



Making Disability Rights Real in a Pandemic

Te Whakatinana i ngā Tika Hauātanga i te wā o te Urutā

The Independent Monitoring
Mechanism's report on the
New Zealand Government's
response to the COVID-19 emergency

Aotearoa | New Zealand January 2021



Making Disability Rights Real in a Pandemic 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.

Creative Commons licence: Attribution 4.0 International (CC BY 4.0)
<https://creativecommons.org/licenses/by/4.0/deed.en>

Cover image: Manaakiao Timoti – a young boy – concentrates as he blows a large bubble. Manaakiao returned with his whānau (family) to Ruatahuna during lockdown. Being in the countryside gave Manaakiao, who lives with Williams Syndrome, the chance to enjoy his affinity with animals. *Ka mate kāinga tahi, ka ora kāinga rua* (A first home dies, a second home lives). Photograph by Alan Gibson / Courtesy of Life Unlimited.

ISBN: 978-0-473-55899-4 (Print) 978-0-473-55900-7 (PDF)

January 2021

Making Disability Rights Real in a Pandemic

Te Whakatinana i ngā Tika Hauātanga i te wā o te Urutā

The Independent Monitoring Mechanism's report
on the New Zealand Government's response to the
COVID-19 emergency

Aotearoa | New Zealand

January 2021

**DPO
COALITION**

Ombudsman
Tuia kia ōrite • Fairness for all

 **NZ
Human
Rights.**
Human Rights Commission
Te Kāhui Tika Tangata

Contents

Foreword	3
Report format	6
Methodology	6
Terminology	6

Introduction	8
The Disability Convention	8
Independent Monitoring Mechanism (IMM)	9
COVID-19 in New Zealand	9
COVID-19 timeline in New Zealand	11

Executive Summary	12
--------------------------	-----------

Full list of recommendations	16
-------------------------------------	-----------

‘Our marae was built to manaaki’: a te ao Māori perspective	20
--	-----------

Access to essential goods, services, and spaces	26
--	-----------

Decision making, participation, and data	33
---	-----------

Access to information and communications	38
---	-----------

Education	45
------------------	-----------

Health	50
---------------	-----------

Work and employment	56
----------------------------	-----------

Access to justice and disabled people in places of detention	61
---	-----------

Acknowledgements	67
-------------------------	-----------

Contact information	67
----------------------------	-----------

Endnotes	68
-----------------	-----------



Caption: Tuhoro and Jessica cuddle their young son, Te Aurere Hita-Paki. Photograph by Alan Gibson / Courtesy of Life Unlimited.

Foreword

New Zealand's Independent Monitoring Mechanism (IMM) is pleased to publish *Making Disability Rights Real in a Pandemic, Te Whakatinana i ngā Tika Hauātanga i te wā o te Urutā*. In this report, we examine New Zealand's adherence to the United Nations Convention on the Rights of Persons with Disabilities (Disability Convention) during the COVID-19 emergency from late March to mid-June 2020.

New Zealand's IMM partners are the Disabled People's Organisations (DPO) Coalition, the Ombudsman, and the Human Rights Commission (HRC). The IMM's role is to evaluate and report on the extent to which disabled New Zealanders are realising their universal human rights as set out in the Disability Convention. The IMM agreed that an addendum to our third monitoring report, *Making Disability Rights Real*,

Whakatūturu Ngā Tika Hauātanga published in June 2020, would not be sufficient to convey the responses to this complex, distressing, and rapidly changing emergency situation. A discrete report was necessary.

The first cases of COVID-19 were detected in New Zealand in late February and early March 2020. On 22 April 2020, the World Health Organization (WHO) declared the pandemic as a humanitarian emergency, which posed a critical threat to the health and safety of the global community in general, and disabled people in particular. The Disability Convention requires signatory governments to protect and promote the rights of disabled people. In particular, Article 11 requires governments to uphold disability rights in situations of risk and emergency, and put in place measures to protect and ensure the safety of disabled people.

At the centre of *Making Disability Rights Real in a Pandemic* are the real experiences of disabled New Zealanders during the COVID-19 emergency. These stories have shown resilience, strength, and commitment. Some stories have been distressing, others caring and inventive. Disabled New Zealanders reported varied experiences of the COVID-19 emergency. For many disabled people, it exposed, and exacerbated, existing inequities. Although this report places its focus on these inequities, it is important to note that New Zealand's approach to the COVID-19 emergency has resulted in shorter periods of restrictions compared with other countries. Disabled people also voiced positive experiences and noted some encouraging progress.

Situations of risk and emergency, such as pandemics, affect all aspects of disabled people's lives, and therefore shines a spotlight on the implementation of the Disability Convention in its entirety. This report, therefore, is more than an evaluation of Article 11 of the Disability Convention. Through the lens of COVID-19, it provides a 2020 snapshot of the state of disability rights in New Zealand and re-affirms many of the gaps identified in the *Making Disability Rights Real* report.

It contains recommendations that are intended to inform the Government's pandemic planning, and ensure that New Zealand is well equipped to ensure disabled people's rights are upheld during future humanitarian emergencies.

Additional information about the implementation of the Disability Convention serves as an update for the United Nations Committee on the Rights of Persons with Disabilities and its upcoming periodic review of the implementation of the Disability Convention in New Zealand.



Peter Boshier

Chief Ombudsman

Ombudsman | Kaitiaki Mana Tangata



Penelope Banfield

Chair

Disabled People's Organisations Coalition



Paula Tesoriero MNZM

Disability Rights Commissioner | Kaihautū Tika Hauātanga

New Zealand Human Rights Commission | Te Kāhui Tika Tangata

Report format

Making Disability Rights Real in a Pandemic is based on disabled people's experiences during New Zealand's response to the COVID-19 emergency between 25 March and 8 June 2020.¹ The main section of the report sets out the key themes identified by the IMM as crucial to address. It identifies areas of the response that were handled well, and recommends ways the Government can improve responses to future emergency situations. First-hand accounts and observations from disabled people appear throughout the report.

Methodology

At the heart of this report are the real experiences of disabled New Zealanders who navigated these stressful and uncertain times, and continue to do so. This report is largely based on information from DPOs and the experiences of their members during the COVID-19 emergency. Additionally, the IMM held seven in-person public consultation hui around the country, from Whāngārei to Invercargill. When restrictions prevented us from holding face-to-face meetings, additional virtual meetings were held. Consultation meetings were also held with organisations and individuals. Meetings and consultation hui had enhanced flexibility to enable the participation of disabled people. Disabled people were encouraged to share their stories by emailing or writing to us if they could not attend meetings. We heard primarily from disabled people, along with their whānau and people working in the disability sector. This report was also informed by disabled people's experiences conveyed through other means, such as reports, surveys and information published by DPOs and other groups.

Terminology

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

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

COVID-19 has been used in this report, as opposed to 'coronavirus'. The term 'COVID-19 emergency' is used throughout this report, and predominantly refers to the period of a nationwide state of national emergency and the National Transition Period (25 March 2020 to 8 June 2020).

The term 'bubble' is used to describe mandatory household arrangements during periods of the COVID-19 emergency, where the Government instructed people to limit physical contact to their household or 'bubble'. Dr Tristram Ingham, Chairperson of Muscular Dystrophy New Zealand, coined this term as a way to empower disabled people to keep themselves safe during the pandemic.²



Caption: A usually busy main road in Auckland is clear of all traffic.

Introduction

The Disability Convention

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

Independent Monitoring Mechanism (IMM)

New Zealand has set up an IMM, as required by Article 33(2) of the Disability Convention. The IMM independently monitors the Government to make sure it implements the Disability Convention. The IMM partners are the Disabled People's Organisations (DPO) Coalition, the Ombudsman and the Human Rights Commission. The IMM make-up reflects Article 4(3) of the Disability Convention, which provides that decision-making processes affecting disabled people should actively include them.

The COVID-19 emergency focused the IMM's attention on disabled New Zealanders' experiences of the pandemic. Along with the development of this report, each of the IMM partners had standalone responsibilities. The DPO Coalition supported their members, documented and escalated issues, engaged with the Government and stakeholders, advocated for disabled people's rights, and produced accessible materials. As a designated National Preventative Mechanism, the Chief Ombudsman ensured oversight of the rights of disabled people in places of detention. The Chief Ombudsman also considered complaints about administrative conduct and requests for official information, and monitored disability issues across the state sector. The Human Rights Commission proactively engaged with stakeholders, while documenting and escalating issues to officials and Ministers. The Human Rights Commission also highlighted disability rights issues in the media and advocated across all platforms for the involvement of DPOs, and for equal access during the COVID-19 emergency.

COVID-19 in New Zealand

On 28 February 2020, the first case of COVID-19 was reported in New Zealand. Nearly a month later, on 21 March 2020, the New Zealand Government introduced a new Alert Level system.³ Four days later, on 25 March 2020, the country entered Level 4 'lockdown'. New Zealand declared a nationwide state of national emergency on the same day.⁴ At Alert Level 4, people were required to stay home, with a few exceptions such as performing or accessing essential services.

The Government took an elimination approach to COVID-19, rather than a suppression or mitigation approach.⁵ The IMM acknowledges that the elimination approach has been supported by many disabled New Zealanders for the following reasons.

- Disabled people are more likely than non-disabled people to have support needs that require close contact from community care workers or support workers, increasing risk and reducing the ability to physically distance.

- Some disabled people live with compromised immunity that makes them more vulnerable to COVID-19 complications.
- Disabled people who live in group homes or residential care facilities have a heightened risk of getting COVID-19 through a close-contact cluster.
- As observed overseas, an overstretched health system can lead to prioritising life-saving treatments by calculating who would benefit most. This calculation may indirectly discriminate based on age and disability.

