengthening the human rights dimension of existing laws, and improved access to supported decision-making in some areas.

- In 2016, a national supported decision-making forum generated positive consensus among diverse stakeholders and contributed to resource development. However, initial momentum stalled. A renewed programme in 2019, led by the Ministry of Social Development, has the modest intent to provide definitions of supported decision-making and guide practice within current policy settings. On a positive note, this programme involves a range of government agencies and community stakeholders and should build capability and ownership during the development process.
- Within the co-designed Mana Whaikaha prototype of a new model for disability support services, a more systemic approach to supported decision-making has been taken, including dedicated resources for independent paid support for decision-making. However, in the immediate term at least, this will only benefit a small proportion of disabled people.
- In 2017, the Ministry of Health issued a discussion paper seeking feedback on improvements to human rights protections within the Mental Health (Compulsory Assessment and Treatment) Act 1992, and is currently revising its Guidelines for use of the Act.¹¹³

As indicated earlier, in 2019 the Government accepted the recommendation of the *He Ara Oranga* report to review the Mental Health (Compulsory Assessment and Treatment) Act 1992. People with lived experience are being included in initial consultations, but the pace and resource intensity required for participation in the current process may inhibit the full involvement of disabled people. Significant and immediate change is required to ensure that disabled people whose lives will be profoundly affected by this legislation are not excluded from participation on an equal basis. We recommend that people with experience of mental distress be enabled to participate though their representative organisations, with adequate resourcing to support that participation.

Overall, the sporadic momentum for building competence in supported decision-making is disappointing. There has not been the necessary urgency, resource or sustained focus needed to progress enjoyment of this fundamental right.

Rates of compulsion remain high by international standards (disproportionately for Māori), and have increased over time, raising concerns that compulsion may have become a default setting rather than option of last resort.¹¹⁴ Further, it is thought that around 75 percent of people subject to compulsory treatment orders have treatment decision-making capacity.¹¹⁵

There is a growing body of evidence of both the harms of compulsion, and effective alternatives to it.¹¹⁶ Initiatives demonstrating good practice in supported decision-making, such as advance directives, are not accorded the same legal status as substituted decision-making authorities. This is despite the *Code of Health and Disability Services Consumers' Rights* recognising the right to make advance directives.

As highlighted in a collection of perspectives on the provision of aged residential care without consent, procedural safeguards may not be consistently followed or routinely monitored.¹¹⁷

During the IMM consultation hui, disabled people reflected how coercive practices rendered them 'lesser' before the law.

Examples were also provided of medical professionals driving substitute decision-making—for example, general practitioners being unwilling to provide primary care services without the consent of a third party.

There is a lack of understanding of, or commitment to, disabled people's right to participate fully and equally in decisions affecting them.

Access to peer and other decision-making supports, second opinions or independent advocacy is limited. Disabled people's organisations have developed resources that support people in decision-making, but they frequently lack sustainable funding for this work to be routinely offered on the scale required.

Piecemeal improvements to further limit coercion, or to strengthen safeguards in existing legislation, risk consolidating substitute decision-making rather than dissolution. Upholding this right requires a bold shift to eliminate substitute decision-making, and to invest in culture, practice and infrastructure that actively support disabled people's autonomy and free and informed consent.

Recommendations

- 35. Repeal and replace any legislation allowing forced interventions that are based on and, reinforce negative or deficient notions of disabled people, and permit compulsory 'treatment' interventions, including:
 - a. Mental Health (Compulsory Assessment and Treatment) Act 1992 (noting that this is already committed to in the Disability Action Plan);
 - b. Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003;
 - c. Substance Addiction (Compulsory Assessment and Treatment) Act 2017; and
 - d. any sections of the Oranga Tamariki Act 1989 Children's and Young People's Well-being Act 1989 that enable arbitrary detention, solitary confinement, restraint, or actions that may constitute cruel, inhuman or degrading treatment or punishment.
 - 36. Request that the Law Commission's review of 'adults with impaired decision-making capacity':
 - a. is co-designed with disabled people;
 - b. is informed by a human rights approach that recognises universal legal rights to access support to make decisions, and that maximises participation;
 - c. reflects an understanding of substitute decision-making as an option only of last resort after all supported decision-making options are exhausted, and that any substitute decision should be based on the best interpretation of the person's rights, will and preference;

- d. enshrines the importance of regular reviews and robust monitoring mechanisms; and
- e. considers a unified framework that could be applied irrespective of the reason for (temporary or longer-term) decision-making substitution.
- 37. Ensure disabled people and their representative organisations have sustainable resources to lead the development of supported decision-making capability for disabled people, whānau, and duty bearers such as the health and disability workforce, legal profession, and financial institutions.

Article 13: Access to justice

Access to legal help—lawyers cost \$500 per hour and community law can't help.

Hui participant

Auckland Disability Law (ADL) is the only community law centre in Aotearoa New Zealand which solely provides legal services and activities to Disabled and Deaf People around their disability-related legal issues.

Survey respondent

Introduction

This article builds on provisions in international human rights law supporting access to justice, such as the right to an effective remedy and to fair procedures, and the right to be heard in proceedings affecting the person.

General comment

Article 13 addresses access to justice in the context of disability as a human right, and imposes concrete and binding obligations on State Parties. At its core, the article relates to reasonable accommodation in a legal/justice context. It has not yet been discussed in a General Comment by the Disability Committee.

Barriers to exercising this right can include:

- physical access;
- information;
- attitudes;
- communication;
- access to legal advice; and
- regulatory and procedural matters.

Importance of Article 13 to disabled people in New Zealand

Interaction with the justice system can be challenging for anybody. For a disabled person, the experience can be particularly stressful and confronting.¹¹⁸

It is imperative that disabled people access and receive reasonable accommodations, personalised for their diverse communication, learning, comprehension, and any other access requirements in the justice system.

It appears there are significant numbers of disabled people in both the youth and adult justice systems. Of these, people with a neurodisability¹¹⁹ could constitute a significant proportion.

International research has identified oral communication difficulties in about 50 to 60 percent of young people in the criminal justice system. Recent research in New Zealand established that 64 percent of the young people assessed in a youth justice residence had significant language impairment, compared to only 10 percent of young people as a whole.¹²⁰

Research in New Zealand has shown that the prison population has a higher incidence of traumatic brain injury (TBI) than the general population. Of New Zealand male offenders, 63.8 percent have sustained a TBI across their lifetime, with 33 percent of these having experienced multiple injuries.¹²¹

The cost to a disabled person of the rights in this article not being realised is extremely significant. For example, in 2014 the United Kingdom Privy Council quashed a murder conviction for a New Zealander, Teina Pora, who had undiagnosed Fetal Alcohol Spectrum Disorder (FASD).

That disorder affected the confessions that the accused made at the time: 122

...it really cannot be plausibly argued that the crucial evidence that he suffered from a form of FASD does not have a potentially significant impact on the safety of the conviction.

Mr Pora was wrongly imprisoned for 21 years, and was subsequently awarded more than \$2 million dollars in compensation by the State.

Current place of Article 13 in New Zealand law and practice

Justice service providers are obligated to reasonably accommodate a person's disability, including with specific services or facilities. The Human Rights Act 1993 does not define what is 'reasonable', as this depends on the specific circumstances.

Legal aid is available for people based on a range of criteria such as financial hardship. The type and amount of grant can be designed for an individual's needs, including whether a disability might hinder that individual's access to justice.

The Human Rights Act provides for an escalating system of redress, from mediation up to a formal review by an independent body—the Human Rights Review Tribunal.

The Human Rights Review Tribunal can hear claims relating to breaches of the:

- Human Rights Act 1993;
- Privacy Act 1993; and
- Health and Disability Commissioner Act 1994.

Claims could relate to discrimination, sexual or racial harassment, privacy principles, and the Code of Health and Disability Services Consumers' Rights. The Tribunal can award compensatory damages for losses suffered. Awards are typically for injury to feelings, humiliation, and loss of dignity. In terms of final remedy, New Zealand has acceded to the Optional Protocol to the Disability Convention.

New Zealand needs better data on the prevalence of neurodisability to inform targets, and indicators to ensure better service delivery in a justice context to people with a neurodisability. Data is critical to early, effective identification and intervention. If people with neurodisabilities do not access early support—for example, in an education context—they face an increased risk of interaction with the justice system and poor outcomes within it. The IMM understands from anecdotal Youth Court evidence, some targeted studies, and studies from comparable jurisdictions¹²³ that there is a significant overrepresentation in our youth justice system of people with neurodisabilities.

Disabled people need to be active participants in legal processes, and to have information communicated in accessible ways tailored for them as individuals. There have been some pleasing initiatives to improve access to justice for people with diverse ways of communicating.

- Talking Trouble Aotearoa New Zealand is an organisation of speech language
 therapists that provides justice sector workforce development as well as courtappointed Communication Assistant roles in the Youth, District and High Courts,
 and Family Group Conferences for witnesses or defendants who need assistance
 with understanding and participating in these settings.
- The *Benchmark Project*, funded by the New Zealand Law Foundation and the IHC Foundation, provides a range of tools that legal professionals can use to ensure that people who may be vulnerable in a legal context (including disabled people) are fully included in the legal issues and proceedings that concern them.¹²⁴
- Auckland Disability Law is a community law centre that solely provides free and accessible disability-related legal advice. It is the only one of its type in New Zealand.

 Following some work by the Disability Rights Commissioner during her term as Patron of a Police College wing, Police national headquarters has shown positive commitment to disabled person-led staff development for improved communication with disabled people.

Committee's previous dialogue with the State on Article 13

In its *List of Issues*, the Disability Committee asked for information related to measures taken:

- a. to review the processes for assessing compensation by ACC to ensure that adequate legal aid is available, that its processes are fully accessible to all claimants, and that the mechanism has a human rights-based approach;
- b. by tribunals to adopt a responsive and flexible approach to the admission of evidence, and to provide free legal aid to ensure full access to judicial remedies—particularly by disabled people who have scarce economic resources and those who are still institutionalised:
- c. to collect data related to the prevalence of young people with psychosocial and/ or intellectual disabilities in the juvenile justice system. Currently there is no consistent and robust way of collecting cross-agency disaggregated disability data in the juvenile justice system; and
- d. to conduct training programmes on the Disability Convention by the Institute of Judicial Studies (IJS), in cooperation with organisations of disabled people, and on the rights of disabled people who come before the State Party's courts and tribunals.

In its response, the Government noted:

- ACC is committed to an accessibility charter;
- whether someone is eligible to receive legal aid depends on specific factors;
- data is not collected on the prevalence of young people with psychosocial and/ or intellectual disabilities in the juvenile justice system; and
- the Government has informed the IJS of the recommendation.

Comment on the realisation of Article 13 in New Zealand

While there have been a number of useful small-scale research and intervention initiatives, the IMM considers the New Zealand justice system is still a challenging environment for disabled people to navigate.

There needs to be more dedicated investment in the identification and provision of any accommodations required by disabled people. There also needs to be comprehensive training for lawyers, court staff, and the judiciary about reasonable accommodation and the impacts of disability.

There are significant delays (in some cases years) with the operations of remedy bodies that disabled people depend upon, such as the Human Rights Review Tribunal.¹²⁵ In response to IMM data requests, the Tribunal acknowledges that due to delays in appointing a new Deputy Chairperson (October 2019), it will not be until the first half of 2020 that any 'appreciable progress' will be made in the rate of cases/ decisions being actioned.

Recommendation

- 38. Undertake a strategic review of the justice system to ensure that it is accessible and fit for purpose for disabled people to ensure equal access. Recommended actions include, but are not limited to:
 - a. improving data collection by the Ministry of Justice and the courts;
 - b. undertaking mandatory and funded 'accessibility audits' of all courts and Ministry of Justice and Department of Corrections facilities;
 - c. ensuring information about the justice sector is fully accessible, both in terms of its individual components and the various journeys that an individual may take through the justice system as a whole;
 - d. providing further training on disability rights and accessibility within the justice sector, including the effects of multiple discrimination;
 - e. encouraging and funding a significant increase in legal expertise on disability and human rights;
 - f. establishing and funding an independent advocacy service for disabled people;
 - g. reviewing any barriers that affect lawyers in private practice responding to disabled clients:

- h. increasing resources for community law providers that provide disability-related legal interventions; and
- i. increasing an understanding of 'neurodisability' within the justice system and developing specific cognitive and communication responses to people with neurological impairments.

Article 14: Liberty and security of person

Young people who have an invisible disability such as Fetal Alcohol Spectrum Disorder (FASD) and autism often end up in prison, because they didn't get the support they need.

Survey respondent

[Seclusion] continues to be used inappropriately, especially with people experiencing dementia.

Survey respondent

Introduction

Article 14 recognises that disabled people should have their freedoms protected by law on an equal basis with others. Any deprivation of liberty must be in conformity with the law, and the existence of disability shall not justify a denial of human rights.

General comment

This article is of pivotal importance, as it deals with disabled people who are in prison, secure health or disability services, or other places of detention. Disabled people in these environments can be particularly vulnerable to exploitation or abuse. Reasonable accommodation should be provided to ensure a person's disability does not lead to unintended and further deprivations of liberty.

Importance of Article 14 to disabled people in New Zealand

Realisation of the rights in this article requires changes to New Zealand's current legislative environment, where a number of Acts have been criticised for their lack of human rights principles, or the absence of free and informed consent. Protecting the liberty and security of disabled people who are in restrictive environments is paramount, and must continue to be monitored.

Current place of Article 14 in law and practice

Current law and practice in New Zealand does not adequately reflect Article 14 of the Disability Convention. New Zealand's current legal framework (particularly legislation

pertaining to health and disability) is based on a process of substituted decision-making, rather than supported decision-making. As outlined in Article 12, a number of Acts should be reviewed,¹²⁶ with a focus on replacing the medical model with contemporary disability thinking, such as the recovery model.

The IMM acknowledges the Government is currently reviewing the Mental Health (Compulsory Assessment and Treatment) Act 1992. However, overall progress is too slow in this area, and some legislation adopted by the Government after ratifying the Disability Convention violates the rights of disabled people to liberty and security. There is no systematic programme of legislative review and reform in place to ensure that non-compliant legislation is identified and progressively brought into alignment with the Disability Convention.

Committee's previous dialogue with the State on Article 14

In its 2014 *Concluding Observations*, the Disability Committee recommended that New Zealand:¹²⁷

...take all the immediate necessary legislative, administrative, and judicial measures to ensure that no one is detained against their will in any medical facility on the basis of actual or perceived disability.

The Disability Committee was concerned that the Mental Health Act has been criticised for its lack of human rights principles and recommended that:¹²⁸

...all mental health services are provided with free and informed consent of the person concerned in accordance with the Convention.

It further recommended that the Mental Health Act be revised so that it complies with the Disability Convention.

The Disability Committee was also concerned that the criminal justice system in New Zealand includes conditions in which disabled people are declared 'unfit to stand trial', and on this basis can be deprived of their liberty. It stated that the system does not recognise that a disabled person should only be deprived of their liberty when found guilty of a crime, after a criminal procedure has been followed, with all the safeguards and guarantees applicable to everyone. Based on this, the Disability Committee recommended a review of safeguards and guarantees for disabled people in New Zealand's criminal justice system. It further recommended that New Zealand ensures that disabled people in prison were afforded reasonable accommodation.

Comment on the realisation of Article 14 in New Zealand

There is much work to be done. Since New Zealand last reported to the Disability Committee, the Substance Addiction (Compulsory Assessment and Treatment) Act

2017 has been enacted. The Act allows for compulsory assessment and treatment of people that is counterintuitive to contemporary mental health philosophy. The IMM made written submissions against the Act, noting issues with respect to Article 14 of the Disability Convention. Our submission emphasised the Disability Committee's previous comments on the Mental Health Act, and our belief that the Disability Committee will make similar criticisms of the coercive aspects of the Act, along with the fact that New Zealand now has additional legislation that allows compulsory assessment and treatment. Section 120 of the Act requires the Ministry of Health to conduct a review of the operation and effectiveness of the Act, and report to the Minister of Health, after the legislation has been in effect for three years.

New Zealand, like most countries, has significant work to do in order to comply with Article 14. United Nations Special Rapporteur on the Rights of Persons with Disabilities, Catalina Devandas-Aguilar, made the following statement in her report to the Human Rights Council in 2019 about the global situation:¹²⁹

The deprivation of liberty on the basis of impairment is a human rights violation on a massive scale. Persons with disabilities are systematically placed into institutions and psychiatric facilities, or detained at home and other community settings, based on the existence or presumption of having an impairment. They are also overrepresented in traditional places of deprivation of liberty, such as prisons, immigration detention centres, juvenile detention facilities, and children's residential institutions. In all these settings, they are exposed to additional human rights violations, such as forced treatment, seclusion, and restraints.

Ms Devandas-Aguilar's concerns are echoed by members of the Deaf community in New Zealand, who feel there is a lack of reasonable accommodation in the provision of culturally and linguistically accessible mental health services and support services for Deaf people.

Recommendations

The IMM recommends that the Government:

39. Implement the formal recommendation, made in the *Inquiry into Mental Health* and Addiction, to repeal and replace the Mental Health (Compulsory Assessment and Treatment) Act 1992, in partnership with people with experience of mental distress, including wide consultation with tangata whaikaha, without delay.

- 40. Action paragraphs 33 and 34 of the Disability Committee's *Concluding Observations*, to eliminate detention in medical facilities on the basis of (actual or perceived) disability, provide treatment only on the basis of free and informed consent, and eliminate the use of seclusion and restraint in medical facilities.
- 41. Ensure that the review required by section 120 of the Substance Addiction (Compulsory Assessment and Treatment) Act 2017 is implemented comprehensively.

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

Understand that seclusion and restraint is cruel and inhumane treatment and there is no justification. Loopholes should be closed.

Hui participant

Abusive practice—pinning people down, removing clothing to inject drugs.

Hui participant

Broaden definition of seclusion and restraint beyond physical—include social, emotional deprivation.

Hui participant

Introduction

Article 15 states that no person, with or without disability, should be tortured, humiliated or treated cruelly. Disabled people also have the right to refuse to be part of medical or scientific research. These rights should be protected by effective administrative, legislative and judicial measures.

General comment

This article is important due to the existence of some legislation in New Zealand (previously covered in Articles 12 and 14) that allows compulsory assessment and treatment.

Disabled people who are subject to such assessment or treatment must not be subjected to any form of torture, or cruel, inhuman or degrading treatment or punishment. Article 15 is also relevant to disabled prisoners who, on many occasions,

require reasonable accommodation so that they can access all services in the prison environment.

Importance of Article 15 to disabled people in New Zealand

Realisation of the rights in this article is needed to protect disabled people who have been deprived of their liberty. Disabled people living in prisons or other secure facilities are amongst New Zealand's most vulnerable people, and do not have regular access to the same services and facilities the general public does.

Current place of Article 15 in law and practice

At present, no legal measures have been taken to eliminate the use of seclusion, restraints, night safety orders, tie-down beds and non-consensual treatment. However, the Government has advised it is committed to reducing the use of seclusion, restraints and other similar measures. In April 2019, the Department of Corrections removed tie-down beds from Intervention and Support Units (ISU) in prisons. Further, the Government has published guidelines on night safety procedures and aims to eliminate this practice by 2022. A process is also underway to restrict the use of mechanical restraints in prisons through the Corrections Amendment Bill.

The New Zealand Health Quality & Safety Commission has set up a *Zero Seclusion policy*, working in collaboration with 19 district health boards and Te Pou o te Whakaaro Nui (a national centre of evidence-based workforce development for the mental health, addiction and disability sectors in New Zealand). The Commission's aim was to eliminate seclusion by 2020 through working with teams of consumers, their families and whānau, and service providers. As noted earlier, this time-frame is now seen as aspirational. The elimination of seclusion has been part of New Zealand Government policy for more than a decade, and reducing restrictive practices in mental health has been discussed for more than 20 years. New Zealand ratified the United Nations Convention Against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment (the Convention Against Torture) in 1989.