COVID-19 timeline in New Zealand

The Government took an early and cautious approach to the COVID-19 emergency, as set out in the following timeline:⁶

January 2020 WHO declares the novel coronavirus (later named COVID-19) outbreak to be of international concern.

February 2020 28 February: the first case is reported in New Zealand.

March 2020 Early March: more cases are confirmed in New Zealand.
8 March: WHO declares COVID-19 an official pandemic.
21 March: the Government introduces a four level alert system to fight transmission of the virus.⁷

Alert Level 4 – Lockdown (likely the disease is not contained)

Alert Level 3 – Restrict (high risk the disease is not contained)

Alert Level 2 – Reduce (the disease is contained, but the risk of community transmission remains)

Alert Level 1 – Prepare (the disease is contained in New Zealand)

21 March: New Zealand moves to Alert Level 2.

23 March: New Zealand moves to Alert Level 3.

25 March: a nationwide state of national emergency is declared. New Zealand moves to Alert Level 4, country is in lockdown.

April 2020 27 April: New Zealand moves to Alert Level 3.

May 2020 13 May: state of national emergency ends (after six reviews and extensions) and is replaced by a National Transition Period. New Zealand moves to Alert Level 2.

June 2020 8 June: New Zealand moves to Alert Level 1. National Transition Period officially ends.

The COVID-19 pandemic continues as this report goes to print. New Zealand has experienced subsequent changes to Alert Levels, including national periods of Levels 2, and Alert Levels 2 and 3 in Auckland.



Caption: Lover of the outdoors, Corey Wilkie enjoys quiet-time in the bush. Photograph by Jeff McEwan / Courtesy of Life Unlimited.

Executive Summary

The COVID-19 emergency and the new Alert Level system required people to change their everyday lives suddenly to prevent the spread of COVID-19. New Zealanders had to physically distance; confine themselves to their homes, sometimes for weeks on end, and radically change the way they worked and learned. While disabled people voiced some positive experiences of the COVID-19 emergency, the restrictions exposed, and exacerbated, some existing inequities in disabled people's enjoyment of human rights.⁸

Making Disability Rights Real in a Pandemic, Te Whakatinana i ngā Tika Hauātanga i te wā o te Urutā, directly reflects disabled New Zealanders' experiences of the COVID-19 emergency and details areas where the Government did well, and where improvements are needed. Based on all the information analysed, the IMM considers there are seven key areas where urgent attention is required.

1. Access to essential goods, services, and spaces

Disabled people have the right to access essential goods, services, and spaces on an equitable basis. Access during the COVID-19 emergency was variable for disabled people. Access to food, transport, habilitation services, housing, and public spaces were identified as key areas for improvement.

2. Decision making, participation, and data

Articles 4(3) and 33(3) of the Disability Convention affirm disabled people's right to participate in decision making processes. Despite decision making groups that some disabled people and DPOs participated in, disabled people felt this was primarily of a consultative nature, often an afterthought, and they were not always remunerated for their contributions. Further, disability data collection is important for monitoring the situations of disabled people in times of humanitarian emergencies, but this was not routinely part of COVID-19 impact research and monitoring.

3. Access to information and communications

The Government has obligations under Article 21 of the Disability Convention to ensure disabled people can seek, receive, and share information and communicate in ways that are accessible to them. The COVID-19 emergency highlighted four key areas: access to digital information and communications; accessible information formats; relevance and consistency of information and communications; and facilitation of communication. A key finding within these areas was that disabled people often experienced delays receiving accessible information and communications.

4. Education

Article 24 of the Disability Convention affirms disabled people's right to access to equitable, inclusive, and quality education. The COVID-19 emergency and associated changes to education during Alert Levels 3 and 4 highlighted inequitable access and quality of education experienced by disabled people.

5. Health

Disabled people have the right to enjoy the highest attainable standard of health. During the COVID-19 emergency, disabled people reported health and wellbeing experiences less favourable than those of the general population. COVID-19 created some novel health challenges, including access to personal protective equipment (PPE) and testing. The COVID-19 emergency also exacerbated some existing inequalities for disabled people, such as mental health outcomes and access to health services.

6. Work and employment

Equal employment opportunities and conditions are important to disabled people. Changes to working environments brought about by the COVID-19 emergency created opportunities for some disabled people by improving workplace flexibility. On the other hand, it exacerbated some of the existing employment-related inequalities that disabled people are faced with on a day-to-day basis, including underrepresentation in the workforce.

7. Access to justice, and disabled people in places of detention

Article 14(2) of the Disability Convention states that disabled people who are deprived of their liberty should be treated on an equal basis with others. During the COVID-19 emergency, disabled people in places of detention encountered barriers, particularly around access to information, communications, and essential services. Article 13(2) also affirms disabled people's right to access justice on an equitable basis with others. The COVID-19 emergency and associated Alert Levels affected some disabled people's access to justice and legal services.

Overall observations — the equal citizenship of disabled people

Fundamentally, equality requires the recognition of disabled people's right to equal citizenship with others. Citizenship includes every aspect of a person's life. Reducing the barriers that disabled people face can have a profound impact of their sense of citizenship.

The human rights model of disability recognises disability as a social construct and one of several layers of identity. This model also recognises that human rights are interdependent, interrelated, and indivisible.⁹ The WHO has recognised that factors such as employment status, housing, and education can have direct and indirect impacts on health.¹⁰ This concept, 'the social determinants of health', is just one example that signposts the interdependence of the themes in this report. Employment status is a determinant of income status, and inadequate housing conditions can be a direct cause of poor health.

Conversely, reducing digital barriers could enable a disabled person to access information about transport that, in turn, could enable use of public transport. Having more transport options could enable a disabled person to independently do their

shopping or more easily participate in the labour market. Reducing barriers in one area can enable disabled people's contribution in other areas of society. One of the IMM's key findings in this report is that disabled people who experienced improved access in one area also reported increases in participation, wellbeing, and sense of belonging.

Article 3 of the Disability Convention affirms disabled people's inherent dignity, and right to be treated as equal citizens in all aspects of their lives. Progress in fully recognising disabled people's rights will remain stagnant without extensive recognition of disabled people as equal citizens, along with the acknowledgement that the rights affirmed in the Disability Convention are inherently interconnected. Disabled people's experiences of the COVID-19 emergency demonstrate that true equal citizenship requires genuine implementation of all Articles of the Disability Convention.

Talk to us

Things got confusing in the Government space. Government agencies didn't appear to be talking to each other. Sometimes government decisions were made that were detrimental to our community. There are some people in the Deaf community that raised issues directly with the Government and the Government started running with their suggestions, instead of coming to us as a representative group. They need to be aware of Art 4.3 — they must talk to DPOs. We have a few examples of this. Individuals were consulted on some things, where we, a DPO, were not, and this affected our community.

Stress-free

The Prime Minister should be given some praise, 'cos when I was in lockdown in my shed with my flatmate and my family, my mind calmed down massively. Being in one place and not being able to go anywhere, was very calming. The world was on hold. For some, it was as if all the stress was taken away.

Trust

I guess one of the good things to come out of this is that we've learnt to trust the Government more. We've got people like Dr Ashley Bloomfield on TV, and we've got to know some people that normally sit behind the politicians. They've been brought up to the front, and we know more about their expertise, as they've educated us a lot about the virus and the things we need to do to protect ourselves and others.



Caption: Sign on Auckland's Mission Bay beach reminding people to physically distance.

Full list of recommendations

Tāngata whaikaha Māori (disabled Māori)

The IMM recommends that the Government:

1. strengthens existing channels to ensure tāngata whaikaha Māori and their representative groups are part of the decision making processes in all phases (preparing, planning, execution, and recovery) of emergency responses and management, ensuring tikanga is considered in the decision making processes.

Access to essential goods, services, and spaces

The IMM recommends that the Government:

- urgently reviews and increase investment in fully subsidised transport schemes for disabled people who cannot access public transport, and provide access to reliable and consistent transport options nationwide;
- works with disabled people and their representative organisations to develop and introduce regulations for retailers and providers of essential goods and services during humanitarian emergencies. Regulations should assist retailers to establish priority processes and, therefore, ensure disabled people can access essential goods and services on an equitable basis with others; and
- develops an urgent action plan to enable families with high support needs to access respite care, and those receiving individualised funding retain flexibility to respond to any future COVID-19-related restrictions.

Decision making, participation, and data

The IMM recommends that the Government:

- works with disabled people and their representative organisations to ensure that equal opportunity is available to participate in decision making processes during emergency situations. Both the consultation process and the key information must be accessible, to ensure disabled people can provide input, and disabled people must be compensated fairly for their time and expertise;
- continues to offer disabled people the opportunity and flexibility associated with attending meetings through online meeting platforms; and
- includes data collection on disability in formal reviews of COVID-19 pandemic preparedness or outcomes.

Access to information and communications

The IMM recommends that the Government:

- establishes a multisector advisory group, involving disabled people and their representative organisations, to advise the Government on accessible information production best practice;

9. introduces accessibility legislation that requires all private providers of media to ensure information and communications are accessible; and
10. ensures there is regular and accurate data collection on the number of disabled people without access to the internet or electronic devices, and develop action plans to reduce the digital inequities that disabled people face.

Education

The IMM recommends that the Government:

11. ensures learning resources are accessible when there is a government mandate for home-based learning, including access to devices, internet, and appropriate learning material; and
12. establishes a reference group, including disabled people, their whānau, and representative organisations, reporting directly to the Ministry of Education to work on strategies to improve the access to, and quality of, home-based learning for disabled people.

Health

The IMM recommends that the Government:

13. works with disabled people and their representative organisations to establish a comprehensive understanding of their health experiences and challenges during the COVID-19 emergency, and use this information to inform future emergency planning;
14. ensures health-related information relevant to emergency situations is communicated in a logical, consistent, and accessible manner, through more than one mode of communication;
15. contractually requires providers of home-based health and support services to ensure continuity of service for disabled people during emergencies and, in doing so, ensure non-discrimination of disabled people, and people over 70 years of age employed as care and support workers;
16. ensures clear protocols for personal protective equipment (PPE) use are updated in a timely fashion in response to emerging evidence and community needs; and
17. encourages health professionals to provide reasonable accommodation to disabled people who request flexibility around the use of PPE, particularly people who are Deaf and hard-of-hearing who find face masks act as a barrier.

Work and employment

The IMM recommends that the Government:

18. implements a financial compensation policy to ensure disabled people who are expected to work from home during situations of humanitarian emergencies have access to the required technology and training;
19. increases resourcing of the Employment New Zealand Labour Inspectorate and increase the frequency of visits to workplaces where employees are on minimum wage exemption permits (while they continue to exist); and
20. provides targeted employment opportunities for disabled people as part of the Government's COVID-19 economic recovery plan, and ensures funding and contracts to the private sector include requirements to ensure employment is accessible for disabled people.

Access to justice, and disabled people in places of detention

The IMM recommends that the Government:

21. ensures reasonable accommodation, particularly disability support aids, is provided to disabled people in places of detention to allow them to effectively communicate in emergency situations;
22. ensures information on complaints processes and mechanisms is accessible and available to all disabled people in places of detention at all times without intermediary involvement of staff, and that disabled people feel supported to express their needs or concerns;
23. engages with disabled people and their representative organisations to better facilitate disabled people's access to legal advice and information during emergency situations; and
24. strengthens intersectional collection and analysis of data about disabled people at risk of violence in order to accurately record, monitor, and reduce violence towards them, including in situations of risk and emergency.



Caption: Millie Matahiki (Ngāti Porou, Ngāpuhi) stands at the lookout on Titirangi / Kaiti Hill in Gisborne. Behind her is the steel Te Maro sculpture featuring an intricate koru pattern representing a significant tipuna (ancestor) for Tairāwhiti region. Photograph by Alan Gibson / Courtesy of Life Unlimited.

‘Our marae was built to manaaki’: a te ao Māori perspective

Manaaki (support)

Going back to the marae, to close your marae, I’ve never seen that in my lifetime. It’s a place you gather, it’s an extension of your home. To see our marae be closed, that was confronting, a little bit scary. As well as that fear of the marae being closed, not being able to gather. Well no one can die, because we aren’t going to be able to grieve in the only way we know.

Tikanga (protocol)

I am a spokesperson for my marae, to man the paepae, to kōrero, I have the information that has been handed down to me I like to share with my people ... To be forced because of this COVID thing to have to change everything that you've ever known, it still doesn't sit right with me. I was brought up by my grandparents, and they were native speakers of Te Reo. We didn't have Te Reo as young kids, but we always had tikanga. My grandparents were Kaumātua and Kuia. It was because of who they were that we spent a lot of time on our marae. I know that place better than many sighted people that turn up to my marae. Tikanga Māori is a very big part of my life, and to have that disrupted like that was very hard, very hard. Especially when you couldn't go back and celebrate the lives of your loved ones.

Introduction

New Zealand needs to protect the rights of tāngata whaikaha Māori (disabled Māori) in emergency humanitarian situations. COVID-19 highlighted that the human rights of Māori are still to be fully realised. These rights are set out in Te Tiriti o Waitangi, the Disability Convention, and the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP).¹¹ Māori continue to be disadvantaged when compared to non-Māori in terms of general health outcomes, and this gap has been amplified in previous epidemics and pandemics, with our indigenous population decimated during the Spanish Flu in 1918.

Tāngata whaikaha Māori told us they were not engaged in a meaningful way from the outset of the pandemic response, even though there were existing forums and networks that could have accommodated this engagement. While the rights of indigenous people are not directly provided for in the Disability Convention, Article 4(3) requires governments to involve disabled people in decisions directly involving them and Article 30 reflects disabled people's rights to cultural life. Article 18 of UNDRIP recognises the right of indigenous peoples and their representative organisations to participate in decision making.

What happened?

Importantly, tāngata whaikaha Māori told us they saw themselves as Māori first, and hui participants spoke of issues affecting Māori generally rather than only through a disability lens.

Tāngata whaikaha Māori felt that their human rights had been breached due to tikanga being side-lined in the national response, due to the lack of a representative voice at the decision making table.

A number of marae were shut during Alert Level 4, which many found confronting and confusing. Māori view their marae as a place to manaaki (care) for their people. They stressed that marae would not put people at risk, with kaumātua (elders) taking the necessary precautions to keep everyone safe. As raised at the hui, and set out in a report by the HRC,¹² iwi worked to protect their people, especially the more vulnerable. Essential goods were distributed by iwi, and many marae workers undertook shopping for those at risk. In some remote regions, roadblocks were put in place during Alert Levels 3 and 4, when non-essential travel or travel outside the region was prohibited. Although these were in some cases supported by Police, media reporting tended not to focus on the protective aspect of these measures.

Information about COVID-19 was not always trusted by tāngata whaikaha Māori, and was often confusing. Participants felt that if tāngata whaikaha Māori had been collaboratively engaged at the beginning, the information would have been more meaningful and trusted by Māori. They also felt essential information was presented in a 'very Pākehā way' and was not always appropriate for a Māori audience. Some information on the *Unite against COVID-19* website has been translated into te reo Māori, but not all of it.¹³ Te Rōpū Whakakaupapa Urutā website proved to be a useful and trusted tool during the crisis. It offered information about COVID-19 '*for Māori, in Māori communities*'.¹⁴

During Alert Level 4,¹⁵ all gatherings were prohibited, including weddings and tangihanga (funerals). Many participants spoke of the personal loss of whānau and friends during the initial period of lockdown. They told us of the turmoil felt in their time of grief, and the importance of tangihanga. The confusion around the rules at different alert levels intensified the feeling of loss. Many spoke of trying to manage tangihanga with the new restrictions, but usually reverted back to traditional tikanga. However, it was stressed that at the centre of any decisions was the safety of those involved, and marae kaumātua should have been given the responsibility and resources to keep their people safe.

What did tāngata whaikaha Māori tell us?

Tangihanga

- Loss was experienced by many tāngata whaikaha Māori during lockdown. The confusion around permitted funeral arrangements made this feeling of grief and distress worse, as people did not believe they were able to pay their respects.
- Virtual tangihanga was seen by some, particularly kaumātua, as culturally and personally inappropriate.
- During the transition between the alert levels, particularly from Alert Level 4 to 3, whānau interpreted rules in such a way as to enable appropriate tikanga and respect for the deceased. Where attendance was limited, whānau arranged multiple groups of ten, or rotating carloads, of mourners at burials. This allowed for more people to farewell their loved one respectfully according to traditional tikanga.
- One region (Taumaranui) celebrated the lives lost during Alert Level 4 later in Alert Level 2 at a marae with many affiliations throughout the region. Karakia (rituals/prayers) were offered, and whānau brought photographs of their loved ones and were given the chance to kōrero (speak/discuss).

Tikanga

- A number of people felt that their human rights had been breached, with tikanga being overlooked and, in some cases (such as tangihanga), banned.
- Many expressed the importance of the marae to the community. Some marae delivered kai (prepared meals), groceries, hygiene packs (basic essentials), and PPE to those considered vulnerable or isolated. Some marae workers were, in turn, classified as essential workers.
- Some marae closed as, due to age and health, kaumātua were required to stay home and could no longer run events and gatherings.
- There were changes to everyday tikanga such as hongī — other ways of greeting were encouraged, with the traditional hongī replaced by raising of the eyebrows, known as the 'Kahungunu wave'. Although adaptations were generally accepted as needed, they were not always welcomed.
- Serious concerns were raised at the possibility of Police being able to enter marae without notice, based on historical context.

- Regional travel restrictions caused concern for tāngata whaikaha Māori living away from their marae. This was particularly the case for those with particular responsibilities on their marae for example, kaikōrero (orators) and kaikaranga (ceremonial callers).

Information

- Information about the rules and regulations for alert levels and restrictions was often confusing. It was presented in a 'Pākehā way', and some Māori organisations altered it to suit their communities.
- Some Ministry of Health information was translated from Easy Read into te reo Māori. This meant a loss of meaning in the translation for the intended Māori audience.
- The 'bubble' in a Māori context (whānau, hapū, and iwi) was confusing to some, as people tried to negotiate who should be included in and excluded from their respective bubbles.

Education

- Local kura (schools) delivered resources directly to homes and developed different ways to communicate with whānau and students. Some kura delivered kai, usually used for lunches, to members of their school community.
- The Ministry of Education provided a te reo Māori resource pack through its website Ki te Ao Mārama.¹⁶
- A number of kura had already set out on a path of virtual learning, which allowed for change to a virtual classroom within days. Plans were put in place for families that were unable to afford devices or internet data charges. Some kura purchased top-up cards for whānau and later sought reimbursement from the Ministry of Education, or delivered loan devices directly to households.
- Many kura provided daily karakia and traditional Māori exercise classes via online platforms. This helped school communities to stay connected and engaged.

What needs to change?

Representative tāngata whaikaha Māori organisations need to be at the decision making table and actively involved in a meaningful way. This will ensure tikanga is protected and essential information is trusted. Tāngata whaikaha Māori need to be involved at the outset, and during all planning processes leading up to emergency situations, throughout, and in the recovery phases. Working through the lens of both Te Tiriti o Waitangi and UNDRIP will support the Government to fulfil its obligations under the Disability Convention, in particular Article 4(3).