Despite evidence that more than 90 percent of prisoners have a lifetime diagnosis of mental health or substance abuse disorders,¹³³ and a considerable number of prisoners have other disabilities, the Chief Ombudsman (in the role as a National Preventative Mechanism under the Crimes of Torture Act 1989) continues to observe disabled prisoners living in unsuitable prison environments. In recent inspections, a number of prisoners with physical disabilities, who were assisted by either a wheelchair or a prosthetic, had trouble accessing key services in a particular prison.¹³⁴ For example, Deaf prisoners were observed as having not been provided with access to New Zealand Sign Language interpreting services or information on emergency



Caption: A seclusion room in a mental health facility without ensuite facilities. A mattress lies on the ground in the middle of the room.



Caption: Another example of a seclusion room in a mental health facility. The door directly in front of the mattress leads to an ensuite bathroom.

procedures, given they would not be able to hear alarms.¹³⁵ This indicates that reasonable accommodation is not always being proactively considered. However, the Chief Ombudsman did observe an example of good practice of reasonable accommodation at the Auckland South Corrections Facility which has installed incell telephones and user interfaces. This is a positive initiative that ensures disabled prisoners can effectively communicate.¹³⁶

The Chief Ombudsman has raised concerns that prisoners or clients in ISUs can be seen on camera by staff when they are naked or using the toilet.¹³⁷ The Chief Ombudsman considered this to be degrading treatment or punishment.

The Chief Ombudsman has also publicly remarked on the circumstances of those living in secure mental health and secure intellectual disability facilities. For instance, in 2016, he stated it was 'cruel and inhuman' that an individual was living in a sparse room with a mattress on the floor, directly beside a de-escalation unit at a facility in Wellington. This individual's mood was regularly affected by behaviour and noise of other clients, and they spent the vast majority of their time without mental or physical stimulation. In 2018, they were moved from the secure unit where they had lived for more than eight years to more humane accommodation in the community with appropriate support staff and services in place. The Chief Ombudsman remains concerned about several other individuals who have been in secure intellectual disability services for extended periods, and is currently undertaking a systemic investigation into facilities and services that encompasses a number of case studies.

The Chief Ombudsman also has long held concerns that overcrowding in secure mental health facilities can amount to degrading treatment under the Convention Against Torture, as can use of rooms such as day rooms, offices, or seclusion rooms as long-term or temporary bedrooms for service users.¹⁴¹ Concerns have also been raised

regarding staff retention and high turnover rates, leading to security staff being used to assist with personal restraint in some facilities.¹⁴²

Committee's previous dialogue with the State on Article 15

In its 2014 Concluding Observations, the Disability Committee commented that New Zealand continues to use seclusion and restraint in some secure health and disability facilities. It noted that although there has been a decline in this practice, the situation at that time was not satisfactory. The Disability Committee recommended that immediate steps be taken to eliminate the use of seclusion and restraint in these facilities in New Zealand.

Comment on the realisation of Article 15 in New Zealand

There is still work to be done to ensure that Article 15 is upheld in New Zealand. While there appears to have been a reduction in the use of some restrictive practices, including an end to the use of tie-down beds in prisons and seclusion in schools, the Government has not moved to eliminate seclusion and restraint.

In 2017, Dr Sharon Shalev, an internationally renowned criminologist and expert on prisons, completed an independent review of seclusion and restraint practices in New Zealand. The review was funded by the United Nations Office of the High Commissioner for Human Rights. Dr Shalev's report, *Thinking outside the Box: A review of seclusion and restraint practices in New Zealand*, highlighted a number of serious issues. These included high rates of seclusion and restraint, impoverished physical environments for people belonging to vulnerable groups, and concerns around the record keeping associated with seclusion and restraint in various settings. 144

Māori and Pacific peoples experience seclusion at double the rate of other New Zealanders.¹⁴⁵ In 2017, a report undertaken by Te Pou o te Whakaaro Nui found that while seclusion has reduced in recent years, there were differences in the use of seclusion by district health boards throughout New Zealand.¹⁴⁶ This is echoed by data from the Health Quality & Safety Commission, which shows that while seclusion rates have been declining since 2009, they have recently plateaued.¹⁴⁷

It appears that there is increasing knowledge in various settings that disabled people can request accommodation that meets their needs, particularly when they are in places of detention. The IMM is hopeful that organisations and individuals working in these environments will begin to proactively consider the rights of disabled people, rather than simply respond to requests for assistance as required.

Advancements have also been made in the education sector. The Education (Update) Amendment Act 2017 prohibited seclusion and regulated the use of restraint in New Zealand schools. As a result, no school should be secluding or isolating students.

Restrictions on the use of restraint were also set so this practice can only be used when serious and imminent harm is evident.

Seclusion and restraint practices were a recurring area of concern at the consultation hui. Participants also strongly asserted that compulsorily medicating a person is both cruel and inhumane and should not be used in any setting. Many participants also felt that seclusion and restraint could be avoided with appropriate education and training for staff in prisons and secure healthcare facilities.

It was also evident that people see seclusion and restraint in a much wider context than that defined in law or in treaties. Survey respondents and hui participants talked about the restraints imposed on personal freedoms and choices by services, for example the removal of a disabled person's access to assistive equipment, or sleep routines that suit staff rather than the disabled person.

Recommendations

- 42. Strengthens its commitment to reduction of rates of restraint of persons with disabilities, and the rapid reduction, towards elimination, of use of seclusion in secure health and disability facilities, through robust, achievable and time-bound policies.
- 43. Pending elimination of these practices, require district health boards to regularly release annual statistics indicating performance against these policies, including reporting comprehensive data relating to long-term stays in seclusion.

Article 16: Freedom from exploitation, violence and abuse

Violence against disabled people—there are very high rates...There are no services to respond to the abuse of disabled people and currently very little work going on despite the Government saying that this is being included in the sexual and domestic violence work plan. Violence against disabled people isn't really on the agenda at all...

Survey respondent

Introduction

Article 16 requires governments to take all appropriate measures to protect disabled people from all forms of exploitation. This includes violence, abuse, and neglect related to a disabled person's gender (see Article 6) or age.

The Government must ensure that disability services are independently monitored to ensure that disabled people are not subject to violence, abuse or neglect when using such a service.

General comment

Violence, abuse and neglect of disabled people can occur in residential settings, in a disabled person's home, in an education setting or at work. Such abuse can be hard to detect, and disabled people are at particular risk of sustained and ongoing abuse over prolonged periods of time.

It is mostly disabled people themselves and allied organisations that raise issues of violence, abuse, and neglect within the disability community. Such groups have precarious funding—for example, the Auckland Domestic Violence and Disability Group has disbanded as it was unsustainable as a volunteer group.

Two international reviews reported that children with disabilities are almost four times more likely to experience some form of violence, with disabled adults being more than one-and-a-half times more likely to be victims of violence than non-disabled people.¹⁴⁸

Current place of Article 16 in law and practice

Government-funded anti-violence and abuse programmes have been, at best, slow to address issues of violence, abuse and neglect of disabled people and many of them do not have accessible information or premises.

In 2017, Parliament's Justice and Electoral Committee asked for submissions on the Family and Whānau Violence Legislation Bill. The Chief Ombudsman made a submission with the following suggestions.¹⁴⁹

Care should be taken to ensure that where a disabled person receives personal care or support in their home, this employer/employee relationship is covered by the law, in order for disabled people to be afforded legal protection where violence, abuse or neglect are perpetrated by a paid 'carer'.

- Two clauses should be added to the definition of 'psychological abuse' to ensure the Bill further protects disabled and older people: 150
 - financial or economic abuse (for example, denying or limiting access to financial resources, or preventing or restricting employment opportunities or access to education; and
 - denying or limiting access to support, medication, communication or mobility aids or equipment that a person needs to be independent and/or have a good quality of life.
- Protection orders should be made to be more accessible with regard to the format of forms and language used, the accommodation needs of disabled people should be prioritised when making protection orders, and evidence of supported decision-making should be required in the protection order process.
- The law should provide more means to safeguard adults who have care and support needs, and who are experiencing (or are at risk of) family, whānau and/ or domestic violence as a result of those needs—for example, by making it an offence to fail to take adequate steps to protect a 'vulnerable' adult from family violence.

Committee's previous dialogue with the State on Article 16

The Disability Committee noted programmes under the Domestic Violence Act 2013 to assist disabled people who suffer violence, especially women, girls and boys with disabilities. However, the Disability Committee was concerned that the 2013 Act was unclear as to whether it protected disabled people experiencing abuse in homecare/live-in support situations, and whether the definition of a domestic relationship included relationships between disabled people and other resident service users, their caregivers, and other support staff.

The Disability Committee recommended that New Zealand strengthen these programmes and initiatives to protect disabled people, especially those living in institutions, from violence and harm, and put in place a system to detect and respond effectively to cases of abuse. It also recommended that legislation, policy and practice relating to domestic violence covered disabled people in the domestic situations that they encounter.

Comment on the realisation of Article 16 in New Zealand

By passing the Family Violence Act 2018, which came into effect on 1 July 2019, the Government has made some legislative changes to better protect disabled people from violence, neglect and abuse.

The meaning of 'family relationship' has been expanded to clarify that people in a carer/care-recipient relationship may be included. The Act also recognises family violence as including the withholding of care, aid, medicine or a device or support, or restricting access to employment or education.

However, the Act does not make provision for the accommodation needs of disabled people when making protection orders, nor does it contain specific safeguarding measures to reduce family violence experienced by disabled people.

New Zealanders continue to experience high rates of family violence, and there is little data available with regard to how many disabled people are affected. Police collection of disaggregated data on disabled people's experience of violence and abuse would allow the IMM to monitor the situation more effectively.

Recommendation

- 44. Develop a range of initiatives to ensure that disabled people experience the same protection from domestic and other forms of violence as non-disabled people, and that 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 accessible material for disabled people;
 - b. increasing awareness of abuse experienced by disabled people and of the mechanisms to address it, and providing sustainable funding for disabled people–led organisations working in this area;

- c. increasing resourcing for disabled people–led initiatives to ensure there are better systems of recognition, prevention and rapid response to abuse;
- d. ensuring that data collection by the Police enables disaggregated data to be collected to allow for accurate recording and analysis of violence and abuse towards disabled people; and
- e. ensuring people subject to compulsory detention on the basis of disability have ready access to trained advocates free of charge, and ensuring advocates cannot be prevented from visiting clients on demand to act as witnesses to situations and conditions.

Article 17: Protecting the integrity of the person

Make inclusion a reality—by ensuring everyone gets the same opportunities and disabled people do not have to fight for their rights. Ensure agencies are accountable to make this a reality.

Hui participant

Ban forced drugging ... Forced drugging is an abuse and a crime against another human being. Let's not complicate it.

Hui participant

Introduction

Article 17 states that no one can treat a person with a disability as inferior because of their physical or mental abilities. In short, disabled people should be treated in the same way as everybody else, and have the right to be respected for who they are and be treated on an equal basis with others. This includes when making decisions about medical procedures and interventions affecting them directly, with the disability or impairment in no way excluding disabled people from being involved in the decision-making processes.

General comment

Although generally covered by legislation, it appears that there are instances where the bodily integrity of disabled people is not protected on an equal basis with their non-disabled peers. This is of particular concern in relation to non-therapeutic medical procedures and non-therapeutic sterilisation.

Importance of Article 17 to disabled people in New Zealand

This article is of particular importance to those people who are least likely to be able to voice their own will and preference, with others instead making choices on their behalf. Some disabled New Zealanders are denied the opportunity to have full control over their own bodies due to substitute decision-making practices. The reality of putting supported decision-making into practice is yet to be realised, and is a concern the IMM has raised in its last two reports.

Current place of Article 17 in New Zealand law and practice

Section 11 of the New Zealand Bill of Rights Act 1990 states that '[e]veryone has the right to refuse to undergo any medical treatment'.

However, it is still reported that non-therapeutic sterilisations and other medical procedures have taken place without the consent of the disabled child or adult. For those under 18 years, the courts do not usually need to be involved where the parents or guardians are deemed to be acting in the child's best interests. For people over 18 years old, the Protection of Personal and Property Rights Act 1988 can be used to seek court approval for sterilisation without consent.

Under the Contraception, Sterilisation, and Abortion Act 1977, non-consensual sterilisation and provision of contraception to disabled people is deemed to be lawful in certain circumstances. Until very recently, an abortion could be performed without consent on women deemed to be 'mentally subnormal' under that Act. New Zealand courts have also ruled that non-consensual sterilisation may lawfully be undertaken: when deemed medically necessary and approved by the courts, in an emergency situation, or when approved by a person's welfare guardian to save a person's life or prevent serious harm.

Compulsory treatment and solitary confinement continue to be permitted under the Mental Health (Compulsory Assessment and Treatment) Act 1992 and the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003.

In 2016, the Ombudsman dealt with an enquiry from a disability service provider about the lack of data available around the number of involuntary sterilisations performed on women and girls with intellectual disabilities in New Zealand. The provider had attempted to obtain statistics from both the Ministry of Health and the Ministry of Justice, but was advised the information is not held by the ministries but by the courts, while reporting on sterilisation procedures explicitly prohibits patient identification orders.

The Ombudsman made a number of enquiries to both the Ministry of Health and the Ministry of Justice, noting that the lack of data in this area makes it difficult to monitor important disability rights for an already vulnerable population group. The Ombudsman considered that the involuntary sterilisation of women and girls with intellectual disabilities in New Zealand is a 'matter of significant public interest', and noted that the Disability Committee, in its 2014 Concluding Observations, had stated that New Zealand ought to:¹⁵¹

...enact legislation prohibiting the use of sterilization on boys and girls with disabilities, and on adults with disabilities, in the absence of their prior, fully informed and free consent.

The Ministry of Health and the Ministry of Justice undertook some research around the number of such orders that have taken place in the past five years, and uncovered only a single example of the involuntary sterilisation of a female with an intellectual disability.¹⁵² However, the Ombudsman considered that the electronic information system for recording such information was inadequate, and noted it was possible that other such orders have taken place but not been recorded (a manual review of a large number of physical files would be required to determine whether other orders took place). The Ombudsman felt this was a 'surprising state of affairs in 2016 when electronic data can be easily collected and analysed', ¹⁵³ and suggested both agencies update and review their mechanisms for recording sterilisation orders.

The Ombudsman reminded the Ministry of Health and the Ministry of Justice that New Zealand's Disability Action Plan 2014–2018 included a new priority to protect against non-therapeutic sterilisation, and that there was an expectation that New Zealand passes legalisation prohibiting such sterilisation altogether. The Ombudsman also reminded both agencies of Article 31 in the Disability Convention which requires that 'State Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect the [Disability] Convention'.

Action Item 7B of the New Zealand Disability Action Plan 2014–2018 was to 'explore the framework that protects the bodily integrity of disabled children and disabled adults against non-therapeutic medical procedures, including the issue of consent'. The initial focus was to be on options to protect against non-therapeutic sterilisation without the consent of the individual. Despite a Project Reference Group being set up in 2018 to discuss the action item, the IMM believes progress on this initiative has stalled. The IMM considers it essential that the Government responds to the updated Disability Action Plan 2019–2023 by ensuring that this action is completed as a first step to preventing further involuntary sterilisations.

Committee's previous dialogue with the State on Article 17

The Government's first report to the Disability Committee explained the exceptional circumstances in which treatment may be given. In its response, the Disability Committee requested data about the number of sterilisations carried out on women and girls with intellectual disabilities without their consent. The Government reported that while information on sterilisations is collected, it does not include information about whether the patient is disabled.

Questions asked in the current reporting cycle include the measures that have been taken to enact legislation prohibiting non-consensual treatment, including sterilisation, with particular attention to disabled children. The response outlined the legal framework under which non-consensual treatment may be undertaken.

The Disability Committee also asked about the practice of Ashley Treatment, or growth attenuation procedures. The response stated the legality of the use of Ashley Treatment has not been fully tested in the New Zealand Family Court,¹⁵⁴ and the extent of its use is unknown but deemed to be rare. They confirmed that people who have been subject to this treatment overseas are able to receive medical care in New Zealand on an equal basis with others. There is at least one confirmed instance of a New Zealand child being subject to Ashley Treatment overseas.¹⁵⁵

Comment on the realisation of Article 17 in New Zealand

Although concerns remain about the possible practice of involuntary sterilisation, particularly of disabled girls and women, there is no robust data available on the prevalence of this practice.

Work is planned to involve government and disabled people's organisations in finding ways to address this issue, and to protect disabled people from non-therapeutic sterilisation without the full consent of the individual. The Law Commission has an upcoming programme of work to review laws related to adults with impaired decision-making capacity.

Hundreds of people continue to be subject to compulsory assessment and treatment, seclusion and electroconvulsive therapy under the Mental Health (Compulsory Assessment and Treatment) Act 1992, and the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003. ¹⁵⁶ Forced medication can be regarded as a threat to mental integrity.

Participants at the IMM consultation hui were particularly vocal in their aversion to the use of seclusion or restraint, and the many forms these take on, with one participant saying, 'Stop it! No more. Put it on a T-shirt.'

Recommendations

- 45. Enact legislation to prohibit the use of sterilisation or any other non-therapeutic medical procedure on disabled children and disabled adults without their prior, fully informed, and free consent.
- 46. Improve methods of collecting and reporting on statistics on sterilisation and other non-therapeutic medical procedures in New Zealand, whilst ensuring all data collection is anonymised in such a way to prevent identification.

Article 18: Liberty of movement and nationality

Introduction

This article affirms the right of disabled people to acquire and change a nationality on an equal basis with others, and not to be deprived of their nationality arbitrarily or on the basis of disability.

General comment

The realisation of rights in Article 18 does not always align with New Zealand's laws on immigration.

A joint statement by the Committee on the Protection of the Rights of All Migrant Workers and Members of their Families, and the Disability Committee, highlighted their general concerns regarding issues around identification of, and services to, disabled migrants and refugees in many countries.¹⁵⁷ The joint statement also noted that the situation of disabled people should be addressed as part of a new global framework for refugees and migrants, and that the design and monitoring of this framework should involve disabled people.

Importance of Article 18 to disabled people in New Zealand

Without realisation of these rights, disabled people may experience additional barriers to obtaining citizenship (from the Department of Internal Affairs) or residence (from Immigration New Zealand).

Many in the disability community believe that New Zealand has immigration policies in place that unfairly impact disabled people and their family members. Some disabled people are concerned that New Zealand's immigration policies perpetuate negative stereotypes that devalue disabled people. For instance, there is a perception that disabled people entering New Zealand are seen to be a burden who will place excessive demand on New Zealand society and its resources.

Current place of Article 18 in law and practice

The current legal framework concerning immigration in New Zealand does not fully reflect disabled people's aspirations and rights under Article 18 of the Disability Convention. The effect of the Human Rights Act 1993 and the Immigration Act 2009

means that it is not possible to bring a claim of disability discrimination to the Human Rights Review Tribunal in respect of an immigration decision.

New Zealand does not confer on an applicant for residence (or citizenship) an entitlement to be granted such status, and requirements need to be met. There may also be a residual discretion not to grant either residence or citizenship even if requirements are met, if granting such status is not considered to be in the interests of New Zealand. The Immigration Act effectively permits Immigration New Zealand to discriminate in deciding who should be permitted to enter, and remain in, New Zealand. Provisions of this nature are not uncommon to many immigration systems around the world, but they have the potential to impact disabled people unfairly.

Committee's previous dialogue with the State on Article 18

The Disability Committee did not make any comment on Article 18 in its 2014 *Concluding Observations*.

Comment on the realisation of Article 18 in New Zealand

In recent years, there have been a number of cases reported in the media of disabled people (including families with disabled children born in New Zealand) being refused residence on the grounds of 'not meeting an acceptable standard of health'.