Recommendation

The IMM reiterates Recommendation 1 in the *Making Disability Rights Real* report, which called on the Government to take immediate steps to progress a mechanism by which the voice of tāngata whaikaha Māori can be formally included in policy and legislative development.¹⁷ With that in mind, the IMM further recommends that the Government:

1. strengthens existing channels to ensure tāngata whaikaha Māori and their representative groups are part of the decision making processes in all phases (preparing, planning, execution, and recovery) of emergency responses and management, ensuring tikanga is considered in the decision making processes.



Caption: Disability advocate Michael Pulman is hugged by his partner, Jess. Photograph by Alan Gibson / Courtesy of Life Unlimited.

Access to essential goods, services, and spaces

100% freedom

Taxis were free for Total Mobility (TM) card holders from 14 April to 30 June 2020 for fares up to \$80.

People with access needs meaning it is too challenging to use public transport — too stressful, too tiring, too expensive, too hard — had the freedom to go out when they wanted to. It meant we could go and experience our world independently, on our own terms, without having to worry about planning our own lives, getting from A to B. There is so much to be said about what that means for the perception of disability.

When we're not out there — engaging in our community, engaging in education, and engaging in employment — we're unseen, we're invisible. It's a matter of out of sight, out of mind. People don't perceive a problem, so the problem doesn't get fixed. So, come the 1st July, we went back to the status quo. People, again, who couldn't access public transport were relegated to relying on their friends and family and not being able to get around independently. I just find that so wrong. The Disability Convention has transport as one of its key areas of focus, specifically access to affordable and accessible public transport. The free TM scheme cost the Government \$3 million, and if continued would cost about \$12 million annually. To do this would be such a profoundly life changing, positive impact that would reach far beyond COVID.

Empty

What about the people that don't have as many options as we do, who are not online for example? Two people in particular contacted our DPO. They had mild learning disabilities, which meant they were assessed that they needed assistance to navigate the health system and have assistance with things like shopping. Their shopping support was cancelled. This was the way they got groceries, it was how they did their shopping. These are not credit card people, they would take cash out of a bank or ATM and then with a helper go and get their shopping and bring it home. It is astounding that service providers would unilaterally cancel those services. The recipients of these services do not know their way around the system, or how to stand up for themselves. These people were in genuine trouble, out of their depth and didn't know what to do. Suddenly we found ourselves doing advocacy, first of all with their service providers but in the end when it proved to be unsuccessful, we contacted Taikura (Trust) and I congratulate them for stepping up and understanding the circumstances these two people were in. It was gob-smacking that this should happen.

Introduction

The Government has an obligation to ensure disabled people can access the things they need, and have a means to move about their communities. This obligation endures during times of humanitarian emergencies. Disabled people experienced barriers to equitable access to certain goods, services, and spaces during the COVID-19 emergency.

What happened?

Disabled people experienced variable access to essential goods, services, and spaces during the COVID-19 emergency across geographic regions. Many essential services enhanced their remote platforms during Alert Levels 3 and 4. Food retailers worked with the Government to increase online shopping services and prioritised online services and delivery of groceries to disabled people partway through Alert Level 4. Regional Civil Defence emergency management groups worked with some local authorities to deliver food to some people who could not get it on their own.¹⁸ In some cases, Civil Defence funded emergency management groups and local authorities to deliver essential goods to people in self-isolation or those who had exhausted other means of government support.¹⁹

The New Zealand Transport Agency (NZTA) introduced free public transport (between 24 March and 30 June 2020) and free taxis (between 14 April and 30 June 2020) for Total Mobility Card holders. This meant disabled people who held Total Mobility Cards were eligible for free buses, trains, ferries, and taxis.²⁰

Some habilitation services for disabled people continued to operate during Alert Levels 3 and 4. The Government did not initially recognise some of these providers as essential services, but this changed partway through Alert Level 4. The Ministry of Social Development provided additional funding for disability providers, along with a Community Awareness and Preparedness grant for community groups. The Ministry of Health and the Ministry of Social Development also provided funding assurances for contracted Community Participation and Very High Needs services during the COVID-19 emergency.²¹ The Ministry of Health also allowed for more flexible use of some personalised budgets during Alert Levels 3 and 4, although this was not universally known by users.

Most energy, telecommunications, and financial service providers closed physical premises during Alert Levels 3 and 4 and moved their contact platforms online and over the phone. This created some difficulties for disabled people who relied on services that provide face-to-face access. During Alert Levels 3 and 4, some telecommunications companies provided additional internet data at no extra cost.

What did disabled people tell us?

Food

- Issues with supply and demand in supermarkets in Alert Levels 3 and 4 jeopardised the food security of disabled people who could not afford to bulk-buy items, who could not go to the supermarket in-person, or could only go during certain hours, and who had limited or no access to online shopping services.
- Reduced operating hours and restrictions on the number of people allowed in supermarkets in Alert Levels 3 and 4 meant there were often queues. Many disabled people are only allocated a few hours of home support services to assist with shopping. Waiting outside the supermarket for long periods used most, or all, of this allocation for some.
- Online grocery shopping operations were not initially set up in a way that was accessible to all. Food retailers introduced priority access for online services partway during Alert Level 4, but many disabled people did not know about these or could not access them. Many disabled people who were accustomed to using online food shopping and delivery platforms were unable to access these systems due to high demands from non-disabled users.
- Some disabled people had household management services cancelled during Alert Levels 3 and 4. This meant that people who needed assistance had to rely on whānau or community members to buy and prepare food.
- Many disabled people were advised to stay home due to their increased risk of infection. Some disabled people experienced food shortages because the support required to shop was reduced or stopped, and many had difficulty accessing online shopping services. Disabled people who relied on deliveries endured higher costs from delivery fees. Some disabled people use Work and Income food payment cards, which must be used in person.
- Some food retailers allowed one person per household at a time to shop during Alert Level 4, aside from exceptional circumstances. Some disabled people assisted by support workers were turned away from some food retailers. Some disabled parents who could not leave children at home encountered similar problems.

Transport

- Free public transport and taxis for members of the Total Mobility scheme during Alert Level 4 offered disabled people some freedom of movement. However, many disabled people were not aware of this scheme.
- Local transport authorities were not consistent in their practices. During Alert Levels 2, 3, and 4, some transport operators only allowed boarding at the back of buses, whereas the accessible entry points are at the front. When front access was unavailable, people with mobility impairments had difficulty entering at the back.

Habilitation services

- Many respite care and day activity services closed during Alert Levels 3 and 4. Some of these services have remained closed under Alert Levels 1 and 2. Some disabled people enjoyed spending more time at home, whereas some raised concerns about the effects of the prolonged closure of these services.
- The Government did not initially recognise some community care workers and support workers as essential workers. This meant some disabled people went without personal care and support for part of Alert Level 4.
- In some cases, support workers joined households during lockdown periods to provide care and support. In other cases, disabled people or their whānau had to provide this care and support. In both scenarios, the associated expenses were higher than normal without increases to Individualised Funding or Funded Family Care budgets.
- Some community care and support services had difficulties sourcing PPE during Alert Levels 3 and 4, leading to unsafe practices, sudden changes in staff, or cancellations.

Housing and public spaces

- Many disabled people felt isolated from whānau and friends during Alert Levels 3 and 4.
- The inadequate and inaccessible nature of some disabled people's homes was more oppressive under Alert Level 3 and 4 restrictions.
- Some disabled people told us that it was harder to maintain physical distancing in group home environments and residential facilities.

- Public facilities and spaces, such as libraries and cultural buildings, closed during Alert Levels 3 and 4. This was problematic for disabled people who rely on regular use of these facilities and spaces. For disabled people who rely on a routine, the closure of services and facilities was highly disruptive and upsetting. This also widened the digital divide, as many disabled people rely on the free digital resources in libraries and other public facilities.

Other essential goods and services

- Disabled people are twice as likely to be unemployed than non-disabled people and, therefore, are more likely to rely on income support. Benefit payments occur on similar days for many benefit recipients. This, in turn, led to more people utilising supermarkets on these days, increasing the risk of a disproportionate impact on disabled people of any community transmission.
- Some disabled people experienced difficulties accessing essential power, internet, financial, and welfare services during Alert Levels 3 and 4 due to limited or no physical access to premises.

Disabled People's Organisations

Disabled people told us that many DPOs and disability service providers went beyond usual expectations to protect disabled people's rights to access essential goods, services, and spaces during the COVID-19 emergency. For instance, some DPOs coordinated food parcel deliveries to disabled people, and advocated for those who had trouble accessing habilitation services. During Levels 3 and 4, some DPOs gathered data on member enquiries regarding access to essential goods, services, and spaces to identify themes and assist to resolve issues.

What needs to change?

Article 9 of the Disability Convention states that governments should ensure disabled people have access to public services and facilities on an equal basis with others. Many public services and facilities physically closed during Alert Levels 3 and 4. For disabled people who rely on in-person services rather than online or phone alternatives, physical closures hindered equitable access.

Disabled people have the right to access support services to live in the community. Article 19(b) of the Disability Convention states that disabled people should have access to a range of in-home, residential, and other community support services,

including assistance necessary to support living and inclusion in the community. Disabled people expressed their frustration with getting reliable and appropriate access to support services and personal care during Alert Levels 3 and 4. The Government needs to involve disabled people in planning to ensure continuity of appropriate support to facilitate full participation in the community on an equal basis with others, including during humanitarian emergencies.

Article 20 of the Disability Convention states that disabled people have the right to move about their communities and be independent, and that governments have an obligation to help them to do so. Lack of access to public transport, and unaffordable transport alternatives, are barriers for disabled people in New Zealand. The full Total Mobility subsidy scheme during Alert Levels 3 and 4 gave disabled people the freedom and independence to move about their communities. However, permanent changes are required to ensure disabled people have ongoing personal mobility independence in New Zealand.