The Immigration New Zealand Operational Manual contains a list of medical conditions deemed to impose significant costs and/or demands on New Zealand's health services. Anyone with one or more of these conditions may be refused residence in New Zealand. A person who is assessed as likely to incur \$41,000 or more in medical costs over a five-year period is deemed to impose significant medical costs, and will ordinarily be required to seek a medical waiver before being granted residence or a temporary entry visa. Immigration New Zealand uses panels of consultant physicians when estimating medical costs.

Excluding disabled people solely on the grounds of disability from entering New Zealand on a temporary or permanent basis is inconsistent with the values associated with international human rights protections such as the Disability Convention. While immigration will necessarily involve the imposition of entry requirements and selection criteria, disabled people should not face additional barriers. In considering whether a disabled person meets health requirements, particularly those relating to residence, there should be an assurance that immigration officers take the Disability Convention into account in determining whether a medical waiver is required, and if so, granted.

Recommendations

- 47. Review relevant legislation and policy to ensure that disabled people do not experience additional barriers over and above others when applying for entry into New Zealand, including but not limited to:
 - a. ensuring that immigration officers have regard to the Disability Convention when making decisions under the Immigration Act; and
 - b. repealing section 392 of the Immigration Act to enable the Human Rights Commission to receive complaints about immigration matters.
- 48. Work with disabled people to create immigration instructions that fulfil the Government's obligations under the Disability Convention and the *Disability Strategy*.

Article 19: Living independently and being included in the community

My son can't do any of this independently; he could [do] with some funding allocated to a door he can open, a ramp he can use, a vehicle that transports him safely. This means as a family we all miss out, as we can't exclude him from what we are doing so we do nothing.

Survey respondent

I need modifications to help but I don't know where to access them. In particular, I struggle to stand in the shower, etc.

Hui participant

I am finding it difficult to find an affordable, adapted flat/house in my area. There is a need to build more universally designed homes and to ensure that modifications can be adequately funded and carried out efficiently and quickly once approval is granted.

Survey respondent

Introduction

Article 19 provides that disabled people have the right to make choices about where they live. Disabled people should have access to support services if they need support to live in the community.

General comment

Even though New Zealand is ostensibly deinstitutionalised, and disabled people are living in the community, there are access and structural issues preventing realisation of Article 19, including lack of accessible housing, limited disability supports, and inaccessibility of community facilities.



Caption: Ian from The Garage Project signs to his Deaf colleague Ryan at the launch of The Garage Project's New Zealand Sign Language Week beer. Photo courtesy of Deaf Aotearoa.

Importance of Article 19 to disabled people in New Zealand

Disabled people believe that it is crucial to be able to live where they choose, and to have the support needed to be able to do this.

Current place of Article 19 in New Zealand law and practice

Aside from people detained under specific legislation such as the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003, and the Mental Health (Compulsory Assessment and Treatment) Act 1992, there is nothing in New Zealand law preventing disabled people from living in the community in a place of their choosing.

However, there are affordability, accessibility, and support issues that often create significant barriers to disabled people being able to realise this right. There is a difference between access to support for people covered under the Accident Compensation Act 2001 and those covered by Ministry of Health funding. There is no legislation requiring that new housing be made accessible.

The New Zealand General Social Survey: 2016 showed that fewer disabled people than non-disabled people have high life satisfaction and a strong sense of purpose. Disabled people also experience longer periods without meaningful companionship.¹⁵⁹

Committee's previous dialogue with the State on Article 19

In its List of Issues, the Disability Committee asked the Government about:

- the *Enabling Good Lives* programme;
- consultation with representative organisations of disabled people, including organisations of persons with psychosocial and/or intellectual disabilities;
- the impacts of the deinstitutionalisation strategy on ensuring inclusion in the community;
- investment in supporting independence in the community using personal assistants, peers and coaching, according to age, sex, and ethnic background;
- affordable and accessible housing including legal requirements and duties of accessibility for private constructors;
- strategies to enhance access to community services; and
- data on the proportion of disabled people whose subjective belief is that society is inclusive and responsive, as well as objective data disaggregated by sex, age, ethnicity, disability, and any other relevant dimensions.

The Government responded with information about the extension of the *Enabling Good Lives* programme including details of budget funding, findings of the 2008 research from the Donald Beasley Institute showing positive effects from deinstitutionalisation, and the pilot of *Choice in Community Living*.

On housing, the Government's response commented on Housing NZ Corporation (now Kāinga Ora—Homes and Communities) houses meeting basic accessibility standards and short-term accommodation requirements, but confirmed that there are no government strategies to ensure accessible and affordable housing, and no legal requirements for new private housing developments to include accessible housing. The Government does fund limited housing modifications, but only through narrow criteria from the Ministry of Health and ACC.

Comment on the realisation of Article 19 in New Zealand

Disabled people experience significant difficulties in obtaining affordable accessible housing which can lead to situations where they find themselves homeless and living rough. Kāinga Ora has some accessible housing stock, but there are long waiting lists. Not all stock deemed to be accessible actually meets the needs of the disabled person to whom it is provided.

Disabled people report that housing modifications paid for by the Ministry of Health are often slow to be implemented, and that private landlords are often unwilling to

have modifications made to their properties. Lack of long-term tenancies means that disabled people may be forced to leave a rental property that has been modified for them, and may not be entitled to further modification grants.

There are instances of disabled people being refused housing by private landlords or letting agents as a result of being disabled, or because of their use of assistance animals such as guide dogs or mobility dogs.¹⁶¹

Funding for support to live independently in the community limits the ability of some disabled people to live where they choose, and to participate in community activities. For a long time, disabled people have voiced concerns over the difference in the level of support and quality of equipment paid for under the Accident Compensation Act 2001, which is viewed as being more generous than the provision made under Ministry of Health–funded disability supports. Many disabled people continue to live in residential services with little choice and control over where, with whom, and how they live. Younger disabled people who require access to 24-hour support continue to find themselves living in aged care facilities because of the lack of support available in the community.¹⁶²

In 2019, there were reports that the Government was proposing to cut back on disability supports to deal with a budget shortfall.¹⁶³ Although this proposal was not implemented, there are still concerns that individuals are having their hours of support reduced on an ad hoc basis, further limiting their ability to live independently and participate in the community. Delays in accessing mobility equipment can also leave disabled people unable to access the community.

Hui participants told the IMM they are happy to be involved in the co-design of new funding and disability support models that should put the individual in control of how their funds are used (including the Mana Whaikaha prototype currently being trialled in the Mid-Central region). However, they remain concerned about the slow progress on implementing the model more widely, and about whether there will be sufficient funding for it to fully enable people to live independently.

Community events and facilities in some regions provide some access for disabled people. However, full community inclusion is limited by the availability of accessible facilities, accessible and affordable transport, and a lack of access to New Zealand Sign Language interpreters, audio description and support workers. People are being directed to online shopping rather than being supported to conduct their own grocery or other shopping in person. Many people struggle to access regular services in the community—not only leisure activities, but also health and dental care—due to lack of funding and limited access to support and transport.

The notion of 'reasonable accommodations', or what constitutes discrimination, are not defined well in many areas of life in New Zealand, including in legislation.

This creates multiple situations where disabled people are forced to advocate for their right to live in a house, stay in a motel or eat in a restaurant, among other examples. The process for resolving such issues can be lengthy, or, in many cases, leads to mediation with the Human Rights Commission which results in either a confidential agreement that cannot be used to settle future disputes, or in no agreement. The one exception to this is in the banking sector, where clear guidelines for accessibility that can be used by customers have been established.¹⁶⁴

Recommendations

- 49. Implement legislation requiring all newly built housing to conform to universal design standards (refer also Article 9).
- 50. Require Kāinga Ora—Homes and Communities to:
 - a. adopt a comprehensive definition of universal design;
 - commit immediately to a policy of implementing universal design in all new housing builds across all housing types;
 - c. commit to replacing or retrofitting all existing housing stock to universal design standards over ten years;
 - d. design a range of accessible specifications for each housing type available (that is, consistent with NZS4121:2001 design standards);
 - e. implement a comprehensive accessibility audit of its housing stock;
 - f. commit to ensuring that a representative proportion of their housing stock is retrofitted to meet accessibility standards (that is, per the accessible specifications developed above), as opposed to solely bespoke customisations. The proportion of accessible houses should, at minimum, be the proportion of Kāinga Ora tenants with an impairment; and
 - g. increase the tenure for any disabled tenants requiring bespoke modifications to ensure they can stay in homes that have been modified to their specifications.
- 51. Revise and/or expand all disability-related equipment and vehicle funding schemes to ensure that disabled people have access to the equipment they need to live independently and access their community.

- 52. Fully implement the recommendations of the 2008 Social Services Select Committee report (*Inquiry into the quality of care and service provision for people with disabilities*)¹⁶⁵ to reduce the number of disabled people forced to live in rest homes.
- 53. Introduce accessibility legislation requiring all community services and facilities to be accessible by disabled people, and explicitly stating what is expected of all service providers.
- 54. As a matter of urgency, develop sustainable and equitable funding models so that all disabled people, irrespective of cause, can access flexible and integrated supports that facilitate independent living and full participation in the community.
- 55. Ensure that central government, local government, and any other housing providers determine the numbers and types of accessible housing in such a way that they can be assessed against the community's need.
- 56. Put more emphasis on the need for housing to be designed and built with accessibility in mind, and ensure disabled people have increased and quick access to sufficient housing modification funds to allow them to move about their own homes safely.

Article 20: Personal mobility

Have an understanding that we need to be able to get out and socialise, not be stuck at home by ourselves. So the priority would be to make it easier for transport, such as making mobility taxis free and being able to stay with you until you are finished if you have a day of several stops to make...Trips that are short stops currently require booking a taxi then waiting around to be picked up, taken to next stop, dropped off, then waiting to be picked up again, etc, making for a very long tiring day, so then it becomes easier to do everything online and become isolated.

Survey respondent

Introduction

This article states that people with disabilities have the right to move about their communities and be independent, and that governments have an obligation to help them to do so.

General comment

Disabled New Zealanders continue to experience frustration in relation to exercising the right to personal mobility—in particular the differences between the equipment, vehicles and modifications available from ACC, compared to Ministry of Health–funded supports.

Importance of Article 20 to disabled people in New Zealand

Personal mobility is vital to disabled people's ability to live safely in their own homes, study, work and participate in the community—therefore, this article is viewed as highly important.

Current place of Article 20 in New Zealand law and practice

Funding for personal mobility aids and training is divided in New Zealand into two groups:

- those who are eligible for support under the Accident Compensation Act 2001;
 and
- those whose funding is covered by the Ministry of Health and district health boards.



Caption: Mary Fisher, pictured here using a cane, is walking along the footpath approaching a yellow tactile strip on Adelaide Road, Wellington. Photo courtesy of Access Alliance. Photographer Victor Komarovsky.

The Government has included references to accessibility of public transport and alternative transport options for disabled people in its policy statement on land transport issued in 2018. Some local authorities also include specific reference to access for people with disabilities, such as Auckland's Transport Alignment Project 2018. As noted in *Article 9* there have been some improvements in the area of public transport, however, disabled public transport users continue to experience challenges on their journeys.

Committee's previous dialogue with the State on Article 20

The Government was asked to comment on measures taken to facilitate personal mobility, and to ensure equity of provision regardless of the cause of impairment. The response included details of Ministry of Health funding for equipment, housing modifications and vehicle purchase or modification, and acknowledged the differences in funding between ACC and the Ministry of Health.

Comment on the realisation of Article 20 in New Zealand

Inaccessible housing, lack of access to personal mobility aids, inaccessible public transport, and unaffordable transport alternatives are some of the greatest barriers to personal mobility for disabled people.

Many people report significant challenges in accessing support to make essential housing modifications to enable them to move safely around their own homes. People relying on Ministry of Health funding report longer delays for modifications, and less access to funding for modifications, which can mean they are living in unsuitable or unmodified homes.

The funding inequity extends to mobility training and access to equipment, with Ministry of Health clients reporting being on longer waitlists, receiving less funding, and being offered fewer equipment choices and cheaper equipment options than ACC clients. Ministry of Health clients who are in work or training tend to be prioritised for funding, which means that many disabled people are on long waitlists for equipment.

The relatively small size of the New Zealand market limits the availability of equipment and provides few incentives for developers, although there are some individual examples of innovative equipment being designed in New Zealand. One example is the Omeo Technology hands-free wheelchair, which uses body motion to allow the user to control and manoeuvre the wheelchair.

Recommendations

- 57. Urgently review and extend investment in subsidised taxi and other travel schemes for disabled people unable to access public transport so they can secure consistent and transferable 24/7 access to a range of transport options nationwide.
- 58. Urge local government to embed accessibility requirements within its procurement processes for public transport to ensure that disabled people have equitable access to public transport.
- 59. Require that all taxi fleets must have all, or at least a substantial proportion of, vehicles that are wheelchair accessible, and ensure those vehicles are available in proportion to the general fleet.
- 60. Set expectation and implementation targets for territorial authorities to ensure that their roads, transport infrastructure, and pedestrian routes are constructed, retrofitted, and maintained to meet accessibility standards.

- 61. Equalise the funding for mobility training and equipment for all disabled people, regardless of the cause of impairment, thus removing the difference between Ministry of Health and Accident Compensation Corporation (ACC) clients.
- 62. Provide additional investment into research and development of mobility aids, and to develop or import innovative mobility aids.

Article 21: Freedom of expression and opinion and access to information

Stop labelling and change language too—all people to have access to information and communication tools and assistance.

Hui participant

Difficult getting accessible information—disabled people need to become visible in our country.

Hui participant

The amount of care taken in regards to accessibility varies a lot across government websites. Some are easy to access, some are harder.

Survey respondent

[Referring to government websites] Not all headings are well marked for a screen reader. Filling out forms can be patchy. Some don't give alternate means of making contact if the site doesn't work. Sometimes hard to complete responses in the right places.

Survey respondent

Introduction

Article 21 provides that people with disabilities have the right to express their opinions, and to seek, receive and share information in forms that they can understand and use.

General comment

This article requires a whole-of-government approach to ensuring accessibility in the two-way flow of information and legislation to ensure that this is extended beyond government and into the broader public arena.

Importance of Article 21 to disabled people in New Zealand

Missing out on information and being unable to express opinions prevent disabled people from participating fully as citizens, and being able to fulfil their rights to interact with government and the wider community.

Current place of Article 21 in New Zealand law and practice

Government agencies are mandated to meet web accessibility guidelines. The Government's Accessibility Charter aims to increase the amount of government information made available in a range of accessible formats.¹⁷⁰

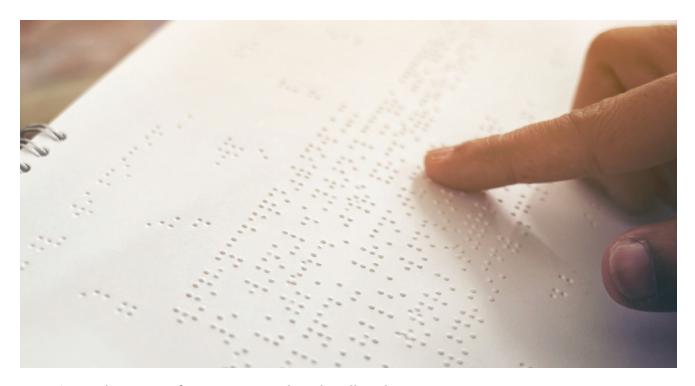
Currently, there are no legal or financial penalties for private companies that do not meet accessibility guidelines in the websites or information they produce. Nor is there a legal requirement for mass media to include accessibility in the content that is available on television or via the internet.

The Government's accession to the Marrakesh Treaty may make it easier to access and share some forms of accessible information.¹⁷¹ The treaty's aim is to allow people who are blind, visually impaired or otherwise print disabled to access books and other literary works in accessible formats.

Committee's previous dialogue with the State on Article 21

In its List of Issues, the Disability Committee questioned the Government on:

- funding for New Zealand Sign Language (NZSL), including interpreters;
- accessibility of information for disabled Māori, in particular those with hearing and vision impairments;
- steps being taken towards making the accessibility of information legally binding, including being able to access information and to convey views in a range of formats such as braille, Easy Read, audio description, and captioning; and
- measures taken to ensure organisations meet web accessibility standards and invest in assistive technologies.



Caption: Close-up of a person reading braille. Photo source www.twenty20.com.

The Government's response highlighted increased funding of \$30.2 million for sensory schools and NZSL in the 2018 Budget, and \$1.25 million in funding through the NZSL Board Strategy 2018–2023.¹⁷² It acknowledged the shortage of NZSL interpreters, particularly trilingual interpreters. There was also recognition of challenges around the proficiency and fluency of interpreters, and the variation in access to qualified NZSL interpreters based on geographic location. The needs of Deaf Māori and Pacific peoples are included in the priorities of the NZSL Board, but there is no specific funding for access to information for Māori and Pacific people.

The Government's response to the Disability Committee notes that the use of NZSL is increasing, including more schools offering NZSL, and also notes the likely increase in demand for interpreters through individualised funding.

The Government reports that it hopes that the introduction of its Accessibility Charter will provide increased access to information, with a focus on increasing provision of government information in Easy Read, braille, NZSL, and audio formats.

Government funding of \$2.8 million was provided in 2019 for television captioning and audio description. Currently this funding is only allocated on a year-by-year basis, with no assurance provided to the agency contracted to deliver captioning and audio description services that this funding will continue beyond each financial year.

Comment on the realisation of Article 21 in New Zealand

Although government agencies have been required to meet web accessibility guidelines since 2017, there are still aspects of government information that are not

available in accessible formats. The Accessibility Charter should help ensure that more government information is provided in accessible formats.¹⁷³

NZSL interpreters are now used at the Prime Minister's post-cabinet press conferences, and were used in 2019 for many public announcements, including events following the Christchurch mosque shootings.

Captioning and audio description are limited to a few television channels. Some captioning, but no audio description, is available on TVNZ OnDemand television accessed via the internet.

The Government has ratified the Marrakesh Treaty, and the Copyright (Marrakesh Treaty Implementation) Act was granted Royal Assent on 12 August 2019. This treaty was adopted to amend copyright law in such a way as to allow access to printed works by providing them in accessible formats. The Government is considering implementing accessibility legislation that could have a positive impact on the realisation of Article 21.¹⁷⁴

Although progress is being made, participants at the IMM consultation hui expressed their frustration at the lack of accessible information available to ensure full access to community life. Some reported difficulties arising when using new technologies with automation, making access to some services difficult or even impossible, saying, 'Bring back the people—it can make the process [much] easier than a robot'.

Recommendations

- 63. Expand the Accessibility Charter to include local authorities and district health boards.
- 64. Pass accessibility legislation requiring private providers of information, websites, and mass media to include accessibility.
- 65. Enable disabled people to communicate more effectively with government agencies by increasing the number of accessible formats available so that disabled people can express their views in New Zealand Sign Language, and use braille, Easy Read and audio formats to engage fully.
- 66. Increase access to information and communication for disabled Māori, including increased provision of interpreting, captioning, audio description, and Easy Read in te reo Māori.

Article 22: Respect for privacy

I cannot access anything I would like to access without support from another person.

Hui participant

Introduction

This article notes that a person must not interfere in another person's private affairs, whether they have disabilities or not. People who hold information about others, such as their health status, should keep this information private.

General comment

Disabled people are often required to interact with a number of agencies (government and non-government) to receive support, and so privacy of information and rules around how information is shared are important to protect the rights of individuals.

Importance of Article 22 to disabled people in New Zealand

Disabled people have the right to have their information kept private—in particular their health and disability information.

Current place of Article 22 in New Zealand law and practice

In New Zealand, an individual's rights of access to their own personal information is governed by the Privacy Act 1993. The Privacy Commissioner has the power under this Act to issue Codes of Practice that set rules on how different kinds of information, including health information, must be treated, and to investigate breaches of these rules.

Committee's previous dialogue with the State on Article 22

In the Government's first report to the Disability Committee, it outlined general rights under the Privacy Act and specific rights relating to health information. It also mentioned a review undertaken by the Law Commission leading to the Government of the time considering using technology to share health information.