Article 28 affirms disabled people's right to an adequate standard of living and social protection. Being confined to inadequate and inaccessible housing during Alert Levels 3 and 4 exacerbated associated negative impacts for some disabled people. The IMM identified housing as a key recommendation for the Government to take urgent action on in the *Making Disability Rights Real 2014–2019* report.

Recommendations

In addition to the recommendations under Articles 9, 19, and 20 in the *Making Disability Rights Real 2014–2019*, *Whakatūturū Ngā Tika Hauātanga* report, the IMM recommends that the Government:

2. urgently reviews and increase investment in fully subsidised transport schemes for disabled people who cannot access public transport, and provide access to reliable and consistent transport options nationwide;
3. works with disabled people and their representative organisations to develop and introduce regulations for retailers and providers of essential goods and services during humanitarian emergencies. Regulations should assist retailers to establish priority processes and, therefore, ensure disabled people can access essential goods and services on an equitable basis with others; and
4. develops an urgent action plan to enable families with high support needs to access respite care, and those receiving individualised funding retain flexibility to respond to any future COVID-19-related restrictions.



Caption: The Beehive, a New Zealand Parliament building. Source: Getty Images.

Decision making, participation, and data

Valuing us at the table

When Alert Level 4 Lockdown commenced, a number of COVID-19 pandemic steering and working groups were established by government agencies. I was asked to serve on at least three, yet at first, I was offered no meeting preparation or participation fees. I'm usually paid according to the State Sector Commission's guidelines for work done ... there was an opinion coming through from some that seeing that in-person contact is not required because meetings were scheduled virtually, that it's not a big deal. I let those agencies know that all of the staff on those boards and working groups are getting their salaries paid while doing this additional work and that they're (government agencies) are making use of us, exploiting our input because we want to be at the table and they think we should be thankful for being invited. The expertise of disabled consumers is not valued at equitable and equal level and although agencies make the comment that they've not got enough budget, there was clearly enough budget to get those pandemic groups mandated at a higher level.

Introduction

The IMM acknowledges that the Government has consulted more widely with the disability community in recent years.²² However, some concerns remain about a lack of genuine partnership in legislative and policy design. Article 4(3) of the Disability Convention describes the obligations of governments to consult and actively involve disabled people through representative organisations. The IMM considers that full participation of disabled people in government decision making is necessary to improve planning for future humanitarian emergencies and create positive outcomes for disabled people.

What happened?

The Minister for Disability Issues met directly with the DPO Coalition on two occasions to consider and respond to issues and risks for disabled people. The Ministry of Health set up a COVID-19 Sector Leadership Response Group, primarily comprising itself, the Ministry of Social Development (MSD) Disability Support Providers, Unions, disabled people and DPO representatives. The National Emergency Management Agency set up a National Welfare Coordination Group (NWCG) and Network of Networks including a disability network administered by the Disability Rights Commissioner, the Director of the Office for Disability Issues,²³ and a Ministry of Health Disability Advisor seconded during the COVID-19 emergency. The administrators of this network were also part of a Department of Prime Minister and Cabinet liaison mechanism designed to identify and resolve issues brought to their attention.

Senior officials from Government met on a weekly basis during the COVID-19 emergency to identify, maintain, register and initiate action on human rights, wellbeing and service issues and risks for disabled people. The Ministry of Health also set up a COVID-19 Response Communications Group, which later became the All of Government Accessible Information Group. The purpose of this group was to advise on the information required in accessible formats, to produce the information, and to monitor its publication. The Joint Venture on Family and Sexual Violence set up a Family and Sexual Violence pandemic working group which included at least one DPO representative.

These mechanisms did not necessarily function to involve disabled people in decision making, but did provide a mechanism to receive information, raise issues, and receive progress reports on actions taken.

What did disabled people tell us?

- Tāngata whaikaha Māori felt that they were not involved in decisions and that they used their own initiatives to support tāngata whaikaha Māori, rather than being able to rely on the Government to respond to their needs. Tāngata whaikaha Māori felt government officials should have engaged more closely with iwi, who could have ensured their active participation.
- Several disabled people told us that their involvement in decision making was consultative rather than genuine co-design. There were also delays in learning about Government decisions that impacted disabled people.
- Disabled people felt that their lack of participation in decision making processes was a contributing factor in several negative outcomes during the COVID-19 emergency. This lack of participation in decision making led to some disabled people feeling they had to follow guidelines that were not well considered. For instance, disabled people reported confusion over the supply of face masks to support workers, while also being unsure of the policy around the wearing masks at each Alert Level.
- While acknowledging the need for the Government to act promptly to avert a health crisis, some disabled people felt that the questions or views they raised were not fully considered. Several DPOs experienced frustrations working with Government and participating in decision-making.
- A number of disabled people adapted to using video conferencing software, such as Zoom. Disabled people, particularly those who described themselves as immuno-compromised, felt that virtual meetings provided the opportunity to participate in group meetings safely. Virtual meetings also helped people with physical impairments participate, as inaccessible venues and transport were no longer barriers. A number of disabled people felt that virtual meetings ensured equal speaking opportunities for all attendees; this was appreciated.
- Some disabled community leaders consulted were not initially offered meeting fees for their time and expertise. This was usually remedied when the issue was raised.

Disabled People's Organisations

DPOs told us that the Government made some decisions about disabled people during the COVID-19 emergency without their input or involvement. This caused frustration, as disabled people and their representative organisations are best placed to ensure effective decisions that affect them are made. Where DPOs were actively consulted on decisions, this often led to continuous improvements in accessibility

and responsiveness. For example, placement of New Zealand Sign Language (NZSL) interpreters at daily Government briefings was refined over time, based on advice from DPOs. This eventually resulted in a standalone broadcast specifically for the Deaf community, showing the NZSL interpreter in the full-screen image and the speaker in a smaller picture-in-picture.

DPOs supported disabled people to become involved in government decision making through comment and feedback during the COVID-19 emergency. DPOs played a significant role in the All of Government Accessible Information Group, as well as other COVID-19-related advisory groups. Several DPOs collected information and data on the concerns raised by their members. One organisation set up a specific enquiry line to record and collect data about concerns being raised by their community during the lockdown. This information was then used to help inform government departments of any trends that were occurring, and to help advocate for change where required.

Data

Article 31 requires the Government to collect appropriate data and statistical information to give effect to the Disability Convention. Such data should be disaggregated to assist in determining how the Government is fulfilling its obligations under the Disability Convention, and to identify and address barriers faced by disabled people.

The HRC published *Human Rights and Te Tiriti o Waitangi: COVID-19 and Alert Level 4 in Aotearoa New Zealand* in April 2020.²⁴ This report noted that the absence of disaggregated data had distinctive impacts during the COVID-19 emergency. The report also noted that out of several generic government COVID-19 surveys administered by the Government, only one appeared to ask about disability status. Further, there was limited data on COVID-19 testing of disabled people.

The Office for Disability Issues undertook four online surveys seeking feedback from the disability community about their experiences of COVID-19.²⁵ These surveys, known as *How is Life Going for the Disability Community*, also collected information from service providers and community advocates. Surveys were primarily online, but were also produced in a range of alternative formats. There were more than 800 cumulative responses across the four surveys. Most respondents felt they were managing well, and relatively positive findings were maintained across the series of the four surveys. These surveys mark an important step in collecting data to better understand disabled people's experiences of the COVID-19 emergency. In saying this, care needs to be taken to ensure that the relatively positive results do not mask the difficulties and issues that some disabled people experienced.

What needs to change?

The COVID-19 emergency highlighted areas where there is room to improve consultation and engage in co-design with disabled people. The lack of participation in some decision making was linked to other issues during the COVID-19 emergency, such as inaccessible information and difficulties accessing key goods and services. A prominent stakeholder in the disability community summarised this situation by stating *'If accessibility is not built into the DNA of our systems, issues around the participation of disabled people will continue to arise'*.

Disabled people expressed concern that consultation on preferences and needs often took place after an official decision had been made. Several DPOs said that they should have been consulted earlier on matters affecting disabled people, reported inadequate consultation and co-design in their areas of expertise. Where the Government sought advice for meeting accessibility needs of people with a specific impairment, in some instances, that advice was obtained from individuals rather than representative organisations. Lack of participation in decision making processes caused confusion, made worse by delays in updating online information or messaging. Many disabled people told us that a greater degree of participation could have helped guide government agencies on the best methods to disseminate key pandemic-related information.

We need to ensure disabled people's participation is not further disadvantaged during emergency situations. Active consultation needs to occur with DPOs to determine what their members and communities need, and how their ongoing participation can be both guaranteed and valued.

Recommendations

In addition to the recommendations under Articles 4, 31 and 33 in the *Making Disability Rights Real 2014–2019* report, the IMM recommends that the Government:

5. works with disabled people and their representative organisations to ensure that equal opportunity is available to participate in decision making processes during emergency situations. Both the consultation process and the key information must be accessible to ensure disabled people can provide input, and disabled people must be compensated fairly for their time and expertise;
6. continues to offer disabled people the opportunity and flexibility associated with attending meetings through online meeting platforms; and
7. includes data collection on disability in formal reviews of COVID-19 pandemic preparedness or outcomes.



Caption: Two government COVID-19 information posters – Stay home. Save lives. – feature along with four other advertising posters on wall facing the street in Ponsonby, Auckland.

Access to information and communications

Accessible information

Information was not produced in accessible formats in a timely way. Government agencies relied on DPOs and non-government organisations to translate material at an unreasonable pace. These organisations worked really hard to meet these deadlines, then it often took about two to three weeks to publish these accessible formats online after the information had already been released to the general population. When the accessible formats were finally uploaded, they were really difficult to find, and not all formats were available.