Comment on the realisation of Article 22 in New Zealand

Concerns about privacy for disabled people fall into four main categories:

- organisations' and individuals' failure to maintain appropriate standards of privacy;
- difficulties experienced in exercising privacy rights;
- the need to involve third parties in private matters due to inaccessibility of information; and
- repeated requests for proof of eligibility.

Under the Privacy Act, agencies must follow rules when dealing with personal information. In reality, many disabled people report frequent breaches of their privacy. The IMM is aware of anecdotal instances of service providers sharing information about disabled people without permission:

- a homecare coordinator notified the client's babysitter, who answered the home phone, of changes to support worker schedule;
- taxi drivers discuss the other disabled people they have taken on trips in the past week; and
- staff gossip about clients in the canteen area.

These breaches, while not always of a serious or personal nature, create a sense that the lives of disabled people are scrutinised and public in a way that the lives of others are not. During consultation hui and survey to inform this report, some disabled people also reported concerns that their private information is passed on to third-party organisations without their permission when their services are outsourced from their main service provider to other contractors.

People with mental health diagnoses report that the inappropriate sharing of sensitive information leads to them feeling stigmatised and being discriminated against by service providers, in particular non-health agencies.

Disabled people have been affected by the Ministry of Social Development's investigations into the private affairs of beneficiaries—a practice found by the Privacy Commissioner to have breached the Privacy Act. 175

When privacy rights are breached, disabled people report challenges with having their complaints heard and resolved. Service providers are reportedly often

unwilling to resolve matters, and complainants are sent to the Health and Disability Commissioner's Office or the Privacy Commissioner—requiring them to further disclose personal information in order to have their complaint heard.

Some disabled people report that when attempting to exercise their rights to access information held about them (as guaranteed under the Privacy Act), the information is provided to them in inaccessible formats.

While some progress has been made in enabling disabled people to provide and access their information in accessible formats, overall progress in this area is slow. The majority of application forms for support services or financial assistance, and information received from government and other agencies, are inaccessible to many disabled users. This means involving a third party when communicating with government departments and other agencies. Many disabled people, when using technology, would prefer to be able to complete forms online using accessible websites, and receive information by accessible email rather than, for example, asking a family member to read their medical test results.

Disabled people reported that they are often required to provide repeated copies of medical verification to prove their eligibility for supports. This means that their private disability information is accessed by more people than might be necessary, and increases the risk of privacy breaches. The Social Investment Agency (SIA) is working on the Data Protection and Use Policy to support New Zealanders to navigate the social sector more easily. It will also help those working in the sector to work collaboratively to improve services for all New Zealanders. Disabled people have been involved in the consultation process, and, once implemented, it is hoped this will work to reduce some of barriers disabled people face when trying to access services and information.

Recommendations

- 67. Conduct an audit and/or situational analysis of disabled people's experiences with privacy and information sharing.
- 68. Instruct all public sector agencies to ensure that any personal information they gather or hold about disabled people is secure, accessible and constitutes the least amount of intrusion necessary.

- 69. Ensure public sector agencies and service providers understand their responsibilities under the Privacy Act 1993 and the Health Information Privacy Code, and be required to demonstrate they have robust training and privacy policies in place in order to receive government funding—particularly in cases where services are outsourced to third parties. This should include improved complaints procedures, and assurances that information provided to complainants will be sent in accessible formats.
- 70. Instruct public sector agencies to provide all official documents in accessible formats, with the option to complete them online, using New Zealand Sign Language, or with the assistance of appropriately trained staff.
- 71. Ensure that the amount of medical data that disabled people are required to provide in order to access services and supports is reviewed and reconciled with a view to reducing repetition, only obtaining necessary information, and ensuring secure data-sharing mechanisms are in place.

Article 23: Respect for home and the family

...Important to recognise that disabled people need to have opportunities to learn more about parenting, reproduction, etc. This is especially important for people with cognitive impairments (autism, learning disability) because their understanding can be distorted due to not having information available to them in ways they can understand.

Survey respondent

Introduction

This article states that people with a disability have the right to live with their families. Governments should assist families with disability-related expenses and services. If a person with a disability cannot live with their immediate family, the Government should help to arrange care within the wider family or community. The article also states that people with a disability should have the same rights as everyone else to reproductive health information, and the ability to marry and start a family.

General comment

Realising this right means supporting disabled families in all their forms, and valuing the role of disabled people as parents and caregivers as well as recipients of care.

Importance of Article 23 to disabled people in New Zealand

Disabled people believe the right to live with their family and to start their own family is vital to society recognising the equal value of disabled people.

Current place of Article 23 in New Zealand law and practice

Changes to the Oranga Tamariki Act 1989 repealed two discriminatory sections (141 and 142) in July 2019. These sections allowed parents to place their disabled children in out-of-home care facilities outside of the mandate of the State care system. These changes recognise that disabled children have the same rights as others to live with their families, and to be safeguarded by Oranga Tamariki—Ministry for Children.

The Adoption Act 1955, while not preventing disabled people from adopting children, still includes two sections that may discriminate against disabled people.

- Section 8 allows adoptions to take place without the consent of the parent if the parent is deemed unfit by a court due to lack of mental or physical capacity that is likely to continue indefinitely. The Government has no plans to review this section.
- Section 11 requires the court to determine whether prospective adoptive parents are deemed to be of 'sufficient ability to bring up, maintain and educate the child'.

Current disability support practice does not adequately recognise the role of disabled people as caregivers or parents, and thus creates barriers for people trying to form their own families.

Committee's previous dialogue with the State on Article 23

In its List of Issues, the Disability Committee asked for information on:¹⁷⁷

- a. Measures adopted for re-examination of two statutes, the Children, Young Persons and Their Families Act 1989 [now Oranga Tamariki Act 1989] and the Vulnerable Children Act 2014, to ensure that children with disabilities have the same safeguards as other children when they are placed in out-of-home care;
- b. Measures taken to repeal section 8 of the Adoption Act 1955 and to amend the statute, to ensure that persons with disabilities are treated on an equal basis with other applicants for adoption;
- c. Measures taken and any legal and policy requirements placed to ensure that doctors and other medical professionals provide full information to people who receive positive prenatal test results for disabilities, particularly Down's syndrome.

The Government responded by stating there are no plans to review the Vulnerable Children Act 2014 or section 8 of the Adoption Act 1955. As noted above, sections 141 and 142 of the Oranga Tamariki Act have been removed from the legislation. In relation to prenatal screening, the Government confirmed that rates were increasing and that contact details for the New Zealand Down Syndrome Association are provided to parents who receive a positive diagnosis.

Comment on the realisation of Article 23 in New Zealand

It is positive that sections 141 and 142 of the Oranga Tamariki Act 1989 have been repealed, affording disabled children the same rights as others with regard to out-of-home placements. However, there remain concerns about the suitability and availability of placements for disabled children taken into care, including their ability to be placed in families alongside their non-disabled siblings.

There also remain concerns that some disabled children, who could otherwise live at home, attend residential special schools as a result of insufficient support being available to enable those children and their families to live together.

There are still concerns that disabled parents, particularly people with intellectual impairments, are at increased risk of having their babies removed at birth and permanently placed with other caregivers (including by adoption) without their consent, due to the lack of support available to assist with parenting. Additionally, disabled people hoping to adopt are concerned that they will face additional scrutiny.

Disabled parents and families with disabled children both report struggling to access the support they need. This includes insufficient financial support for caregivers with disabled family members and a lack of support for disabled people in their role as parents. For example, there are challenges accessing funding for New Zealand Sign Language interpreters to enable disabled people to attend Playcentre meetings and training,¹⁷⁸ or participate in parents' events in schools.

Recommendations

- 72. Ensure disabled people's whānau receive financial and other supports necessary to care for their children—including, but not limited to, assistance at home, accessible parenting courses, and access to communication support such as New Zealand Sign Language interpreters.
- 73. Ensure disabled children's right to remain in the family home is protected through the provision of financial and other support to their families.
- 74. Provide to the IMM evidence that confirms no children are being uplifted from a home situation solely on the basis of disability of any member of the family or whānau, or because of inadequate support.
- 75. Review the Adoption Act 1955 to ensure conformity with the Disability Convention. In particular, act without delay on earlier IMM recommendations to review sections 8 and 11 of the Adoption Act to prohibit adoptions being made on the basis of disability alone or without consent of the parent.
- 76. Ensure that court personnel and those furnishing reports to them are provided with training about disability rights and the Disability Convention, to ensure a human rights approach is adhered to.

Article 24: Education

Too few people delivering too many services.

Hui participant

The modern learning environment was a nightmare for our foster daughter. She flew under the radar, lost in a classroom of 70 with three roaming teachers. She wasn't able to be an independent learner and her anxiety was huge. She got to be in a structured supported learning environment at her new school and it transformed her learning.

Survey respondent

My child was considered unable to achieve at senior high school by his mainstream teachers. Once he was supported by another teacher, he was able to achieve.

Survey respondent

More support to go on courses with non-disabled people. I did the Health Living Course through Sport Wellington last year. It was wonderful! I now get better results with my health. This started when I asked my doctor for a Green Prescription.

Survey respondent

[My] daughter is not entitled to any funding to support her despite having FASD (Fetal Alcohol Spectrum Disorder) intellectual disability and severe speech and language disorder and being five years behind in the curriculum...

Survey respondent

Lack of appropriate resources, not enough NZ Sign tutors. Need to be high standard of interpreters and teachers who are hearing, working with Deaf students. Seen too many hearing teachers, not enough NZ Sign Language, and often don't understand the Deaf students who try to communicate with them.

Survey respondent

Introduction

Article 24 recognises disabled people have the right to access an inclusive, quality education on an equal basis with others. Reasonable accommodation of students' requirements, and the right of students to receive support, should be consistent with the goal of full inclusion.

General comment

This article places an obligation on governments to ensure that disabled people are not excluded from the general education system and are not excluded from free and compulsory primary and secondary education on the basis of disability.

Importance of Article 24 to disabled people in New Zealand

A truly inclusive education system ensures disabled children and students are given the same opportunities as their non-disabled peers to reach their full potential, in order to participate fully in their community life, and in particular in employment later in life.

Current place of Article 24 in New Zealand law and practice

An inclusive education system that meets the requirements of Article 24 of the Disability Convention must demonstrate:

- equality of access to an inclusive, quality education;
- reasonable accommodation of the requirements of disabled students;
- the delivery of support within the general education system; and
- support measures that are effective, individualised, provided in an environment that maximises academic and social development, and consistent with the goal of full inclusion.

Without access to adequate education, disabled people have diminished prospects of gaining employment and taking part in economic, political, and policy discussions. Education plays an important role in social development and interaction. The lack of realisation of this right causes significant, ongoing, and generationally negative impacts for a large proportion of disabled people.

The Disability Committee has described the following four principles (the four 'A's) as central to an inclusive education framework.¹⁷⁹

- Availability—this requires that 'functioning educational institutions and
 programmes must be available in sufficient quantity'. This includes teaching staff
 and resources. In order to ensure that the quantity of services is sufficient to
 meet needs, accurate data gathering and monitoring are required.
- Accessibility—this requires that the entire inclusive education system is accessible, including:
 - buildings and physical infrastructure;
 - information and communication systems;
 - transport systems and services;
 - support services and reasonable accommodation in all educational environments, including sport and recreational programmes and facilities; and
 - economic accessibility in the form of free primary education and (ideally) free secondary education.
- Acceptability—this entails 'an obligation to design and implement all educationrelated facilities, goods and services in a way that takes full account of and is respectful of the needs, expectations, cultures, views, and languages of persons with disabilities'.
- Adaptability—this requires an education environment that can be adapted to the diverse needs of students. The Disability Committee encourages the application of the Universal Design for Learning (UDL) principles, which provide teachers with 'a structure to create adaptable learning environments and develop instruction to meet the diverse needs of all learners'. The Disability Committee also encourages a move away from standardised assessment and testing towards recognition of individual progress towards broad goals, alternative routes for learning, flexible instruction, and multiple forms of student assessment.

In 2016, the Disability Committee released a *General Comment* on the right to inclusive education. The *General Comment* examines how inclusion and reasonable accommodation could, and should, operate at all levels of an education system.

The systemic issues with inclusion in New Zealand's education system have been articulated and explored in a number of reviews and reports.¹⁸¹

Committee's previous dialogue with the State on Article 24

The Disability Committee has previously expressed concern that there is no enforceable right to inclusive education. It had recommended further work to

establish an enforceable right to education, to increase the provision of reasonable accommodation in primary and secondary education, and to increase the levels of entry into tertiary education for disabled people.

In 2016, the United Nations Convention on the Rights of the Child Committee recommended that the ongoing review of the Education Act 1989 comply with the provisions and principles of the Disability Convention. In 2018, the International Covenant on Economic, Social and Cultural Rights Committee recommended that New Zealand's domestic legislation needed to be consistent, notably some provisions of the Humans Rights Act 1993 and Education Act 1989 related to the rights of disabled people.

The Government indicated there is already an enforceable right to education in the Education Act. When considering all the evidence related to outcomes for disabled people in the education system, the IMM disagrees with this assertion. This statute, as a principal means of protection, has not demonstrated its effectiveness in practice in aiding parents, their disabled children, and families to enjoy a right to an inclusive education.

Comment on the realisation of Article 24 in New Zealand

In 2016, the IMM noted that:

- the right to an inclusive education is not legislated for; nor is it appropriately incorporated in policy strategies and plans;
- there is a lack of structured coordination and decision-making between disability and education sector groups;
- data-collection processes that enable effective assessment and monitoring of progress are not robust;
- nothing has happened in the subsequent three years to address those concerns;
 and
- the realisation of this article is difficult to track, given a lack of quality education disability data. We need to know which individuals need what support.

Since 2016 there have remained significant outstanding issues in inclusive education for students with disabilities in New Zealand. These include:¹⁸²

 resourcing frameworks that are not based on accurate prevalence data, and there are no mechanisms in place to respond to increased student roll or need growth;

- significant under-resourcing over a long period of time (schools forced to source money from other parts of school budget);
- significant and historical underfunding of NZSL interpreters that prevents Deaf children and young people being able to fully engage in their studies. For example, teacher aides who often support deaf children and students often have lower sign language skills than the student's own NZSL language capabilities;
- lack of meaningful options for children and their families (choice between potentially poor experience in mainstream school/classroom or being segregated into special schools);
- delayed identification or diagnosis (long waiting lists and then insufficient services to respond);
- an Ongoing Resourcing Scheme that is inaccessible to many people;
- lack of timely responses for specialist interventions and supports;
- delays in making the necessary adjustments to school property;
- poor remuneration of teacher aides, a shortage of other support staff, lack of investment in training, and insufficient hours of support. This means disabled children are excluded from social events and/or sent home early, resulting in many families being forced to become single-income families or being asked to pay for teacher aide hours;
- teachers' having inadequate training and resources to respond adequately to children's needs. Some teachers report that the current Code of Professional Responsibility and Standards for the Teaching Profession is not conducive to building confidence for staff on the ground dealing with these complexities;
- a lack of prevalence data and a lack of information about disabled children and young people's participation and educational outcomes. In response to an IMM data request, the Ministry of Education confirmed a lack of quality education data disaggregated by disability;
- lack of appropriate resourcing and planning for transition points (early childhood to primary, primary to secondary, and end of school to employment);
- anecdotal evidence of disabled children being discriminated against (with 'suggestions' for them to go to another school and/or to be excluded from other parts of the school system);

- anecdotal evidence that disabled children feature disproportionately highly in exclusion statistics;¹⁸³
- disabled children being overrepresented in bullying and victimisation numbers;
- low aspirations of some teachers and parents;
- a lack of accountability in the system for the outcomes of disabled young people;
 and
- a lack of visibility of disabled children in school reporting (presence, participation and achievement).

Responses outlining wide-ranging education challenges that the IMM received in its consultation survey reflect the systemic nature of the issues. People raised practical concerns such as a lack of individualised support, a lack of New Zealand Sign Language interpreters and other communication resources, a lack of assistance and peer support to navigate support and options, and a need for increased training for teachers on inclusion. One parent on the IMM's online survey said the system made a person feel as if 'you had to be grateful for any support you receive'. Many people noted being made to feel unwelcome if they had a disability, as well as noting the stigma, self-doubt, and lack of confidence that can result from a non-inclusive system.

Funding criteria for support for disabled students in education can be confusing and disempowering. Some conditions such as Fetal Alcohol Spectrum Disorder (FASD) receive little or no support. It can be unclear to people whether it is the Ministry of Education or Ministry of Health that is meant to be providing support for a particular condition. The thresholds to receive support can be set too high: 'What happens when people are not funded because they are not disabled enough?' 184

The educational structure continues to focus on teaching the 'normal' child and fitting the disabled learner into the school, with some measures put in place to cater for a disabled learner's needs. For the education system to work for all learners, it needs to be fully inclusive by recognising and understanding the full breadth of diversities within our educational settings. Evidence suggests teaching to the 'norm' disadvantages many students.¹⁸⁵ In short, New Zealand's education system needs to move from an exclusionary system to a fully inclusive one.

Some recent initiatives have signalled a perceived worrying return, in some part, to more segregated education practices. The IMM acknowledges—particularly in the *Learning Support Action Plan* stated desire by the Government to better identify people who need support (particularly those who are neurodiverse), and to provide

them that support at the right time and in the best way. However, these initiatives have not been co-designed in their adoption or implementation. They are yet to be scaled into other education workstreams, and there appears to be no systemic response to this issue across government.

The Government is progressing significant reform to the education system across multiple levels. It is widely accepted that the current education system does not adequately address the needs of disabled young people. The IMM acknowledges the potential for these reforms to address many of the current issues. The reforms have a 30-year vision, so it will be critical that the most significant issues affecting disabled young people are addressed with some urgency.

The Government is involving disabled people in various parts of the reforms; however, at this point it is not clear what the meaningful systemic change will be for all disabled children and young people in the education system and their families.

The Government needs to address underlying attitudes and discrimination, building teacher competence in disability matters, visibility, aspirations, and accountability for non-inclusive behaviours from school leaders and staff. Small-scale interventions, such as better coordination of existing services and supports, or more spending on existing property, are not enough. Mechanisms such as the *Code of Professional Responsibility and Standards for the Teaching Profession* should be updated and strengthened to refer to challenges to inclusion identified by the sector.

If meaningful co-design is adopted in the education space, the shape of recent education reform decisions may track in a more positive direction. The Ministry of Education should establish a multi-sector Inclusive Education Advisory Group comprised of disability and education sector groups.

Recommendations

- 77. Urgently introduce an enforceable right to inclusive education as a key element of the legislative framework, and ensures resource to attain equitable access.
- 78. Build co-design into every stage of the education reform process.
- 79. Establish a reference group, including disabled people via their representative organisations and reporting directly to the Minister(s) of Education, to work on key education initiatives.

- 80. Review, as a priority, existing learner support funding models to ensure they provide meaningful support to enable all disabled students to participate equitably in education.
- 81. Ensure that the implementation of proposed complaint and dispute resolution panels include co-design with disabled people and whānau to ensure there will be timely and effective responses where there is a lack of reasonable accommodation, as well as timely and effective remedy and redress.
- 82. Ensure there is safe and secure data and information sharing from a rights-based perspective.
- 83. Introduce and bolster meaningful training, development and progression for teachers and education leaders to ensure they are welcoming and inclusive of diverse children, including those with neurodisabilities or invisible disabilities.

Article 25: Health

People are left on their own with no company or stimulation. People get bored, and frustrated. Then if they get distressed, the anger and frustration gets blamed on the condition.

Hui participant

Assumptions and stereotypical thinking. I have a mental health issue [this] does not mean that I am going to go out and strip naked or kill someone. Get educated, know me.

Survey respondent

Access to low-cost healthcare, often I put off going to doctor due to cost of appointment and medications, my medical conditions have had a negative impact on my teeth which now require a lot of work; however, this is not subsidised. Limited flexibility in education or employment to cope with health challenges and recover when unwell.

Survey respondent

Introduction

Article 25 recognises that disabled people have the right to enjoy the highest attainable standard of health without discrimination on the basis of disability. Health services for disabled people should be free or affordable, responsive to issues of gender, and of the same range and quality as those available to non-disabled people.

General comment

It is important that disabled people are able to achieve the highest possible level of both physical and mental health. To achieve these rights, it is important that healthcare professionals are trained to provide disabled people with the same quality of care as non-disabled people, on the basis of free and informed consent. Health services and treatment should also be available for people who have specific impairments, and services should ensure health conditions are identified, and supported, at an early stage.

Importance of Article 25 to disabled people in New Zealand

There are well over one million disabled people in New Zealand. People with a disability, particularly a learning/intellectual disability, have significantly worse health outcomes than the general population in New Zealand, including lower life expectancies and an increased risk of chronic health conditions. Māori and Pacific peoples have higher rates of disability than the general population and poorer health and disability outcomes in multiple areas.

Current place of Article 25 in law and practice

Outcome 3 of the *New Zealand Disability Strategy 2016–2026* deals with *'health and wellbeing'*. It focuses on removing barriers to disabled people accessing mainstream health services, and ensuring information about health and disability services is provided in accessible formats. Outcome 3 also stipulates that members of Māori and Pacific communities should be respected and have access to culturally appropriate services.

The Code of Health and Disability Services Consumers' Rights¹⁹¹ (the Code) provides for 10 specific rights when accessing a health or disability service in New Zealand. The Health and Disability Commissioner's (HDC) Office considers complaints about breaches of the Code, and received 92 complaints about disability service providers between 1 July 2018 and 30 June 2019. The Nationwide Health and Disability Advocacy Service¹⁹² (the Advocacy Service) received 181 complaints about disability services in the same period. The HDC's 2018 annual report provides further analysis of the disability-related complaints received by the HDC and the Advocacy Service over that period.¹⁹³

Action Item 9(c) of *New Zealand's Disability Action Plan 2014–2018* sought to improve access to health services for people with intellectual/learning disabilities. The IMM has been informed that government ministers have received advice on proposed actions to improve the health outcomes and access to services for people with intellectual/learning disabilities; however, this is yet to be shared with the IMM.

Committee's previous dialogue with the State on Article 25

In its 2014 Concluding Observations, the Disability Committee noted its concern that barriers still exist preventing disabled people—especially disabled people with an intellectual/learning disability—from fully accessing healthcare services, including sexual and reproductive care. The Disability Committee recommended that further measures be taken to provide access to full healthcare for all disabled people.

At the same time, the Disability Committee recorded its concern that Māori have the poorest health outcomes in New Zealand. The Disability Committee also expressed concern that the prevalence of disability is higher in the Māori population as a result

of socioeconomic disadvantages. The Disability Committee recommended that measures be strengthened to enhance the health outcomes of disabled Māori and Pacific peoples.

Comment on the realisation of Article 25 in New Zealand

Considerable work is needed to ensure that disabled people have health outcomes similar to New Zealand's general population, and the disability community reports that it remains concerned about the lack of progress in this area.

The IMM continues to have significant concerns about health inequities of those with intellectual/learning disabilities.

The Government has acknowledged that health inequalities are most pronounced for Māori, compared with other population groups. The Government is currently developing a Māori Health Action Plan to implement its Māori Health Strategy. Whaia Te Ao Marama 2018–2022: Māori Disability Action Plan was updated in April 2018.

The Waitangi Tribunal is conducting a *Health Services and Outcomes Kaupapa Inquiry* (Wai 2575) based on the persistent inequities experienced by Māori. Phase 1 highlights significant areas of concern affecting primary care and Phase 2 will address outcomes affecting disabled Māori. The *Pathways to Pacific Health and Wellbeing* is also being updated to support better outcomes for Pacific disabled people.

The Ministry of Health has made significant progress in adopting processes of codesign through its design work as part of transforming the disability system using *Enabling Good Life* principles. However, the Ministry has yet to ensure that these same principles and practices are enshrined into the development and implementation of legislation and policies, and other decision-making processes across the health and disability system, as required by Article 4(3) of the Disability Convention.

In regard to adequate representation of disabled people in governance functions within the health and disability system, under the provisions of the Public Health and Disability Act 2000, the Minister of Health has power to appoint members to a range of boards, committees and other health and disability governance bodies. These include ministerial committees, district health boards, boards of other publicly owned health and disability organisations, and boards of health inquiry. Disabled people's representation on health and disability governing bodies is not specifically mandated, disability status of members is not routinely collected, nor is representation monitored. Further, where information on disabled people's representation is available, the extent of that representation is inequitable, and risks being tokenistic, as experienced by Māori and Pacific leaders in similar situations.^{194, 195}

Similarly, although district health boards are required by the Public Health and Disability Act to have a Disability Support Advisory Committee to advise the board on the provision of effective disability services, membership of disabled people is not required under the Act.

The Public Health and Disability Act provides that the district health boards are responsible for, among other things, 'promot[ing] the inclusion and participation in society and independence of people with disabilities'. However, the Ministry of Health funds Disability Support Services directly, rather than via the district health boards—resulting in a lack of clarity about the role of the district health boards in relation to their obligations for providing disability-related supports. This is in spite of section 22(1)(c) and (d) of the Public Health and Disability Act which provide that a DHB has the following objectives to promote:

- effective care or support for those in need of personal health services or disability support services; and
- the inclusion and participation in society and independence of people with disabilities.

Recommendations

The IMM recommends that the Government:

- 84. Reform the Public Health and Disability Act 2000 to introduce provisions to ensure disabled people are meaningfully represented in governance roles across the health and disability system.
- 85. Advance innovative models of funding for integrated and flexible disability support, and provide adequate resourcing of those models, so that disabled people are able to enjoy the highest attainable standard of health; including but not limited to accelerating equitable access nationally to an *Enabling Good Lives* approach.
- 86. Take definitive action to clarify the expectation on district health boards to provide disability-related supports, particularly in relation to section 22(1)(c) and (d) of the Public Health and Disability Act 2000.
- 87. Implement earlier recommendations of the IMM to address inequities in life expectancy for disabled people, particularly people with intellectual/learning and psychosocial disabilities. Work with disabled people and their representative organisations to establish a comprehensive health improvement and monitoring programme.

- 88. Act on the outcomes of Phase 1 and upcoming hearings of the *Wai 2575 Health Services and Outcomes Kaupapa Inquiry*.
- 89. Ensure that the development of initiatives targeting equitable health service access for disabled people are co-designed with disabled people.
- 90. Ensure a co-design process with people with psychosocial experiences in the implementation of the recommendations of the *He Ara Oranga: Report of the Government Inquiry into Mental Health and Addiction*, ¹⁹⁷ and ensure that they are appropriately resourced to carry out this work.

Article 26: Habilitation and rehabilitation

[We need] infrastructure and support workers to allow independence and accessibility.

Hui participant

Quit trying to fit us all into a one [size] fits all. We are all different. We like to be as independent as we can, but that doesn't mean we are not struggling. Help us to be the individual we desire and don't try and fix us, just be there to catch and assist.

Survey respondent

Introduction

Article 26 states that disabled people should be able to attain and maintain maximum independence, full physical, mental, social and vocational ability, and be included in all aspects of life. Support should be provided to organise, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education, and social services.

General comment

It is essential that disabled people have access to habilitation and rehabilitation of a high standard. To achieve this, it is important that habilitation and rehabilitation services commence at the earliest stage possible, and that they take a multidisciplinary approach to individual needs and strengths. Disabled people must also be supported to participate and be included in all aspects of society. It is important that the Government promotes the development of training for professionals and staff working in these services. The Government should also encourage the availability, knowledge, and use of assistive devices and technologies designed for disabled people who access rehabilitation support services.

Importance of Article 26 to disabled people in New Zealand

Ensuring that appropriate and accessible habilitation and rehabilitation services are available to disabled people is essential to support their physical, sensory, intellectual,

psychological, and social needs. Effective rehabilitation can provide the tools disabled people need to attain independence and self-determination.

Current place of Article 26 in law and practice

The Government has advised the IMM that it funds a range of habilitation and rehabilitation services to assist disabled people to remain in, or return to, their home or community, live independently, and participate in education, the workforce, and civic life. Some examples include:

- treatment and rehabilitation services;
- equipment and modification services;
- rehabilitation services for intellectually/learning disabled offenders; and
- a low vision rehabilitation service.

The Government's main rehabilitation funders are:

- district health boards, which fund health, mental health, and age-related rehabilitation;
- ACC, which is responsible for injury prevention, rehabilitation, and support for injury-related needs;
- the Ministry of Health, which funds disability-specific rehabilitation, including assistive technology for people with physical, intellectual and sensory impairments, and housing modifications;
- the Ministry of Social Development, which funds income, and vocational and community participation assistance and supports; and
- the Ministry of Education, which funds rehabilitation for learning support (previously known as special education).

Much of this government-funded rehabilitation work is carried out by disability service providers through contractual arrangements. Many of these organisations also provide such services through their charitable funding.

Committee's previous dialogue with the State on Article 26

The Disability Committee did not make any explicit recommendations concerning Article 26 in its 2014 *Concluding Observations*. However, the Disability Committee did

comment under Article 13 (Access to justice) that ACC appears to lack a human rights focus, and there appears to have been insufficient consultation with persons who have acquired disabilities through injury.

Comment on the realisation of Article 26 in New Zealand

The Government endorsed the draft of the *Western Pacific Regional Framework on Rehabilitation in 2018.* This framework notes the increasing demand for quality rehabilitation services in the Western Pacific Region, and outlines the challenges associated with strengthening health systems in order to improve services. The Government has indicated that it had expected to conduct a baseline country rehabilitation survey in 2019 but this has been delayed. The Government reports that a survey will help to strengthen national rehabilitation services in line with the United Nations Standard Rule 3, which specifies that countries:¹⁹⁹

...should ensure the provision of rehabilitation services to people with disabilities in order for them to reach and sustain their optimum level of independence and functioning.

There has been some concern expressed by members of the disability community around inequities in the provision of rehabilitation services by ACC, compared with other government-funded rehabilitation services. For instance, those who become injured or impaired as a result of an accident generally receive prompt and intensive support and/or treatment from ACC. However, people who are born with a disability, or those who acquire an impairment without an accident, are usually unable to receive services from ACC, and instead access rehabilitation services through district health boards, the Ministry of Health, the Ministry of Social Development and the Ministry of Education. This process can be complex and confusing, and disabled people widely report that it results in the provision of less intensive and less professional services. This system appears to discriminate based on the cause of disability.

Recommendations

The IMM recommends that the Government:

91. Act on earlier IMM recommendations to address disparities between habilitation and rehabilitation services funded by ACC and those services funded by other government agencies, to eliminate inequities in level and standard of services. Particular consideration should be given to disabled people born with an impairment, and those who acquired an impairment without an accident.

- 92. Ensure all disabled people have access to high-quality habilitation services and other preventive measures to proactively address and mitigate progression of impairments with a view to maintaining maximum independence, inclusion and participation in all aspects of life.
- 93. Broaden access to, and adequately resource, a comprehensive range of habilitation and rehabilitation services to enable disabled people to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.

Article 27: Work and employment

Focus on what an individual is able to do.

Hui participant

Employment discrimination is not going to disappear overnight—in fact, it may take decades to reach employment equity for disabled people.

Survey respondent

I am in full-time employment and wanting to progress my career by doing professional development courses. However, there is no clear funding for New Zealand Sign Language interpreters for ongoing professional development education, and I'm constantly struggling to find funding and ways around the current rules. Existing funding for employment support costs is limited and capped, and I have used all the allocated funding available to me. Ongoing education and training is important, but I am clearly discriminated and disadvantaged in this area.

Survey respondent

Discrimination due to lack of understanding by employers.

Hui participant

Introduction

Article 27 affirms disabled people's right to enjoy, on an equal basis with others, decent, freely chosen work and favourable conditions. To ensure realisation of this right, the Government's obligations include:

- ensuring disabled people are protected against discrimination in employment, and are provided reasonable accommodation;
- employing people in the public sector; and
- promoting the universal right to employment in the private sector.



Caption: Woman using an Omeo chair tends to her horse. Photo courtesy of Omeo Technology.

General comment

The right to work, to equal opportunity and to fair conditions in work are all important to disabled people. Work can be a source of social connection and identity, and it is a vital component of an adequate standard of living. This right also provides a means to exercise other rights such as choice of living arrangements and full participation in the community.

Importance of Article 27 to disabled people in New Zealand

In New Zealand, as in many comparable middle-income countries, disabled people have considerably (26 percent) lower rates of labour force participation than non-disabled people.²⁰⁰

This inequity has persisted for decades and has been noted in previous IMM reports.²⁰¹ Disabled people place a high value on employment, and want to see much more investment in equalising employment opportunities and removing barriers. Addressing entrenched inequalities will require an integrated approach across the labour market and social protection systems to respond to the hardship accumulated through extended periods without paid work, the general costs of disability, and additional in-work costs arising from inaccessible environments or transport systems. Without an equalisation in employment and education opportunities, there is little chance of disabled people being able to fully realise their right to have an adequate standard of living.

Disabled people's employment opportunities are also linked with educational opportunity. As reflected in the *Concluding Comments of the Committee on the International Covenant on Economic Social and Cultural Rights (ICESCR) to New Zealand in 2018,*²⁰² further work is required by the Government to align domestic legislation with international standards for reasonable accommodations in employment, and in the right to inclusive education.

Current place of Article 27 in New Zealand law and practice

The Human Rights Act 1993 prohibits discrimination on the basis of disability in both the employment and pre-employment contexts. The requirements apply to private and public sector employers.

Section 29 of the Human Rights Act permits some exceptions in which differential treatment of either a positive or negative nature of a disabled person in employment will not constitute discrimination. This section has been considered consistent with the definition of reasonable accommodation in Article 2 of the Disability Convention, in terms of an obligation to provide modifications unless doing so would constitute an undue burden. However, in the absence of definitive criteria around 'undue burden', the effective enactment and enforcement of the obligation to provide reasonable accommodation is significantly compromised. This can result in employers making insufficient accommodations for disabled people to participate effectively in work.

The State Sector Act 1988 includes responsibilities for the State Services Commissioner and public sector chief executives to promote equal employment opportunities in the public service. The State Services Commission has committed to a diversity and inclusion programme to ensure that the public service values, understands and reflects the communities it serves.²⁰³ This programme includes, but is not exclusive to, disability.

The ability to measure either increased diversity or equality of opportunity is currently hampered by a lack of disability data across the public service. The IMM understands the State Services Commission intends to conduct a disability survey within the public sector in the future but has yet to set a date.

The Ministry of Social Development funds a range of vocational and employment services and, in some circumstances, wage supplements to support disabled people's employment. Investment in active labour market strategies is low by comparison with other OECD countries.²⁰⁴

Outcome 2 of the *Disability Strategy 2016–2026* expresses a desired outcome of economic security and proportionate employment for disabled people, and describes

actions required to achieve this.²⁰⁵ Lead responsibility is assigned to the Ministry for Social Development and includes actions such as improving employer 'disability confidence', and better support for transitions into employment.

A range of resources has been designed for the public service to build employer confidence, challenge myths, guide good employment practices, and ensure equitable access to public services for disabled people. For example:

- a Lead Toolkit for employing disabled people, which has had an uptake of 63 percent within the state sector. Although designed for the public sector, it is also relevant to the private sector and will benefit from wider promotion;²⁰⁶ and
- the Accessibility Charter, which aims to increase the provision of inclusive language, inclusive technology, and accessible information.²⁰⁷

The notion that disabled people are less productive than their non-disabled peers is still reinforced by section 8(1-6) of the Minimum Wage Act 1983, which provides for a minimum wage exemption permit based on disability. In 2019, the Ministry for Social Development issued a consultation document on a proposed alternative to the minimum wage exemption. The outcome of this consultation is not yet known.

A generic national employment strategy was released in August 2019 from which six priority action plans will follow including a disability employment action plan.

Committee's previous dialogue with the State Article 27

In its 2014 Concluding Observations, the Disability Committee recommended that further steps be taken to increase levels of employment of disabled people and that alternatives to the minimum wage exemption be explored.

The Disability Committee's *List of Issues* focuses on measures to increase employment of disabled people, particularly in groups potentially subject to intersectional discrimination based on disability and gender, ethnicity or age. An improvement in disability data collection would be required to disaggregate information according to these characteristics.

In 2014, the Disability Committee also recommended that the Human Rights Act 1993 be amended to include an explicit definition of 'reasonable accommodation' that aligns with Article 2 of the Disability Convention. This recommendation was made in relation to Article 5, (Equality and non-discrimination) but is highly relevant to employment.

Other treaty bodies such as the ICESCR Committee have made similar recommendations to have domestic law reflect international standards for reasonable accommodation.

Comment on the realisation of Article 27 in New Zealand

Despite non-discrimination legislation and some positive initiatives to build accessibility and employer confidence, disabled people are yet to enjoy a material improvement in the exercise of this right to employment.

Hui participants and survey respondents resoundingly reported that many barriers remain to gaining employment:

- application processes may be inaccessible or intrusive—for example seeking medical information that is not relevant to evaluating suitability for a role;
- workplaces are inaccessible:
 - I had two interviews for management jobs. I was the top candidate but did not get either job because the building had stairs;
- discrimination or unconscious bias from employers, assumptions that it is too hard to employ disabled people, or disabled people are less productive, and differential treatment within work, including bullying:
 - Getting an interview, soon as I mentioned my disability I was not interviewed, when disability omitted from CV, I got interviews;
 - Bullied, yelled at, treated as the 'poster' person for disability;
- poor understanding of reasonable accommodation and lack of willingness to negotiate solutions;
- insufficient or ineffective employment support services tailored to individual job seeker requirements; and
- lack of incentives for employers to design or redesign jobs for, and employ, disabled people, especially for those with an intellectual/learning disability.

Disabled people indicate that employment support services are insufficient and inflexible. Examples include being unable to engage simultaneously with different supported employment agencies to access differing expertise at different points in the employment cycle, and inadequate in-work job support funds for ongoing needs such as personal assistants or New Zealand Sign Language interpreting services.

Employers indicate that they find the employment support system confusing, the practice variable, and the requirements onerous. A new employer membership programme, offered through non-government organisations, called the Accessibility Tick, is a promising development, as it signals employers are willing to invest in paid advice to improve their disability competency.

Available data on disabled people's employment outcomes reinforces that despite pockets of progress, disabled people remain significantly disadvantaged in the labour market.

In each of the last five years, employment has been the second most common reason for disability-related complaints of alleged discrimination received by the Human Rights Commission.

The 2013 *Disability Survey* showed that disabled people were almost twice as likely (nine percent) to be unemployed as non-disabled people (five percent).²⁰⁸

The *Household Labour Force Survey* (HLFS) is conducted quarterly. Since 2017, it has included disability measures on an annual basis. There are some improvements shown in the latest 2019 survey, although an enduring gap remains.²⁰⁹ Increased commitment to current initiatives is required. However, new initiatives and investment are also required to ensure improvement in disabled people's employment opportunities.²¹⁰

Table 2: Household Labour Force Survey 2017–19

	June 2017 Disabled	June 2017 Non-disabled	June 2018 Disabled	June 2018 Non-disabled	June 2019 Disabled	June 2019 Non-disabled
Labour force participation	25.2%	72.6%	25%	73.2%	26%	72.7%
Employment rates ages 15 to 64	39.3%	69%	39.5%	78.5%	22.4%	69.9%
Employment rates ages 15 to 24	20.1%	53.6%	13.9%	56.3%	25.9%	57.4%
Unemployment rate	11.4%	4.5%	10.6%	4.3%	8.6%	3.8%

As in many parts of the disability system, there are inequities in the timeliness, volume and financial value of employment supports funded by ACC and those funded by the Ministries of Health or Social Development, with clients of ACC generally accessing more generous provisions.