There was so much information available and it changed so rapidly, it was difficult to make accessible versions of COVID-19 information available to people in a timely manner. It was life or death for some people, disabled people needed the information, everyone needed the information. For example, information around lockdown rules — this would be to ensure people knew the law and wouldn't be arrested or get into trouble for unintentionally breaking lockdown rules.

Too high!

I've been thinking about what I wanted to talk about. First, I thought this was really trivial, but I now know many people had the same problem. For me, the problem was where the QR codes were placed. They were often very high up, and so a person using a wheelchair couldn't use them. Often they were really hard to find at all.

Danger of misinformation

In our region, we don't have good cell phone reception and we have low speed internet. A big problem was with the cell phone towers, because we really need them so we can receive the signals for our homes. Towers were being vandalised due to conspiracy theories. At one point, a 4G tower was burnt down, and we really needed that to allow us to communicate. Misinformation about 5G was rife, and Deaf community leaders were trying to stop this spread of misinformation. It was spreading fear. It's really important for us to have internet access as we are extremely vulnerable if we can't access information. What if we had a medical emergency?

Introduction

Barriers continue to exist for disabled people to freely communicate and access information in New Zealand. Improvements have occurred, but some aspects of Government, news media, and other important information and communication mechanisms continue to be inaccessible for disabled people.

Consistent, accurate, and timely information and communications, available in formats that everyone can understand, is particularly critical during humanitarian emergencies. International research found that effective communication and information practices are key to the success of government responses to the

COVID-19 emergency.²⁶ International academics,²⁷ along with the WHO,²⁸ praised the New Zealand Government for its communication response to COVID-19. However, improvements are still needed to ensure equity in disabled people's access to communications and information.

What happened?

Live daily briefings began as the main form of the Government's communication about the COVID-19 response. These were accessible on television, radio, and online platforms. The Government later developed further avenues of communication and information, such as websites, social media campaigns, smartphone apps, helplines, and multimedia advertisements.

What did disabled people tell us?

Many disabled people praised the Government's clear communication during the COVID-19 emergency. Disabled people also noted that communications and information about COVID-19 improved over time. In saying this, there is work to be done to ensure disabled people have equitable access to information and communications during humanitarian emergencies.

Digital information and communications

- In an increasingly digital world, disabled people are more likely to experience a 'digital divide'. A digital divide means disabled people are less likely to have access to the internet and devices, or to have the tools and skills to utilise digital technology. This is often caused by lower incomes or a lack of discretionary funds to afford devices and connections to the internet. Access to COVID-19 communications and information was highly reliant on people's access to technology. Disabled people who could not access devices or the internet often had difficulty obtaining COVID-19 communications and information elsewhere.
- The *NZ COVID Tracer* app was inaccessible for some disabled people, especially those who did not have access to the internet or a compatible device. While manual processes were available, they came with their own access barriers and privacy concerns.

- The *NZ COVID Tracer* posters were inaccessible for some disabled people. For example, blind and visually impaired people could not find the QR code posters to scan them, and disabled people using a wheelchair could not reach some QR code posters if they were placed too high.
- The Government's *Unite against COVID-19* website was inaccessible to many disabled people and did not follow the guidelines in the latest Web Accessibility Standard.²⁹ For example, some web information was not coded in the correct order for text-to-talk software to relay information logically. Additionally, the *Unite against COVID-19* chart, a primary visual source of information about the Alert Level system, did not initially have an alternative text version available.
- Disabled people reported that, at any one time, key government websites publicly displayed conflicting information, depending on how quickly guidelines were updated after Alert Level changes. These included difficulties pinpointing key information on the *Unite against COVID-19* website, as the structure of the website underwent several changes throughout the COVID-19 emergency.
- Some disabled people told us even when information about COVID-19 was produced in accessible formats, it was difficult to find on websites and other platforms. For example, accessible versions of general information often required multiple clicks and were not easy to find from the homepages of websites.

Accessible information formats

- Some disabled people raised concerns that accessible formats were not published at the same time as general information. By the time accessible formats were available, the information was often outdated.
- Where accessible formats were available on the *Unite against COVID-19* website and other government websites, disabled people had difficulty navigating the sites to find them.
- In some cases, online videos and broadcasting channels imparting important COVID-19 information did not have subtitles, NZSL interpreters or audio description.
- During COVID-19 media conferences, the NZSL interpreter was sometimes difficult to see, as they were featured in a small box on the screen. One DPO partnered with Kordia TV on channel 200 and also online, which provided a larger view of the interpreter during conferences, but the free-to-air channel 200 is not available in some parts of the country, such as Northland.

Relevance and consistency of information and communications

- Many disabled people felt overwhelmed by the large volume of information about COVID-19, some of which was conflicting and changed on a regular basis.
- Many disabled people experienced difficulty finding official information specifically relevant for disabled people. For example, many disabled people did not know that the Total Mobility Scheme — usually providing a 50 percent subsidy — provided free transport during Alert Levels 3 and 4.
- Disabled people who relied on TV and radio for information sometimes missed important live COVID-19 announcements where these were not repeated in later segments.
- Some disabled people told us they preferred to receive and/or had greater trust in COVID-19 information provided by local groups and organisations. This information was more applicable, trustworthy, and relevant than official COVID-19 information from central Government, which could be ‘Wellington-centric’.

Facilitation of communication

- The Government introduced compulsory use of face masks in certain spaces during Alert Levels 2, 3 and 4, such as on public transport. This created difficulty for many disabled people, including Deaf and hard of hearing people, who rely on lip reading to communicate.
- Some disabled people felt the Government's communication was clear during some Alert Levels, unclear during other Alert Levels, and was inconsistent between Alert Levels. For example, during Alert Levels 3 and 4, there were daily press conferences to communicate important COVID-19 information and reinforce expectations to the public. Press conferences occurred less often during Alert Levels 1 and 2, and expectations of the public were not always as clear.

Disabled People’s Organisations

- Disabled people told us that their representative DPOs and community organisations worked hard to ensure they received trustworthy, timely, and relevant information about COVID-19 in a way they could understand. Some disabled people reported that they got most or all of their information from a community organisation or DPO.

- The Government relied on some DPOs to produce COVID-19 information in accessible formats. Additionally, some organisations set up communications teams or freephone numbers to maintain contact with disabled people, as well as to monitor and respond to concerns during Alert Levels 3 and 4. DPOs and other community groups worked together to help disabled people get access to devices and the internet during the COVID-19 emergency.

How did the Government respond to concerns raised?

- The Office for Disability Issues adjusted official COVID-19 information to make it more applicable and relevant to the disability community.
- As a response to the need for timely and accurate accessible information, several government agencies established accessible information reference groups to increase information in accessible formats. The Government also consulted with disabled people and DPOs for expert advice on accessibility. This led to streamlining of accessible formats on the *Unite against COVID-19* website, the NZ COVID Tracer app, press conferences, and other official information and communications.
- The Government provided some device training and funding for disabled people to get access to devices and the internet during the COVID-19 emergency.

What needs to change?

Article 21 of the Disability Convention affirms that disabled people have the right to seek, receive, and share information in accessible formats. Without this, disabled people are often prevented from participating fully as citizens and being able to fulfil their rights to be informed and interact with the Government and the wider community. Interlinked with Article 21, Article 9 of the Disability Convention states that governments must make it possible for people to live independently and participate in their communities. Accessibility of information is vital to ensure that disabled people can receive information on an equal basis with others and, in doing so, participate equitably in society. During the COVID-19 emergency, many disabled people had difficulty accessing information and communications that were relevant, clear, and timely. The Government needs to ensure disabled people have access, on an equitable basis with others, to information and communications relating to emergency situations.

Recommendations

In addition to the recommendations under Articles 9 and 21 in the *Making Disability Rights Real 2014–2019* report, the IMM recommends that the Government:

8. establishes a multisector advisory group, involving disabled people and their representative organisations, to advise the Government on accessible information production best practice;
9. introduces accessibility legislation that requires all private providers of media to ensure information and communications are accessible; and
10. ensures there is regular and accurate data collection on the number of disabled people without access to the internet or electronic devices, and develop action plans to reduce the digital inequities that disabled people face.



Caption: Harper Veli smiles into the camera holding his hands up. Photograph by Alan Gibson / Courtesy of Life Unlimited.

Education

Lockdown learning

I was worried that my youngest wasn't getting much out of online learning. So I spoke to my kura about it, telling them that I couldn't get my baby to engage, to sit down and actually do the work. They said not to stress, they understood, and said don't force her, because she's going to hate it. I took comfort in that. With Māori learning, she was learning, when we were having kai, she learnt karakia; when baking she was learning measurement. I felt she was learning something. Even though I wasn't getting it on paper, fulfilling her daily tasks, she was learning in other aspects and our kura really emphasises alternative learning, because some children can't sit in that classroom environment.

So, I thought that even though I was doing terribly, and not achieving what the Government said I should be getting done, I was reassured by my kura that alternative learning works too.

School is school

I would like to share the journey I had with my daughter. We were trapped in our house, with two young children — a four-year-old and a six-year-old, one of who is autistic. There were no breaks, no respite, no down-time. We were on a treadmill for 24/7, for six weeks straight. Some of you had the luxury of going for walks and things like that. We have a daughter who licks everything, and you can't go for a walk with somebody who does that, especially not during COVID. She simply won't touch stuff. So we were literally trapped in our section with no support. With her schooling, all the materials they sent out were at the wrong level, so it was all way, way ahead of her. We could not sit down and teach her. School is school, home is home. They say, 'it's ok they'll catch up'. But a kid with global development delays does not catch up. Those six weeks was the equivalent of probably a year for her. So, none of that has been taken into account in the system.