A sustained, well-resourced and comprehensive programme is required for the fundamental change required to shift these outcomes. The Disability Employment Forum—a collaboration between disabled people's organisations, employment support services, peak bodies, and the Human Rights Commission (among others)—has advocated for a comprehensive Disability Employment Strategy co-designed by disabled people, employers, and supported employment bodies.²¹¹ A strategy would help create a mandate and accelerate momentum, but also bring coherence to the multitude of disparate employment activities, approaches, and policies. As noted above, a generic employment strategy has been developed and this commits to an inclusive labour market. A draft disability employment plan, currently under consultation, aims to foster a more systemic and flexible approach across education and employment sectors. It is also proposing disability inclusive checks within government procurement processes. Current consultation processes notwithstanding, it would have been preferable to see a full disability specific strategy co-designed by disabled people, employers and relevant government agencies.

Recommendations

The IMM recommends that the Government:

- 94. Consider the development of a more comprehensive rights-based national disability specific:
 - a. provides for solutions by tāngata whaikaha for tāngata whaikaha;
 - b. proactively addresses disabled people's inequitable employment outcomes;
 - c. is co-designed by disabled people and employers;
 - d. facilitates local innovation and ownership;
 - e. lifts investment; and
 - f. includes time-specific milestones, measurable actions and a monitoring framework.

- 95. Pending the fuller review referred to in recommendation 10, consider an immediate amendment of the Human Rights Act 1993 to explicitly define reasonable accommodation in an employment context, create a positive duty for its provision and provide guidance for interpretation of undue burden, informed by Article 2 of the Disability Convention and *General Comment 6* on equality and non-discrimination.
- 96. Initiate affirmative actions or temporary special measures to increase the employment of disabled people within the public service. This could include establishing a quota or target, but could also include the following actions:
 - a. undertake to short-list and interview all appropriately qualified disabled applicants;
 - b. explore ways to incentivise investment by employers in universal design and accessible infrastructures—for example, tax rebates or concessions; and
 - c. consider how government procurement processes, or investments such as the Provincial Growth Fund, could positively contribute to disabled people's employment by requiring vendors or recipients to explicitly demonstrate how their initiative is inclusive of, and accessible to, disabled people.
- 97. Implement the 2014 recommendation to amend the Minimum Wage Act 1983 to eliminate minimum wage exemption permits.

Article 28: Adequate standard of living and social protection

Since diagnosis with intellectual [my son] and physical disabilities as a 1yo, we have struggled to access meaningful professional supports and interventions. As a parent you are made to feel like you should be 'grateful' for the level of support you receive.

Survey respondent

Support agencies working in the 'blank spaces' where people are not disabled enough or too disabled.

Hui participant

Introduction

Article 28 requires that all people have sufficient income and other support to secure an adequate standard of living for themselves and their families. Realisation of this right requires habitable housing, adequate nutrition, and access to essential health and social services.

General comment

An adequate standard of living is essential to disabled people's dignity, to exercising choice and control over decisions, and to securing other rights such as the highest attainable standard of health, and participation in family and community life.

Importance of Article 28 to disabled people in New Zealand

New Zealand has a comprehensive range of income and social protections to assist people, when required, with living costs, housing costs, and disability costs. However, the dignity of many disabled people, and particularly those relying in whole or partly on income from government benefits, is significantly reduced through living in poverty—frequently in inadequate and unhealthy housing.

Disabled people face many other barriers to enjoying this right, including:

high housing costs;

- a lack of accessible housing;
- insufficiency or ineligibility for support to participate in community; and
- inadequate incomes, whether through lack of work, benefit abatement regimes or low benefit rates.

The design of comprehensive universal social protections must also give effect to the rights to self-determination and full involvement in decision-making accorded to indigenous disabled people in the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) and Te Tiriti o Waitangi (Treaty of Waitangi).

Current place of Article 28 in New Zealand law and practice

The Social Security Act 2018 sets out the kinds of income support provided through the Ministry of Social Development and the conditions and eligibility criteria relevant to each type of support.

It is a complex regime, with differing benefit values and obligations, determined not by what is required for an adequate standard of living, but by the reason for seeking income support—such as family caring responsibilities, temporary sickness, or conditions limiting longer-term work. Allowances are available for certain approved disability-related costs.

In May 2018, the Minister for Social Development, Hon Carmel Sepuloni, established a Welfare Expert Advisory Group (WEAG) to review the social welfare system and provide advice about measures to meet current and future requirements of the population.

The WEAG reported its analysis and recommendations to the Government in May 2019 in *Whakamana Tāngata: Restoring Dignity to Social Security in New Zealand.*²¹²

Several recommendations to improve living standards of disabled people were made, alongside suggestions to focus the system on maintaining dignity for those accessing it, although these are yet to be adopted by the Government. On a positive note, the Government agreed to index income support to wages from 2020. The Ministry for Social Development has indicated to the IMM that it is working with the Ministry of Health to explore how they may improve income and employment outcomes for disabled people.

The Ministry for Social Development maintains a social housing register of people assessed as eligible for income-related rental rates. Disability is potentially linked to each of the criteria for social housing eligibility—sustainability, accessibility, affordability, adequacy, and suitability. As at November 2019, there were 14,500 people waiting for social housing.²¹³

Legislation recently passed by Parliament, the Kāinga Ora—Homes and Communities Act 2019, establishes a new Crown entity to combine roles of housing and urban design, in order to address the shortage of quality affordable and diverse housing options, and the resultant impediments to building inclusive, thriving, and sustainable communities.

Committee's previous dialogue with the State on Article 28

In 2014, the Disability Committee expressed concern about the lower socioeconomic status of disabled people, and recommended a review of income support adequacy—in particular responding to the costs of disability.

In its *List of Issues*, the Disability Committee sought detailed information on measures taken by the Government to understand the magnitude of housing modifications required and to implement improvements to the speed and volume of provision.

The Disability Committee also requested information on poverty reduction strategies, including those specifically aimed at reducing poverty for the most marginalised populations of disabled people/tāngata whaikaha, women, children, and people with intellectual, learning and psychosocial impairments.

Comment on the realisation of Article 28 in New Zealand

Currently, disabled people are among the most marginalised populations in terms of social and economic outcomes. Many data sources confirm this situation, including the 2013 *Disability Survey*, which indicates that:²¹⁴

- 64 percent of disabled adults received an annual income of \$30,000 or lower, compared with 45 percent of non-disabled people;
- disabled women fare worse, with 71 percent receiving less than \$30,000;
- disabled people are more likely than non-disabled people to report that their housing is inadequate for their needs, that it is damp, and that they have difficulty keeping their home warm; and
- one in six people with a physical impairment also reports an unmet need for some form of housing modification.

In June 2019, the *Household Labour Force Survey* placed median weekly income (all sources) for disabled people at \$392 per week, equating to an annual income of approximately \$20,000—just over half that of non-disabled people (\$749).²¹⁵ Housing costs alone exceed this total income in many areas of the country.

The 2018 *General Social Survey* demonstrated that compared to non-disabled adults, disabled adults are:²¹⁶

- twice as likely to indicate they do not have enough money to meet everyday needs;
- four times more likely to report poor health status;
- four times more likely to indicate low trust in the health system; and
- twice as likely to give a low rating to life being worthwhile.

A 2018 article, *Breaking the Link Between Disability and Child and Whānau Poverty*, showed that disabled children: ²¹⁷

- are more likely to live in a one-parent household;
- have parents who are more likely than other sole parents to be unemployed; and
- are significantly more likely to be living in poverty, with 28 percent living in a household with less than 63 percent of the national median household income.

The living standards of some disabled people may also be affected by substitute decision-makers authorised to control their financial affairs, who may impose limitations on expenditure in ways that do not reflect the person's preferences.

The standard of living of disabled people whose income or services are supported through the ACC scheme is superior to that of disabled people reliant on the Ministry of Health or Ministry for Social Development.

The Whakamana Tāngata report accurately captures disabled people's experience that the system is complex, risk-averse, and does not respond to disabled people's realities of prolonged exclusion from employment, and additional disability costs.

In their analysis, the WEAG noted that achieving an adequate standard of living requires an immediate increase in the level of income support payments. Modelling a variety of income support types and recipient characteristics reveals income deficiencies from between \$50–\$230 per week for meeting basic costs, to \$110–\$350 per week to allow for minimal participation in the community.²¹⁸

The group recommended that base benefit rates be increased by 40 percent to restore people to a life of dignity. This has not been agreed, but, as noted above, a commitment was made in the 2019 Budget to index income support rates to wages from 2020. This will incrementally improve incomes, but not at the rate or magnitude required.

Hui participants and survey respondents reported living in poor conditions and unsuitable environments due not only to income inadequacy but also diminishing levels of support to live independently in the community.

Given that there is a housing crisis, disabled people face poverty when renting or buying, it's impossible to get a home set up or modified if renting as we can get evicted too easily.

Lack of in-home services to prepare nutritious meals...access library books, assistance in transport to appointments...no socialisation if you can't get out on your own and can't afford outings.

Data provided in the Government's response to the *List of Issues* demonstrates those approved for modified public housing experience wait times of on average one year.²¹⁹ This is likely to be an underestimate, as insecure tenure impacts eligibility for modifications.

Recent media reports highlight the impact of unsuitable housing on dignity and family life, with articles illustrating the long wait for modifications affecting access to sanitation and the ability of a family to enjoy meals.²²⁰

There has been positive engagement with disabled people's organisations by the recently formed Ministry of Housing and Urban Development. A commitment has been made to boost universal design and the supply of accessible housing. In practice, this is still at an exploratory stage of developing universal design standards.

Recommendation

The IMM recommends that the Government:

- 98. Adopt the disability-related recommendations of *Whakamana Tāngata*, the report of the Welfare Expert Advisory Group. The IMM endorses the report's stated purpose for a welfare system and encourages the holistic implementation of all recommendations as a matter of urgency, but specifically the following recommendations relating to housing availability and affordability, and income adequacy:²²¹
 - a. Increase, as soon as possible, overall income support to levels adequate for meaningful participation in the community, as defined by the minimum income standard (which reflects different family circumstances, for example, children, disabilities and regional area) and maintain this level of support through appropriate indexation.
 - b. Urgently expand and accelerate Government efforts to substantially increase public housing on an industrial scale and continue urgent efforts to end homelessness.

- c. Increase the range of home ownership and tenure options for people on low and low–middle incomes.
- d. Increase the capacity of third-sector community-based housing providers.
- e. Develop and enact laws and regulations to ensure healthy homes and housing security, decent standards of housing quality, universal design, and accessibility.
- f. Subsidise housing costs for people on low incomes (in addition to raising main benefit rates to provide an adequate income) and ensure the combination of changes to housing support and abatement rates make households better off.
- g. Improve access to affordable, suitable housing support for people on low and low–middle incomes, including a range of affordable home-ownership products and papakāinga housing.
- h. Improve the health and wellbeing of people with health conditions and disabilities, along with carers of people with health conditions and disabilities who interact with the welfare system by:
 - providing financial support that is adequate to live a life with dignity and is equitable across the social sector
 - implementing evidence-based approaches to support engagement in good, suitable work and the community where this is possible
 - implementing strategies to prevent work-limiting health conditions and disabilities.
- i. Include in the scope of the New Zealand Health and Disability System Review the relationship between the health and disability system and the accident compensation scheme and how the relationship between these and the welfare system could be changed to improve outcomes for people with health conditions and disabilities and carers.

Article 29: Participation in political and public life

Going ahead with a law for accessibility that has been worked on by the Access Alliance. Increasing funding for the disability sector. Having more disability representation/lived experience in government.

Survey respondent

The disappointment in the delay in the latest Census results was felt deeply within the disability sector. Funding is reliant on accurate data and the fact the latest health survey is not going to even address learning difficulties confirms government lack of understanding of the real issues.

Survey respondent

Introduction

Article 29 obliges governments to guarantee disabled people political rights and the opportunity to enjoy them on an equal basis with others. Governments must also ensure that disabled people can effectively and fully participate in political and public life.

This extends to ensuring that disabled people are provided adequate opportunity and support to autonomously express their right to vote, stand for election, and, if they are elected, to hold public office roles. Additionally, this article requires the promotion of the opportunity for disabled people to engage in public affairs through working in non-governmental organisations (NGOs), and to assemble groups and organisations representing disabled people without discrimination.

General comment

The right to equal participation in political and public life is a core platform of citizenship. Disabled people who seek to work as public officials should have access to reasonable accommodations to make autonomous and informed decisions, and should be given resources to enable supported participation and decision-making if required.

Importance of Article 29 to disabled people in New Zealand

In order to fully recognise Article 29, it is essential that disabled people can access and participate in decision-making systems—in particular, those that impact on disabled people and their communities. The visibility of disabled people at central and local government level is low, despite 24 percent of New Zealanders being identified as having some kind of disability in the 2013 Census.²²² This suggests a need to provide widespread support for disabled people to fulfil the right to participate and vote. A lack of universally accessible systems for public participation is a social and political barrier.

Current place of Article 29 in New Zealand law and practice

Under section 12 of the New Zealand Bill of Rights Act 1990, disabled people are legally entitled to vote by secret ballot. However, for some disabled people, this right can be restricted. For instance, section 80(1)(c) of the Electoral Act 1993 disqualifies people from voting who are detained in a hospital under the Mental Health (Compulsory Assessment and Treatment) Act 1992, or in a secure facility under the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003, when certain other criteria also apply. These criteria relate largely to interaction with the justice system, such as being found unfit to stand trial or not guilty on the grounds of insanity, or being a person detained in a prison but for whom transfer to a hospital for specialist psychiatric care is assessed as being more suitable.

These types of legislative restrictions have a disproportionate exclusionary effect on disabled people—particularly those with neurodiversity or intellectual/learning disabilities, who are overrepresented in the justice system, and whose support requirements may not be well understood.

Improving the accessibility of New Zealand's political and public infrastructure has been recognised as an area needing improvement with the release of the Electoral Commission's *Access 2020 Disability Strategy*. This strategy outlines an incremental plan for improving voting accessibility across three successive electoral cycles, with the intent of implementing different objectives for each cycle. Described more fully below, telephone dictation voting was introduced in 2014, and improvements to the enrolment process were made in 2017. The Electoral Commission hopes to fully roll out online voting for the 2020 electoral cycle.²²³

Improving capacity for disabled candidates to run for office in the General Election is the purpose of the Election Access Fund Bill introduced in 2018.²²⁴ This Bill would create an access fund, controlled by the Electoral Commission, which non-profit organisations and registered parties could access to meet accessibility-related costs for disabled candidates.

Committee's previous dialogue with the State on Article 29

The Disability Committee's 2014 Concluding Observation for Article 29 recommended that the Government consider the introduction of accessible electronic voting to enable disabled people to cast their votes in a truly secret manner.²²⁵

Comment on the realisation of Article 29 in New Zealand

Full participation by disabled people in political and public life has not been a key design feature of current political systems. For example, until recently, printed and paper-based voting meant visually impaired or blind voters required assistance in completing a ballot vote, which undermines the right to 'secrecy'.²²⁶ For disabled people to participate fully, they are heavily reliant on agencies providing information in accessible formats and/or providing reasonable accommodations to ensure there are no barriers to full participation. Such accommodations include providing voting papers in alternative formats, and personal voting supports for people according to their access needs.

While disabled people are extended a definitive right to vote and some improvements have been made, in practice, the existing infrastructure to support this right is haphazard. In 2011, Green Party MP Mojo Mathers was elected as New Zealand's first Deaf Member of Parliament. Her election raised questions about Parliament's willingness and ability to provide appropriate accommodations to Ms Mathers, including who should fund New Zealand Sign Language (NZSL) interpretation, or any other staff required to facilitate participation on an equal basis with others.²²⁷

Further questions around the accessibility of New Zealand's political processes were raised during the 2017 Election, when a petition was launched to ensure NZSL interpreters were available in televised political debates.²²⁸ Broadcasters received complaints that Deaf and hard of hearing citizens would experience delayed access to NZSL interpreted or closed captions versions of televised debates between the major party leaders.²²⁹

Data on disabled people's representation, especially that of disabled Māori and Pacific peoples, remains unknown—with few current Members of Parliament openly identifying as being disabled or having access needs since the departure of Ms Mathers in 2017.

Additionally, little disaggregated data about disabled people working in central and local government is available.

As part of the Electoral Commission's disability strategy, telephone dictation voting was introduced in 2014 and trialled for the General Election.²³⁰ Telephone dictation voting enabled registered voters with visual impairments to vote independently or secretly without violating the current terms of the secret ballot voting system.

Recommendations

The IMM recommends that the Government:

- 99. Review the parameters for disqualification of voters subject to the Mental Health (Compulsory Assessment and Treatment) Act 1992 and the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 to ensure conformity with the Disability Convention.
- 100. Implement legislation and other measures to increase accessibility of election processes for disabled people, co-designed with disabled people.
- 101. Work closely with disabled people and the Electoral Commission to ensure that information about local and general elections can be provided in accessible formats, and that the necessary supports are in place to ensure that there is not a disproportionate exclusion from voting of people with an intellectual impairment.
- 102. Review the support for disabled candidates and electoral processes; and resource and provide reasonable accommodations at both local and central government levels.

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

There are regularly workshops and talks or short courses in my community that I want to attend and participate in, but there is no government funding to cover New Zealand Sign Language interpreter costs to access community events.

Survey respondent

Access to public events/activities—such as sports events, live theatre, and movies—should be accessible. Often families with a disabled family member are excluded where accessibility precludes access or participation.

Survey respondent

Introduction

This article requires that disabled people have the same rights as others to participate in and enjoy the arts, sports, games, films, and other similar activities.

General comment

New Zealand's rich multicultural society provides opportunities for people to participate in a wide range of cultural and sporting events. Disabled people often feel excluded through lack of access and, as a result, can become disconnected from their own communities.

Importance of Article 30 to disabled people in New Zealand

Article 30 reflects the strong desire by disabled people to be involved in the cultural life and activities of their communities at a local and national level.

Current place of Article 30 in New Zealand law and practice

Beyond the general provisions of the Human Rights Act 1993, the New Zealand Bill of Rights Act 1990 and the Building Code, there is no specific legislation promoting access to cultural and sporting events in New Zealand.

The Copyright (Marrakesh Treaty Implementation) Amendment Act 2019 removed some copyright restrictions to enable more works to be produced in accessible formats. This means that those with a print disability will now have access to a broader range of literary, artistic and dramatic works.²³¹

There is currently no legislation that provides for mandatory captions on television and TVNZ OnDemand platforms. Calls have been made to regulate the use of captions to increase access for the estimated one in six New Zealanders who use them.²³² The inquiry into captioning in New Zealand, which reported to the House of Representatives in 2017, recommended that:²³³

- provision of captioning content be a requirement for New Zealand On Air and Film Commission funding; and
- further progress should be made in improving captioning access, including all platforms from broadcast to TVNZ OnDemand content, and film screenings.

There are a number of initiatives promoting accessibility in New Zealand in sporting and cultural areas. However, these are mostly driven at an organisational or individual level, rather than a government level, and are largely promoted through charitable funding.

The Government has been considering the introduction of a 'Companion Card' to entitle disabled people to take a companion to cultural and sporting events free or at a reduced price.²³⁴ No decision has been made on this to date.

Committee's previous dialogue with the State on Article 30

In its *List of Issues*, the Disability Committee asked the Government to report on measures taken to enhance accessibility in sports facilities, museums, cultural and natural heritage sites, and any place for the cultural life of disabled people.

In its response, the Government made reference to the *Accessibility Design Guide* and *Self-Assessment Checklist* (Sport NZ 2014),²³⁵ and an increase in funding for TV captioning per year from \$2.4 million to \$2.8 million. It also referenced funding for organisations that work to improve accessibility, including Arts Access Aotearoa, Touch Compass Dance Company, the Halberg Disability Sport Foundation, Special Olympics New Zealand, and Paralympics New Zealand.

The response conceded that there is no government policy to enhance accessibility in museums, but made reference to provision for accessibility by the Museum of New Zealand Te Papa Tongarewa²³⁶ and Heritage New Zealand Pouhere Taonga.

Comment on the realisation of Article 30 in New Zealand

Progress has been made in the area of accessibility to culture, sport and leisure since the last report to the Disability Committee. However, there is still work to be done to ensure this is rolled out consistently and equitably to the diverse communities across the country.

There are still many events that take place in New Zealand that are inaccessible to people with limited mobility, people who use wheelchairs, Deaf, and other disabled people. This includes events where disabled people might choose to attend as spectators, as well as cultural and sporting events in which disabled people might want to participate.

The first year that audio description was made available to a live audience in te reo Māori was 2019. This initiative was achieved without government funding. Unfortunately, government-funded captioning and audio description for television is not available in any language other than English, and is not available on all free-to-air channels. There is a limited amount of captioning, but no audio description, currently available on TVNZ OnDemand. Neither audio description nor captioning are available on Māori TV.

Some progress has been made at local authority levels to increase accessibility to cultural events. For example, Auckland Council has funded New Zealand Sign Language (NZSL) interpreters and audio describers at the ANZAC Dawn Service for the past few years, and a number of other local events include some accessible provision, including NZSL interpreters, audio description, accessible parking, and toilets.

It is pleasing to note that closed captions are increasingly available at New Zealand cinemas.

Despite the success of high-profile para-athletes, disability organisations report that disability sports are funded to a lesser degree than sporting activities for non-disabled people. Combined with the additional costs that many disabled people face in accessing sporting opportunities—including cost of travel, access to appropriate support people, and access to suitable training facilities—there are currently fewer opportunities for disabled people to participate in sports, compared to their non-disabled peers.

Even though te reo Māori and NZSL are two of New Zealand's official languages, Deaf Māori are disadvantaged due to the lack of trilingual interpreters for tāngata whaikaha access to events of cultural significance.

At the consultation hui, participants said that access to public events and activities, such as sports events, live theatre, and movies, should be accessible. At present,

families with a disabled family member are often excluded, as inaccessibility precludes access or participation.

Recommendations

The IMM recommends that the Government:

- 103. Take steps to mandate that publicly funded sporting and cultural initiatives and facilities, including those provided in partnership with local government, are made accessible as a requirement of standard procurement procedures and existing facilities to best practice accessibility standards.
- 104. Ensure that all tourist facilities, hotels and other accommodation providers, public attractions, and sporting and cultural facilities are required to provide detailed information on their websites outlining the accessibility features of the venue and/or service.
- 105. Require all sporting, cultural, entertainment and/or recreational facilities to make provision for accessibility features proportionate to the prevalence of those access needs in the community.
- 106. Introduce a discount scheme for disabled people's companion tickets to enable disabled people to take a support carer to events and performances at a reduced cost.
- 107. Provide increased funding to train and employ trilingual interpreters and audio describers, and to make their services available at civic and cultural events. This will require developing a strategy to build a pool of trilingual personnel.
- 108. Introduce legislation to require an increase in the amount of captioning and audio description on New Zealand television, including the provision of captions and audio description for OnDemand content, including content provided in te reo Māori.
- 109. Require sporting events to provide a live commentary for blind patrons—either generated from within the stadium or via standard radio stations—which must be live and not delayed.
- 110. Introduce new legislation requiring film distributors and producers to include accessibility features, including captions and audio description—particularly when these have been made available in other parts of the world.
- 111. Increase funding for sporting bodies to make their activities and facilities fully inclusive of disabled sportspeople.

Article 31: Statistics and data collection

Data is like a roadmap and gives directions to the Government so they know [where] to put resources. If you don't have a roadmap you will go nowhere.

Hui participant

I suspect the data that is collected is very much skewed towards those disabled people that are sufficiently articulate, organised and 'switched on' to respond to surveys and consultation exercises. I suspect there are many disabled people who are missed by such exercises.

Survey respondent

Data doesn't reflect us.

Hui participant

It [the Census] doesn't capture the nuance of disabled people's experiences. The Washington questions capture data about function, not impairment, and do not capture data on neurodiversity. Data collection needs to reflect the breadth of experiences in the disability communities.

Survey respondent

Introduction

Article 31 requires the Government to collect appropriate data and statistical information to give effect to the Disability Convention. Such data needs to be disaggregated to assist the Government in determining how it is fulfilling the Disability Convention obligations, and to identify and address barriers faced by disabled people in exercising their rights.

Importance of Article 31 to disabled people in New Zealand

This article is fundamentally important for implementing the Disability Convention. Without adequate information, statistics, and data, it is impossible to properly plan and deliver services and provisions for disabled people, or to fully track progress in New Zealand on making disability rights real.

Current place of Article 31 in law and practice

There is a paucity of disaggregated disability information in New Zealand. As a consequence of the *New Zealand Disability Strategy 2016–2026*, the Government has agreed on an Outcomes Framework to measure progress in implementing the Strategy. The Framework has 29 outcomes, many of which do not currently have data sets. However, work is progressing to address this over time. General surveys, such as the Household Surveys, are starting to collect disaggregated disability information

Committee's previous dialogue with the State on Article 31

In its 2014 *Concluding Observations*, the Disability Committee raised concerns over the lack of disaggregated disability information and data. It asked questions on disability data again in its *List of Issues* in 2018.

Comment on the realisation of Article 31 in New Zealand

Both the *Household Labour Force Survey* and the *Household Economic Survey* now collect some disaggregated disability data. However, the Census, and the Disability Surveys that have followed the last few Censuses, are still key in providing information about disabled people in New Zealand. This will remain the case until other data collection sources gather enough disability data.

In 2018, for the first time, the Census was available only online, which posed challenges for some disabled people. Communication about support available to complete the Census was not very clear or timely. The printed verification code sent by mail was not accessible to blind and visually impaired people. There was no Disability Survey following the 2018 Census, so it was not possible to ascertain whether or not lower-than-normal Census completion rates will have an impact on disability data and, consequently, on service planning.

Recommendations

The IMM recommends that the Government:

- 112. From 2023, re-start the Disability Survey following each Census, commencing with the 2023 Census.
- 113. Continue to introduce disability data collection in all general household surveys conducted by Statistics New Zealand.
- 114. Continue to promote the benefits and advise on the limitations of the Washington Group Short Set of Questions on Disability in order to encourage the creation of a consistent cross-agency data set.
- 115. Continue work with disabled people and representative organisations to ensure that Census completion is barrier-free for disabled people, so they can engage as they choose, with independence, confidence, and dignity.

Article 32: International cooperation

Introduction

Article 32 recognises the importance and value of international cooperation in supporting both domestic and international efforts to realise the objectives and articles of the Disability Convention.

The provisions of this article provide examples of different measures states can apply to fulfil this article, including that international programmes, events, and cooperation are broadly inclusive of disabled people. Other provisions include facilitating or supporting capacity-building through sharing best practice, resources and expertise, as well as ensuring that assistance provided is accessible and inclusive of disabled people.

General comment

The premise of this article is to ensure that the Government is active in promoting and supporting the realisation of the Disability Convention domestically, as well as internationally. Further, it articulates the need to ensure that disabled people are not excluded from international development initiatives or cooperation between states, and that any support, whether it be technologically, economically, or practically assistive, is inclusive of disabled people or of benefit to them.

Importance of Article 32 to disabled people in New Zealand

As part of the Pacific region, and with a sizeable Pacific population residing in New Zealand, the Government has a strong responsibility to realise this article. Almost 7.5 percent of New Zealand's population identified with one or more Pacific ethnic groups in the 2013 Census.²³⁷

As both a major, and more affluent, state in the Pacific region, New Zealand has an obligation to help realise the rights of disabled Pacific peoples, and to share resources that will help ensure that the rights of disabled people in the Pacific are protected. It is important and necessary that New Zealand plays a role in sharing and exporting its often more-developed and embedded infrastructure for disabled people with its Pacific partners.

Current place of Article 32 in New Zealand law and practice

The provision of aid and international cooperation is not legislated for, but is instead mandated through the development of public and foreign policy, and through budget decisions.

There are several instances of New Zealand proactively looking to strengthen its international disability sector connections and pushing for greater international cooperation. Recent examples include the formation of a Global Alliance of National Human Rights Institutions (GANHRI) disability working group, chaired by New Zealand Disability Rights Commissioner Paula Tesoriero. The working group has eight members, two from each of the four GANHRI regions. The purpose of the group is to advise the global human rights network about disability inclusion measures and monitoring.

In June 2019, the Government announced a renewed partnership between New Zealand and the Pacific Disability Forum, including funding for disability policy development. The forum is a Pacific regional non-governmental organisation that works to build capacity and advocacy for disabled people's organisations in the region.²³⁸ The aim of the partnership is to help promote the Disability Convention and aid in its implementation among New Zealand's Pacific partners.

In March 2019, the Government's response to the Disability Committee's List of Issues cited multiple initiatives it is involved in as part of implementing this article. Within its broader aid programme:

The New Zealand Aid Programme funds activities to promote the rights of disabled people and empower groups and individuals. ^{239, 240}

This includes economic empowerment for disabled people in India, strengthening inclusive education in Papua New Guinea, and developing and building capacity for disability-inclusive projects, humanitarian responses, and infrastructure projects.

Committee's previous dialogue with the State on Article 32

During New Zealand's review in 2014, the Disability Committee expressed its concern over New Zealand's withdrawal of funding from the Pacific Disability Forum and the implications this had on disabled people in the region.

As part of this, the Disability Committee recommended that New Zealand's aid programme should continue to focus on disability-inclusive development alongside the relevant State Party, and reinstate its provision of financial aid and other resources to the Pacific region.

Comment on the realisation of Article 32 in New Zealand

Commitment by successive New Zealand Governments to international cooperation in the context of disability rights and Article 32 in the Pacific region has been varied.

It has taken until 2019 for the Government to implement the Disability Committee's 2014 recommendation to formally reinstate its partnership with the Pacific Disability Forum. In the intervening period, there was little formal engagement or emphasis on international cooperation for disability rights in the region by the Government, beyond conventional avenues such as the Asia-Pacific Forum and some baseline commitments in New Zealand aid programmes.

The primary international cooperation in the region has historically been facilitated by civil society, with Disabled People's Organisations (DPOs) forming international relationships with, for example, Rehabilitation International, Inclusion International and the World Blind Union. This international cooperation has occurred predominantly without government support. It is therefore pleasing to see a renewed commitment to, and investment in, a Pacific Disability Forum partnership.

Focus on supporting disabled people in the Pacific is largely invisible in publicly available resources about New Zealand's aid programmes, including New Zealand Aid Programme Strategic Plan 2015–19.²⁴¹ This suggests there is plenty of room to improve emphasis on, and inclusion of, disabled people in broader strategic discussions about New Zealand's aid to the Pacific.

Recommendations

The IMM recommends that the Government:

- 116. Continue its commitment to, and consolidate its partnership with, the Pacific Disability Forum.
- 117. Fund disabled people's participation in initiatives of international cooperation, including significant international disability events such as the Global Disability Summits, the annual Conference of State Parties, and at the United Nations when New Zealand is reviewed against the Disability Convention by the Disability Committee.
- 118. Build New Zealand's Pacific aid programmes and initiatives so they are accessible to, and inclusive of, the needs of the disabled people in the region.

Article 33: National implementation and monitoring

Introduction

Article 33 seeks to ensure that the human rights standards in the Disability Convention are effectively implemented by governments.

Article 33(1) encourages the Government to pursue holistic cross-government disability policies. It requires it to designate at least one focal point in government for matters relating to the implementation of the Disability Convention, and to ensure effective coordination across, and throughout, sectors and levels of government.

Article 33(2) requires the Government to establish or designate a framework that includes one or more independent mechanisms to promote and protect the rights of disabled people, and to monitor implementation of the Disability Convention.

Article 33(3) requires the Government to ensure that members of civil society—in particular disabled people and their representative organisations—are involved and participate fully in monitoring the implementation of the Disability Convention.

General comment

On 9 November 2018, the Disability Committee released *General Comment No. 7,* which clarifies the nature of *'organisations of persons with disabilities'*. It outlines the need for governments to involve a wide range of disabled people and their organisations in the development and implementation of policy: ²⁴²

States parties should ensure the close consultation and active involvement of organizations of persons with disabilities, which represent all persons with disabilities, including but not limited to women, older persons, children, those requiring high levels of support, victims of landmines, migrants, refugees, asylum seekers, internally displaced persons, undocumented and stateless persons, persons with actual or perceived psychosocial impairments, persons with intellectual disabilities, neurodiverse persons, including those with autism or dementia, persons with albinism, permanent physical impairments, chronic pain, leprosy and visual impairments and persons who are Deaf, deafblind or otherwise hearing-impaired and/or those living with HIV/AIDS. The obligation

of States parties to involve organizations of persons with disabilities also encompasses those persons with disabilities with a specific sexual orientation and/or gender identity, intersex persons with disabilities, and persons with disabilities belonging to indigenous peoples, national, ethnic, religious or linguistic minorities, and those living in rural areas.

Importance of Article 33 to disabled people in New Zealand

Independent monitoring of implementation of the Disability Convention is fundamental. Monitoring helps connect rights holders not only to domestic duty bearers, but also to the work of the Disability Committee.

Current place of Article 33 in New Zealand law and practice

In New Zealand, Article 33(1) is given effect to by the Office for Disability Issues, which acts as the focal point for government, and coordinates the development and delivery of the *New Zealand Disability Strategy* and the *Disability Action Plan*, and also coordinates the Ministerial Leadership Group on Disability Issues.

The IMM has the monitoring mandate in New Zealand under Article 33(2) of the Disability Committee—a role it was designated by Cabinet in 2010. As noted earlier, the purpose of the IMM is to promote, protect and monitor implementation of the Disability Convention in New Zealand, in order to help make disability rights real. The IMM partners are the Disabled People's Organisations' (DPO) Coalition, a body reflecting the voice of disabled people in the monitoring process, the Ombudsman, and the Human Rights Commission.

The IMM has drafted three previous domestic monitoring reports, two on its general monitoring activities in 2012 and 2014, and one on inclusive education in 2016. It meets regularly with decision-makers, including Ministers of the Crown, to discuss priority monitoring concerns for the disability sector. It has a productive relationship with the Office for Disability Issues.

Committee's previous dialogue with the State on Article 33

In its *List of Issues*, the Disability Committee asked for information on:

- outcomes of the monitoring process;
- the mandate and resources of the IMM; and
- measures taken by the State Party following monitoring.

The Government responded by providing information on the IMM's work and funding, and how the IMM's work influenced key actions of the *Disability Action Plan 2019–2023*. The Government also noted some examples of where IMM recommendations had been implemented.

Comment on the realisation of Article 33 in New Zealand

The IMM faces challenges within current resourcing to maintain as rigorous or comprehensive monitoring programme as we would like. We are not always able to respond quickly to emerging trends or disability rights concerns—for example, when government proposals require rapid response times for submissions. The IMM does not always have as diverse representation as that envisaged by *General Comment 7*.

The IMM has twice-yearly meetings with a ministerial leadership group and individual ministers as required. We currently find ministers, and officials, to be constructive and open in their engagement. However, engagement does not necessarily translate to commitments to integrate accommodation and inclusion meaningfully, or to make the large-scale shifts in systems-level policy required in education, justice, housing or employment.

One example concerns Article 24 and the right to education. The IMM has been emphatic in multiple engagements with the Government that the education system is fundamentally broken for disabled people. While there has been some acknowledgement of this position, within current education reforms, responses are largely only cosmetic, short term, and designed primarily by non-disabled people

Recommendations

The IMM recommends that the Government:

- 119. Create a transparent mechanism to demonstrate that it makes substantive and meaningful changes in response to IMM recommendations.
- 120. Work with the IMM to explore how to formalise increased diversity to reflect the groups detailed in *General Comment 7.*²⁴³

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Appendix 1: Glossary

Term / Legislation	Definition / Explanation		
Access 2020 Disability Strategy	The Electoral Commission's disability strategy. It		
	describes how barriers disabled people may face		
	when enrolling and voting will be identified and		
	reduced, to allow full participation in the electoral		
	process.		
Accessibility Charter	The Government's initiative to ensure		
	communication, services and information provided		
	by state sector agencies are available to everyone.		
	See 'Leading the way in accessible information'		
	below.		
Accident Compensation Corporation	New Zealanders are covered by a no-fault scheme		
(ACC)	if they have been injured in an accident. The cover		
	provided helps pay for the costs of recovery and		
	is administered by the Accident Compensation		
	Corporation, a government agency.		
Ashley Treatment	Controversial treatment in which a disabled child's		
	growth is suspended and other medical procedures		
	are undertaken, to aid the provision of care and		
	prevent perceived discomfort in a child's future		
	adult life.		
ANZAC Dawn Service	ANZAC (Australian and New Zealand Army Corps)		
	Day commemorates all Australian and New Zealand		
	service men and women who have served and died		
	in wars, conflicts and peacekeeping operations. The		
	Dawn Service is held throughout Australia and NZ		
	on ANZAC Day (25 April) in remembrance.		
Arts Access Aotearoa	Focuses on supporting disabled people to create		
	and participate in art of all kinds; encouraging		
	performing arts companies, venues, producers and		
	artists to increase their accessibility; and facilitating		
	arts-based rehabilitative projects and programmes		
	in prisons.		
Auckland Council	Local government council—New Zealand's largest.		
Building Act 2004 and Building Code	All building work in New Zealand must comply with		
	the Building Code. The Building Code is contained		
	in regulations under the Building Act 2004. The Act		
	governs building work in New Zealand.		