Introduction

Disabled people have the right to access equitable, inclusive, and quality education. Without it, disabled people are at risk of ongoing negative socioeconomic outcomes. Despite educational rights outlined in Article 24 of the Disability Convention, educational outcomes for disabled people tend to be lower than those for than non-disabled people.³⁰ The barriers that affect disparate educational outcomes became more evident during Alert Levels 3 and 4, when home-based schooling was in place.

What happened?

During Alert Level 3, schools between Years 1 and 10, and early learning settings were only open to children who could not be supervised at home, and distance learning was provided to children off-site.³¹ Guidelines from the Tertiary Education Commission stated that Tertiary Education Organisations (TEOs) could operate classes of up to 10 students under Alert Level 3, as long as physical distancing measures were in place.³²

When New Zealand went into Alert Level 4, all schools and tertiary institutions closed their physical premises and were only open for distance learning. When New Zealand transitioned to Alert Levels 1 and 2, schools and tertiary institutions were open, and students were encouraged to attend.

The Ministry of Education arranged internet connections and computers for some households that needed them for home-based learning during Alert Levels 3 and 4. Further, the Ministry of Education posted packs of hardcopy learning materials for some households, and designed and delivered sensory and other learning packs for children receiving Ongoing Resourcing Scheme funding.³³ Lessons were broadcast on free-to-air television aimed at all age groups, with closed captioning available from the beginning of Alert Levels 3 and 4. Some classes in NZSL became available on free-to-air television, but only after the rollout of general classes. During Alert Levels 3 and 4, the Ministry of Health engaged a behavioural specialist organisation to provide remote behavioural support to children who would usually receive this support in the education environment.³⁴

What did disabled people tell us?

- Home-based learning during Alert Levels 3 and 4 disadvantaged some disabled children who needed various education supports. While some disabled children had access to remote support, this differed from supports available in a usual education setting.
- During Alert Levels 3 and 4, many parents and caregivers had to educate disabled children from home with minimal support. This was particularly difficult for parents and caregivers who had competing responsibilities, such as employment and other whānau to care for.
- Home-based learning exacerbated the impact of information and communication technology inequities that disabled people experience, known as the 'digital divide'. The Ministry of Education provided and funded some families' internet connection and devices, but this was not universal for disabled people.
- Some disabled people with varying communication preferences told us that home-based learning presented a communication barrier to their education. For example, some blind students received printed educational material in the post, rather than braille or a digital version that could be accessed with a screen reader.

- Māori-medium schools adapted well to home-based learning and provided disabled learners with appropriate tools and support.
- Some disabled tertiary students enjoyed the reduced costs and stress associated with studying from home, whereas some struggled with the isolation and lack of support while in a home learning situation.
- For some disabled learners, particularly neurodiverse learners, the change in routine was disruptive and not conducive to successful learning outcomes. On the other hand, some disabled learners found the change in environment more conducive to focused learning.
- During Alert Level 2, schools and some tertiary institutes returned to in-person learning. Disabled people raised concerns about large classroom capacities, the inability to physically distance, and younger children who are less likely to physically distance from peers. Despite strong encouragement from schools for students to return to school during Alert Level 2, some disabled parents were uncomfortable about the thought of their children returning. This was due to the fear that COVID-19 may have still been active in the community.
- Some disabled parents were not able to fulfil their role in supporting their school-aged children with home-based learning. This was largely due to inaccessibility of arrangements such as online learning tools, and communications from schools.

Disabled People's Organisations

Disabled people told us that several DPOs assisted families to gain access to internet and devices for educational purposes. In addition to this, they provided assistance to bridge communication barriers for disabled people in education settings and advocated for appropriate learning resources and support. For example, one DPO advocated for the Government to offer television-based education classes in NZSL.

What needs to change?

Article 7 of the Disability Convention affirms that governments should take all necessary measures to ensure disabled children enjoy all human rights and fundamental freedoms on an equal basis with non-disabled children. Article 24 recognises disabled people have the right to access an inclusive, quality education. Reasonable accommodation of students' requirements, and the right of students to receive support, should be consistent with the goal of full inclusion.

Recommendations

In addition to the recommendations under Article 24 in the *Making Disability Rights Real 2014–2019* report, the IMM recommends that the Government:

11. ensures learning resources are accessible when there is a government mandate for home-based learning, including access to devices, internet, and appropriate learning material; and
12. establishes a reference group, including disabled people, their whānau, and representative organisations, reporting directly to the Ministry of Education to work on strategies to improve the access to, and quality of, home-based learning for disabled people.



Caption: Entrance to the Waiheke COVID-19 Testing & Assessment Centre.

Health

Personal Protective Equipment – mixed messages

Why wasn't PPE distributed properly to everyone who needed it? There was so much confusion around PPE gear, there wasn't enough and others said there was plenty of PPE. How were we meant to get it? Who was meant to wear it? Support workers or their clients? Or both? Carers and frontline staff, especially in aged care facilities, should've had proper PPE, and had the right training around wearing it properly. Clients should have been offered the chance to wear masks so they could feel safe, and for people caring for them to feel safe, too. They should make sure there is enough PPE for everyone (support workers and clients).

Loss in lockdown

I only found out my father was seriously ill in hospital when the Police arrived on my doorstep to tell me. I had no access to a phone, TV, or internet during lockdown, so I had no way of contacting my family or them contacting me. The Police arranged for me to use my neighbour's phone, so I could call my brother to find out what was happening. My brother could visit my father as he lived in the same city. I live in another city, and it wasn't possible for me to visit him. It was about 10 days later when the Police visited me again. This time the news was worse. My father had died. It was then that I found out he had died from COVID-19. I found this really shocking because I didn't know. I had received no updates about my father's health between these visits, and I didn't get the chance to say goodbye. I know death is part of life, but I felt that my father had simply become a statistic, a number. We didn't even get a chance to have a funeral. The way this was all handled caused a lot of distress for me.

Introduction

Maintaining the health and wellbeing of disabled people was of critical importance during the COVID-19 emergency. As reported in the IMM's most recent *Making Disability Rights Real* report, disabled people — particularly those with a learning/intellectual disability — have significantly poorer health outcomes than the general population, including lower life expectancies and an increased risk of chronic health conditions.

The COVID-19 emergency placed increased pressure on New Zealand's health system and led to disruptions in the way health and disability services usually operate. Lockdown periods also had an effect on the mental health and wellbeing of many disabled people.

What happened?

There was widespread concern that disabled people would be disproportionately impacted if the spread of COVID-19 was unable to be controlled domestically. Most disabled people supported the lockdown measures and felt grateful that New Zealanders abided by the guidelines at each Alert Level.

Disabled people, particularly those receiving home-based support services, expressed concern about the continuity of these services and initial delays in designating some workers as essential during Alert Levels 3 and 4. Some disabled people reported that their health was adversely affected because support workers were unable to visit and provide assistance during the COVID-19 emergency. Some disabled people who were living in group environments felt that their living arrangements placed them at increased risk of infection because physical distancing was more difficult to maintain.

The Ministry of Health's initial guidance for PPE did not specifically address the needs of community care providers. Specific guidance was eventually published, but not until after the Alert Level 4 lockdown was lifted.

What did disabled people tell us?

Access and services

- Disabled people raised concerns about community-based health appointments being cancelled due to the risk of COVID-19 infection. They felt that these postponements were likely to lead to disabled people being further disadvantaged compared to the rest of the population. Disabled people were concerned about the lack of direct consultation afforded to them around prioritisation of essential health treatment. In many cases, disabled people did not know to whom to turn for assistance when appointments were cancelled. Several people said that uncertainties about routine medical treatment caused them anxiety.
- Guidelines and standards were confusing for disabled people who required home-based support services. Some members of the disability community advised that their usual support workers had changed, and that the worker who attended did not have a comprehensive understanding of their needs. Of significant concern was the fact that some disabled people said they did not receive any visits from support workers, despite multiple requests for assistance. It was distressing for some disabled people who were unable to leave their homes without support during the COVID-19 emergency. One individual said they were only able to eat frozen vegetables for several days.
- Some disabled people described physical distancing as a privilege, noting that in-person disability supports led to some disabled people feeling more at risk of contracting COVID-19. Disabled people were also concerned about receiving

support from people who were not wearing appropriate PPE during the initial stages of the COVID-19 response. Additionally, some disabled people reported that these workers did not change their PPE between visits. Some disabled people raised concerns that they were not provided with PPE to wear as protection from visiting carers.

- On a positive note, disabled people felt that community pharmacies were generally efficient, responsive, and able to ensure appropriate physical distancing.

Mental health and wellbeing

- For some members of the disability community, social isolation was very challenging during lockdown. For many, particularly disabled people living alone, this led to increased feelings of anxiety and depression. Some disabled people advised that they experienced a psychosocial impairment for the first time during the COVID-19 emergency. It is clear, however, that those who were proficient users of the internet felt better connected and more supported.
- By contrast, some disabled people advised that they enjoyed the lockdown. It meant they did not have to face common societal barriers on an everyday basis. Some disabled people felt that they were better equipped to deal with lockdown than the general population, given the barriers that disabled people frequently face and overcome. One individual commented that disabled people are well placed to teach the general population lessons in resilience when faced with challenging circumstances.
- Disabled people generally appreciated the daily 1pm briefings from the Government. Some noted these were a source of information they could trust, and provided reassurance. This was not the case for everyone, as some disabled people could not access 1pm briefings, while others stated that the information was not locally relevant. Some disabled people felt distressed when attempting to access health-related information on the websites of Government agencies. It was noted that the format and location of key health information on these websites moved or changed frequently, which could be unsettling. The delay and difficulties in accessing information, which was sometimes confusing, also led to anxiety for many disabled people.