Term / Legislation	Definition / Explanation	
CCS Disability Action	CCS Disability Action is a nationwide non-	
	governmental organisation (NGO) providing	
	support, advocacy, and information for disabled	
	people.	
Code of Health and Disability Services	Sets out the rights that New Zealanders have	
Consumers' Rights	when using a health or disability service. These are	
	called the Code of Health and Disability Services	
	Consumers' Rights or 'the Code'.	
Code of Professional Responsibility	Sets out standards for ethical behaviour expected	
and Standards for the Teaching	of every teacher in New Zealand.	
Profession		
Committee on Economic, Social and	United Nations Committee overseeing the	
Cultural Rights (CESCR)	International Covenant on Economic, Social and	
	Cultural Rights (ICESCR).	
Concluding Observations	Are assessments of the implementation of human	
	rights treaties by a state, issued by the respective	
	treaty bodies after their examination of the State	
	Reports. They also use additional information—	
	for example, from national or international non-	
	governmental organisations. Also referred to as	
	Concluding Comments.	
Convention on the Rights of Persons	See United Nations Convention on the Rights of	
with Disabilities (CRPD)	Persons with Disabilities	
Declaration on the Rights of	See United Nations Declaration on the Rights of	
Indigenous Peoples	Indigenous Peoples	
DIDRR	Disability-Inclusive Disaster Risk Reduction	
Disability Action Plan	Provides a cross-government mechanism to	
	progress action on the implementation of the	
	Disability Strategy. 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 List of Issues.	
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	

erm / Legislation	Definition / Explanation	
isability Employment Forum	A collaboration between disabled people's	
	organisations, employment support services, and	
	peak bodies.	
isability Rights Commissioner	The position of Disability Rights Commissioner was	
	created by an amendment to the Human Rights Act	
	1993.	
isabled People's Organisations	Representative organisations of disabled people	
OPOs)	and which are recognised by Article 4(3) of the	
	Disability Convention.	
istrict health boards (DHBs)	Responsible for providing or funding the provision	
	of most health services in their respective districts.	
ectoral Commission	The agency responsible for all areas of electoral	
	administration in New Zealand.	
etal Alcohol Spectrum Disorder	The umbrella term for a range of disorders caused	
ASD)	by alcohol intake during pregnancy. These	
	disorders can be mild or severe, and can cause	
	a range of impairments. Also referred to as Fetal	
	Alcohol Syndrome Disorder.	
lobal Alliance of National Human	Formerly known as the International Coordinating	
ights Institutions (GANHRI)	Committee of National Human Rights Institutions,	
	sometimes shortened to the International	
	Coordinating Committee (ICC), GANHRI is a global	
	network of national human rights institutions	
	(NHRIs).	
e Ara Oranga	Government Inquiry into Mental Health and	
	Addiction.	
armful Digital Communications Act	An Act of Parliament to deter, prevent, and	
015	mitigate harm caused to individuals by digital	
	communications, and to provide victims of harmful	
	digital communications with a quick and efficient	
	means of redress.	
ealth and Disability Commissioner	An independent watchdog agency whose role is	
IDC)	to promote and protect the rights of consumers	
	as set out in the Code of Health and Disability	
	Services Consumers' Rights. This includes resolving	
	complaints in a fair, timely, and effective way.	
ealth Quality and Safety Commission	A Crown entity working with clinicians, providers	
	and consumers to improve health and disability	
	and consumers to improve health and disability	

Term / Legislation	Definition / Explanation		
Heritage New Zealand Pouhere	The leading national historic heritage agency.		
Taonga			
Hui	A meeting or gathering of people.		
Household Labour Force Survey	This survey provides data on employment and		
(HLFS)	unemployment in NZ. Undertaken by Statistics NZ.		
Household Surveys	Undertaken by Statistics NZ to collect information		
	throughout the country on New Zealanders'		
	wellbeing, employment status, economic status,		
	etc.		
Human Rights Act 1993	Protects people in NZ from discrimination in a		
	number of areas of life including on the ground of		
	disability.		
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.		
Human Rights Review Tribunal (HRRT)	A remedial body, it can hear claims relating to		
	breaches of the:		
	Human Rights Act 1993;		
	Privacy Act 1993; and		
	Health and Disability Commissioner Act 1994.		
	It can award compensatory damages for losses		
	suffered. Awards are typically for injury to feelings,		
	humiliation, and loss of dignity.		
IHC Foundation	Works to ensure people with an intellectual		
	disability are valued and active members of their		
	communities.		
Independent Monitoring Mechanism	The mechanism to monitor the Disability		
(IMM)	Convention/CRPD. In New Zealand, the IMM is		
	made up of the Human Rights Commission, Office		
	of the Ombudsman and the Disabled People's		
	Organisations Coalition.		
Institute of Judicial Studies (IJS)	Professional development arm of the New Zealand		
	judiciary, which provides education programmes		
	and resources.		
KiwiBuild homes	A government initiative to tackle the housing crisis		
	due to lack of stock and affordability. It is working		
	with developers to build high-quality homes for		
	eligible New Zealanders in the areas that most		

Term / Legislation	Definition / Explanation		
Law Commission	Reviews New Zealand law and makes		
	recommendations to government to improve the		
	law.		
Law Foundation	Provides grants for legal research, public education		
	on legal matters, and legal training.		
Lead toolkit for employing disabled	A resource for state sector leaders, managers and		
people	human resource professionals to create an inclusive		
	and welcoming environment for disabled people.		
Leading the way in accessible	An accessibility guide published by the Ministry of		
information	Social Development for writers, communicators,		
	and designers, including web and IT tool designers,		
	production houses and procured services to the		
	public sector. A key part of the Accessibility Charter.		
LGBTQIA+	Lesbian, gay, bisexual, transgender, queer, intersex,		
	asexual +.		
List of Issues	Questions posed by the Disability Committee on		
	what it wants the Government to report back on.		
Mana Whaikaha	Prototype of the transformed disability support		
	system, launched and trialled in mid-central New		
	Zealand in October 2018.		
Minister of Justice	Currently Hon Andrew Little		
Ministry for Business, Innovation and	Plays a central role in shaping and delivering a		
Employment	strong New Zealand economy.		
Ministry of Housing and Urban	Leads New Zealand's housing and urban		
Development Ministry of Control Development	development work programme.		
Ministry of Social Development	Helping to build successful individuals, and in turn		
	build strong, healthy families and communities.		
	It does this by providing:		
	employment, income support and superappuation sorvices:		
	superannuation services;		
	funding to community service providers;		
	social policy and advice to government;		
	student allowances and loans; and		
	social housing.		
Minister for Social Development	Currently Hon Carmel Sepuloni		
Nationwide Health and Disability	Free nationwide advocacy service, operating		
Advocacy Service	independently from all health and disability service		
	providers and agencies.		

Term / Legislation	Definition / Explanation		
New Zealand Aid Programme	Delivers New Zealand's official support for		
	developing countries, with a particular focus on the		
	Pacific Islands region.		
New Zealand Bill of Rights Act 1990	Sets out the rights and fundamental freedoms of		
(NZBoRA)	anyone subject to New Zealand law, as a Bill of		
	Rights.		
New Zealand Disability Strategy	Will guide 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 Film Commission	Promoting and supporting the screen industry in		
	New Zealand.		
New Zealand Sign Language (NZSL)	One of the three official languages of New Zealand.		
Non-governmental organisation	Non-Governmental Organisation		
(NGO)			
NZ On Air	Provides operating funding to a number of		
	targeted platforms and services that provide		
	important public media content. These include		
	Access radio, Pacific and student radio, and		
	disability access services.		
NZS4121:2001	Design standard for access. It provides well-		
	integrated and workable solutions for designing		
	buildings and facilities that can be accessed and		
	used by people with disabilities.		
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 / Legislation	Definition / Explanation			
Ombudsman	An Ombudsman's role includes:			
	investigating the administrative conduct of			
	public sector agencies;			
	reviewing their decisions relating to requests			
	for official information;			
	acting as a National Preventive Mechanism			
	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	Government agency charged with guarding			
Children	children and young people.			
Privacy Act 1993	Controls how agencies collect, use, disclose, store			
	and give access to 'personal information'. Personal			
	information is information held about a living			
	person.			
Privacy Commissioner	Considers complaints under the Privacy Act 1993			
	about breaches of privacy and access to personal			
	information. Also provides guidance on privacy			
	rights.			
Protection of Personal and Property	Provides mechanisms for decision-making on			
Rights Act 1988	behalf of people who lack capacity to make			
	decisions for themselves.			
Provincial Growth Fund	The Government has allocated three billion			
	dollars over a three-year term to invest in regional			
	economic development through this fund.			
Rehabilitation International	A global organisation and network, working to			
	empower disabled people and provide solutions			
	toward achieving a more inclusive society.			
Social Security Act 2018	Repealed previous pertinent Acts to update New			
	Zealand's social security programme.			
State Party/States Parties	Governments that have signed a human rights			
State Convices Commission	treaty.			
State Services Commission	The central public service department of New			
	Zealand charged with overseeing, managing, and			
	improving the performance of the state sector and			
	its organisations.			

Term / Legislation	Definition / Explanation	
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	
Te reo Māori	The first language and an official language of New	
	Zealand.	
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).	
Treaty of Waitangi	See Te Tiriti o Waitangi, above.	
United Nations Convention on the	Also referred to as the CRPD, UNCRPD and the	
Rights of Persons with Disabilities	Disability Convention.	
(UNCRPD)		
Universal Design for Learning (UDL)	A research-based framework that helps teachers	
	plan learning to meet the diverse needs of all	
	students.	
Voice of the Young and Care	An independent service that advocates for the	
Experienced (VOYCE–Whakarongo	approach that the voices of children and young	
Mai)	people in care need to be kept at the centre of all	
	decisions made about them.	
Waitangi Tribunal	Is charged with investigating and making	
	recommendations on claims brought by Māori	
	relating to actions or omissions of the Crown,	
	largely in the period since 1840, that breach the	
	promises made in the Treaty of Waitangi (see Te	
	Tiriti o Waitangi, above).	
Welfare Expert Advisory Group	Established by the Minister for Social Development	
(WEAG)	to undertake a review of New Zealand's social	
	welfare system.	
Whakamana Tāngata: Restoring	Published in 2019 by the Welfare Expert Advisory	
Dignity to Social Security in New	Group (WEAG), this report reviews the New	
Zealand	Zealand welfare system, excluding New Zealand	
	Superannuation, the Veteran's Pension and War	
	Pensions, and the Student Support System.	
Whānau	Family	

Term / Legislation	Definition / Explanation	
World Blind Union (WBU)	Global organisation representing the estimated 253	
	million people worldwide who are blind or partially	
	sighted.	
YWCA	Supports young women's leadership, safe spaces,	
	sexuality and health, and economic independence	
	in New Zealand	

Appendix 2: Examples of engagement with the Human Rights Commission's mediation service

Engagement with the mediation service offered by the HRC is voluntary, but agreed resolutions can extend to systemic improvements as illustrated in the following examples.

- Providers of services and public places improved the accessibility and safety of sites, including those of significant national importance.
- An accommodation provider recognised the role of disability assist dogs and sought to increase awareness throughout the industry.
- An electricity company changed its policy for customers with a medical dependency on an uninterrupted electricity supply.
- A school committed to greater teacher support for students with autism spectrum disorder.
- A health-related organisation agreed to change its recruitment policy to include information about how to avoid unlawful discrimination.
- A major event venue reconsidered access for users of mobility scooters.
- A major government agency reviewed its policy and level of funding for health treatment as a result of a disability discrimination complaint.
- A car parking company sought an independent review of an accessible parking policy and practices.
- An employer amended its recruitment policy on the appropriateness of seeking medical certificates.
- An early childcare facility reviewed its policy to improve the inclusion of disabled children.
- A ticketing agency reviewed its accessibility criteria.
- A media entertainment company agreed to give its contact centre staff training on disability awareness to enable them to respond to disabled customers in an appropriately sensitive manner.
- A liquor store will make changes to processes and train staff on the responsible sale of alcohol to assist with deciding whether a customer is intoxicated (including considering the possibility that some disabilities may affect customers' speech, balance and appearance).

Appendix 3: Endnotes

- Tāngata whaikaha means people who are determined to do well. It reflects the goals and aims of people with disabilities who are determined in some way to do well, create opportunities for themselves and resist being labelled.
- 2 See https://www.odi.govt.nz/home/about-disability/disability-etiquette/, accessed March 2020.
- The group monitoring UNDRIP in New Zealand is the Independent Monitoring Mechanism of UNDRIP (IMM UNDRIP). It was established by the national forum of indigenous leaders in 2015. Members include people from the tangata whaikaha community.
- Other relevant UN human rights instruments include: UN Convention on the Rights of the Child; International Covenant on Economic, Social and Cultural Rights; Optional Protocol to the Convention against Torture; Convention on the Elimination of Discrimination against Women; and International Covenant on Civil and Political Rights.
- 5 See https://www.ombudsman.parliament.nz/resources/making-complaints-un-disability-committee-guide-new-zealanders, accessed March 2020.
- 6 See http://www.ombudsman.parliament.nz/resources-and-publications/disabilities-convention-annual-reports, accessed March 2020.
- 7 The term 'seclusion' has been used in this report but it should be noted that some disabled people believe this is a euphemistic term, preferring the term 'solitary confinement'.
- 8 See https://www.unodc.org/documents/justice-and-prison-reform/Nelson_Mandela_Rules-E-ebook.pdf, accessed March 2020.
- The national centre of evidence-based workforce development for the mental health, addiction and disability sectors in New Zealand.
- Valuing access to work: An NZIER report commissioned by the Blind Foundation for the Access Alliance, February 2017, p ii. See https://nzier.org.nz/static/media/filer_public/b1/be/b1be61f9-cf49-4cde-a0d1-2d2e8bc2ba8f/valuing_access_to_work.pdf, accessed March 2020.
- This recommendation reflects and supports recommendation 11 of the IMM UNDRIP's report regarding the implementation of the UN Declaration on the Rights of Indigenous Peoples in Aotearoa New Zealand, June 2018: Recommendation 11: That Government engage in meaningful dialogue and establish a co-design approach directly with tāngata whaikaha. Report of the Independent Monitoring Mechanism regarding the implementation of the UN Declaration on the Rights of Indigenous Peoples in Aotearoa New Zealand, June 2018, p 11-12. See retrieved May 2019 from https://www.ohchr.org/Documents/Issues/IPeoples/EMRIP/Session11/EMRIP_CRP.2.docx, accessed March 2020.
- This recommendation reflects and supports recommendations 3 and 6 of the IMM UNDRIPS's report: establish, support and sustain effective mechanisms to engage with their te Tiriti partner in order to recognise and protect self-determination in its laws, policies and practices; and incorporate a whānau ora approach to its trial of transformation of the disability support system. Report of the Independent Monitoring Mechanism regarding the implementation of the UN Declaration on the Rights of Indigenous Peoples in Aotearoa New Zealand, June 2018, p 5 and 7. See https://www.ohchr.org/Documents/Issues/IPeoples/EMRIP/Session11/EMRIP_CRP.2.docx, accessed March 2020.

- As referred to in paragraphs 60–64 of General Comment No. 7, to give effect to Article 4(3) of the Disability Convention. Committee on the Rights of Persons with Disabilities, *General comment No. 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention*, 9 November 2018. See https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/7&Lang=en, accessed March 2020.
- 14 Committee on the Rights of Persons with Disabilities, *General comment No. 6 (2018) on equality and non-discrimination*, 26 April 2018. See https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/6&Lang=en, accessed March 2020.
- See https://www.parliament.nz/en/pb/sc/business-before-committees/document/00DBSCH_INQ_7288_1/inquiry-into-the-quality-of-care-and-service-provision, accessed March 2020.
- He Ara Oranga: Report of the Government Inquiry into Mental Health and Addiction, November 2018. See https://mentalhealth.inquiry.govt.nz/inquiry-report/he-ara-oranga/, accessed March 2020.
- Welfare Expert Advisory Group, *Whakamana Tāngata: Restoring Dignity to Social Security in New Zealand*, February 2019, recommendations 26, 29–34, 40 and 41. See http://weag.govt.nz/assets/documents/WEAG-report/aed960c3ce/WEAG-Report.pdf, accessed March 2020.
- Committee on the Rights of Persons with Disabilities, *General comment No. 7* (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention, 9 November 2018, p 10. See https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/7&Lang=en, accessed March 2020.
- 19 Statistics NZ, 2013 Census Quick Stats about income See http://archive.stats.govt.nz/ Census/2013-census/profile-and-summary-reports/quickstats-income/personal-incomeethnic.aspx accessed March 2020.
- 20 Ministry of Health, Life Expectancy. See https://www.health.govt.nz/our-work/populations/maori-health/tatau-kahukura-maori-health-statistics/nga-mana-hauora-tutohu-health-status-indicators/life-expectancy accessed March 2020.
- 21 Ministry of Health, Suicide Facts: 2016 data (provisional). See https://www.health.govt.nz/publication/suicide-facts-2016-data-provisional accessed March 2020.
- Minister orders inquiry into Oranga Tamariki 'uplift' practice retrieved July 2019 see https://www.rnz.co.nz/news/national/392169/minister-orders-inquiry-into-oranga-tamariki-uplift-practice accessed March 2020.
- Stats NZ, He hauā Māori: findings from the 2013 Disability Survey Stats NZ p 6, http://archive.stats.govt.nz/browse_for_stats/health/disabilities/He-haua-maori-findings-from-2013-disability-survey.aspx, accessed March 2020.
- Office of the Director of Mental Health Annual Report 2016. See https://www.health.govt.nz/system/files/documents/publications/office-of-the-director-of-mental-health-annual-report-2016-dec17-v2.pdf, accessed March 2020.

- 25 See https://www.hrc.co.nz/our-work/indigenous-rights/our-work/expert-mechanism-rights-indigenous-peoples/, accessed March 2020.
- These issues are included in claims lodged with the *Waitangi Tribunal (Wai 2575) Māori Disability Inquiry.*
- The Waitangi Tribunal was established in 1975 to provide a legal process by which claims of breaches of the Te Tiriti o Waitangi could be investigated. In 2016, responding to many health and disability-related claims, the Waitangi Tribunal commenced a Health Services and Outcomes Kaupapa (principle/policy) Inquiry that is taking a thematic and staged approach to health and disability related claims. Stage two of this Inquiry includes Māori with disabilities.
- See https://www.hrc.co.nz/our-work/indigenous-rights/our-work/expert-mechanism-rights-indigenous-peoples/, accessed March 2020.
- Please note that there have now been some discussions between the Whānau Ora Interface Group and Te Pūtahitanga o Te Waipounamu (a Whānau Ora commissioning agency) about aligning system transformation with a whānau ora approach.
- Dr Paula Thérèse King, *Māori with Lived Experience of Disability, Part I*, commissioned by the Waitangi Tribunal for Stage Two of the Wai 2575 Health Services and Outcomes Kaupapa Inquiry, 24 June 2019, pp 351–355. See https://forms.justice.govt.nz/search/Documents/WT/wt_DOC_150437272/Wai%202575%2C%20B022.pdf, accessed March 2020.
- 31 Ibid, at p3.
- 32 Whāia Te Ao Mārama 2018–2022: The Māori Disability Action Plan. See https://www.health. govt.nz/system/files/documents/publications/whaia-te-ao-marama-2018-to-2022.pdf, accessed March 2020.
- 33 He Ara Oranga: Report of the Government Inquiry into Mental Health and Addiction, November 2018. See https://mentalhealth.inquiry.govt.nz/inquiry-report/he-ara-oranga/, accessed March 2020. Also Waatea News, 'He Ara Oranga overwhelmed by the mainstream', 5 December 2018. See https://www.waateanews.com/waateanews/x_news/MjA3MzU/Breakfast%20with%20Dale/He-Ara-Oranga-overwhelmed-by-mainstream, accessed March 2020. Also ANZASW Voice, 'Suicide prevention strategies must address social causes' (press release, 11 September 2019). See https://anzasw.nz/suicide-prevention-strategies-must-address-social-causes/, accessed March 2020.
- Bishop Manu Bennett, cited in Human Rights Commission, *Human Rights and the Treaty of Waitangi: te mana i Waitangi,* Human Rights Commission, Auckland, 2003.
- This recommendation reflects and supports recommendation 11 of the IMM UNDRIP's report regarding the implementation of the UN Declaration on the Rights of Indigenous Peoples in Aotearoa New Zealand, June 2018: Recommendation 11: That Government engage in meaningful dialogue and establish a co-design approach directly with tāngata whaikaha. Report of the Independent Monitoring Mechanism regarding the implementation of the UN Declaration on the Rights of Indigenous Peoples in Aotearoa New Zealand, June 2018, p 11-12. See retrieved May 2019 from https://www.ohchr.org/Documents/Issues/IPeoples/EMRIP/Session11/EMRIP_CRP.2.docx, accessed March 2020.

- This recommendation reflects and supports recommendations 3 and 6 of the IMM UNDRIPS's report: establish, support and sustain effective mechanisms to engage with their te Tiriti partner in order to recognise and protect self-determination in its laws, policies and practices; and incorporate a whānau ora approach to its trial of transformation of the disability support system. Report of the Independent Monitoring Mechanism regarding the implementation of the UN Declaration on the Rights of Indigenous Peoples in Aotearoa New Zealand, June 2018, p 5 and 7. See https://www.ohchr.org/Documents/Issues/IPeoples/EMRIP/Session11/EMRIP_CRP.2.docx, accessed March 2020.
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 - extending the care and protection system to include 17 year olds;
 - ensuring the views of tamariki are heard and taken into account;
 - supporting the creation of independent advocacy services (such as VOYCE); and
 - enabling a wider set of professionals to get involved in more ways.
 The Children, Young Persons, and Their Families (Oranga Tamariki) Legislation Act 2017 passed into law on 13 July 2017. Changes provide the foundations for the system by:
 - ensuring an effective and accountable child-centred system;
 - improving outcomes for Māori;
 - sharing information to better respond to vulnerable children and young people;
 and
 - changing the name of the Children, Young Persons and Their Families Act to the Oranga Tamariki Act, to reflect the nature and scope of the changes.
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