Testing

- Some disabled people expressed concern about visiting COVID-19 testing services due to the possibility of long queues and the chance of transmission. This concern was greater for people with immunocompromised health.
- Some disabled people felt they should have been prioritised for testing, and that a specific time of day could have been allocated.
- Some concerns were raised about the accessibility of COVID-19 testing services and stations, and the ability for health information to be discussed privately.

Personal protective equipment (PPE)

- There was confusion throughout lockdown about the supply and distribution of PPE. Some disabled people reported that some health workers they interacted with wore it, while others did not. Many disabled people felt it was difficult to obtain PPE equipment (such as masks and hand sanitiser), and were frustrated when the general population purchased these items in bulk.
- Deaf and hard of hearing people felt there was a lack of reasonable accommodation in considering alternatives to wearing masks. Those who relied on lip-reading outlined negative experiences where health workers refused to remove their masks, even at a distance, and refused to try alternative ways of communicating (such as writing) in order to convey important information.

Disabled People's Organisations

Many disabled people told us that their representative DPOs aided them to navigate a quickly changing health environment during the COVID-19 emergency. Members of some DPOs undertook wellbeing checks by telephone with members of their community who had indicated they wanted assistance or were feeling lonely. Several DPOs undertook 'drive-by' visits to people who had no phone or internet and spoke to them from a safe distance. This was the only support or contact some disabled people had during Alert Levels 3 and 4. The Government created an online directory of mental wellbeing resources, including those produced by DPOs and non-government organisations. DPOs played an integral role in getting health-related information out to their members and communities, and some set up databases to keep a record of their constituents' enquiries, including concerns about wellbeing.

What needs to change?

Article 25 of the Disability Convention recognises that disabled people have the right to enjoy the highest attainable standard of health without discrimination on the basis of disability. During the COVID-19 emergency, disabled people reported health and wellbeing experiences less favourable than those of the general population. The fact that some disabled people believe that they can teach the general population lessons in resilience based on the barriers they routinely face, shows that there is still important work to do to ensure disabled people have equitable health access and outcomes.

We need to make sure that disabled people are not further disadvantaged in humanitarian emergencies. Support for health needs should be available during all stages of an emergency. Services must ensure any additional health needs are identified at an early stage.

Recommendations

In addition to the recommendations under Article 25 in the *Making Disability Rights Real 2014–2019* report, the IMM recommends that the Government:

13. works with disabled people and their representative organisations to establish a comprehensive understanding of their health experiences and challenges during the COVID-19 emergency, and use this information to inform future emergency planning;
14. ensures health-related information relevant to emergency situations is communicated in a logical, consistent, and accessible manner, through more than one mode of communication;
15. contractually requires providers of home-based health and support services to ensure continuity of service for disabled people during emergencies and, in doing so, ensure non-discrimination of disabled people, and people over 70 years of age employed as care and support workers;
16. ensures clear protocols for personal protective equipment use are updated in a timely fashion in response to emerging evidence and community needs; and
17. encourages health professionals to provide reasonable accommodation to disabled people who request flexibility around the use of PPE, particularly people who are Deaf and hard of hearing, who find face masks act as a barrier.



Caption: Shian McCartan stands holding a large bowl, in readiness to gather some herbs for his evening meal. Photograph by Jeff McEwan / Courtesy of Life Unlimited.

Work and employment

Job losses

I heard of people becoming unemployed. My fear for the future is that it is hard enough for 'normal' people during tough times like these, and our fear is that it's going to be harder to find roles for disabled people. There is digital access but it's still going to be a tough ride. We're going to have to look at it differently, and get the Government to look at employment differently for disabled people.

Resilience

COVID has made no difference as disabled people still experience isolation. This time many other people also experienced isolation and adapting to a new world. Perhaps disabled people could lead in helping to build non-disabled New Zealanders' coping skills and resilience in this area, especially with regard to managing the effects of COVID-19. As a country we need to develop resilience, and disabled people have a lot more resilience and have the skills to be able to do this.

Introduction

It is vitally important for disabled people to have equal work opportunities and fair employment conditions. Despite recent initiatives, such as those described in the *Working Matters* disability employment action plan, labour market and employment inequities are persistent and entrenched for disabled New Zealanders.³⁵ Disabled people have considerably lower rates of labour force participation (24 percent) compared with non-disabled people (72 percent).³⁶ Māori and Pacific people are even more underrepresented in the labour force, likely meaning tāngata whaikaha Māori³⁷ and Pacific disabled people³⁸ will face greater marginalisation. For disabled people who are employed, the COVID-19 emergency, and associated lockdowns, highlighted opportunities and increased flexibility, as well as some unfavourable employment conditions.

What happened?

During Alert Level 4, all non-essential businesses closed or had employees work from home. During Alert Level 3, some businesses could open, as long as they followed strict COVID-19 health and safety protocols. The Ministry of Social Development (MSD) introduced a wage subsidy for eligible employers to pay and retain employees during Alert Level 4 and transition periods. This subsidy ran from March to September 2020.³⁹ Many disabled people reported losing their jobs due to the economic disruption caused by Alert Levels 3 and 4, especially in hospitality, tourism, and retail. To provide further assistance, MSD introduced a 12-week COVID-19 Income Relief Payment,⁴⁰ and a COVID-19 Leave Support Scheme to help pay self-isolating employees who could not work from home.⁴¹ MSD encouraged employers to allow more flexibility for staff during the COVID-19 emergency, and provided lump sum payments to disability employment services to support their viability during this time.

What did disabled people tell us?

- Many disabled people praised the wage subsidy, because it enabled employers to continue their employment.
- During Alert Levels 3 and 4, many businesses began working remotely. Working from home better accommodated the needs of many disabled people.
- Maintaining the flexibility that arose as a result of the COVID-19 emergency could improve disabled people's future employment opportunities and working conditions.
- Due to the issues that many disabled people faced accessing the internet and devices, as well as the reliance that remote working has on technology, working from home was problematic or not possible in some cases.
- Some disabled people missed the social contact and routine that going into a place of work offered. In addition to this, many disabled people working from home had difficulty with competing priorities at home.
- Some disabled people reported higher expenses while working from home, including increased energy, telecommunications, food, and delivery costs.
- Communication over the phone and online was difficult for some disabled people who required access to alternative forms of communication.
- Some disabled workers on minimum wage exemption permits (MWEPE) were made redundant during Alert Level 4.⁴² During this time, Employment New Zealand Labour Inspectors conducted fewer workplace visits to monitor and enforce MWEPE standards.
- Disabled people already have low employment rates compared with non-disabled people. Because of this, some disabled people worried about getting a new job due to the economic downturn caused by the COVID-19 emergency.
- Some disabled people found it unfair that the 12-week COVID-19 Income Relief Payment was paid at a higher rate than most benefits.⁴³
- Some disabled essential workers felt their health was put at risk by being on work premises during Alert Levels 3 and 4.
- Employees had 90 days from the end of their employment to raise a grievance.⁴⁴ Some disabled workers considered this was an unrealistic timeline during the COVID-19 emergency, due to limited access to legal and employment assistance.

Disabled People's Organisations

DPOs and disability service providers advocated for fair employment conditions, assisted with job brokering, and facilitated access to the various wage subsidies and income support available during the COVID-19 emergency. For example, some organisations operated COVID-19 helplines, social media information pages, and website information for disabled members.

What needs to change?

Household Labour Force Survey data from August 2020 shows that only a quarter of disabled people are presently employed.⁴⁵ It is discouraging to see that the proportion of disabled people in employment has not increased in the past four years.⁴⁶ Disability Rights Commissioner, Paula Tesoriero, has publicly called for the COVID-19 recovery to invest in initiatives that are inclusive of, and accessible to, disabled people, noting:⁴⁷

COVID-19 is making employment more elusive than ever for disabled people. Businesses can assist by providing flexible work conditions and access to assistive technologies. These are relatively quick gains that can support equal access to employment opportunities for disabled people.

Article 27 of the Disability Convention affirms disabled people's right to enjoy, on an equal basis with others, freely chosen work and favourable working conditions. Many disabled people felt they had less favourable employment situations as a result of the COVID-19 emergency. Many who lost their jobs were not hopeful of gaining new employment. The Government must ensure disabled people are given fair employment opportunities and conditions. The IMM notes that Article 27 obliges governments to:

- prohibit employment discrimination on the basis of disability;
- ensure that reasonable accommodation is provided to disabled people in the workplace;
- employ disabled people in the public sector; and
- promote the universal right to employment in the private sector.

Encouraging flexible working conditions on an ongoing basis will allow more labour force participation. The WHO recommends that governments adopt flexible, work-from-home policies along with financial compensation for the required

technology. The WHO also recommends that governments provide financial compensation for families and caregivers who need to take time off work to care for loved ones. During Alert Level 3 and 4 the New Zealand Government required non-essential work premises to close, leading to large numbers of people working from home and a rapid uptake of remote working practices and technologies. Virtual meetings during Alert Levels 3 and 4 aided those with physical impairments, and provided Deaf people with access to a larger pool of NZSL interpreters. Despite encouraging changes to some employment practices during the COVID-19 emergency, disabled people's experiences of employment are overwhelmingly characterised by underemployment and unfavourable working conditions.

Recommendations

In addition to the recommendations under Article 27 in the *Making Disability Rights Real 2014–2019* report, the IMM recommends that the Government:

18. implements a financial compensation policy to ensure disabled people who are expected to work from home during situations of humanitarian emergencies have access to the required technology and training;
19. increases resourcing of the Employment New Zealand Labour Inspectorate and increase the frequency of visits to workplaces where employees are on minimum wage exemption permits (while they continue to exist); and
20. provides targeted employment opportunities for disabled people as part of the Government's COVID-19 economic recovery plan, and ensures funding and contracts to the private sector include requirements to ensure employment is accessible for disabled people.



Caption: The historic wooden Court House in the small West Coast town, Reefton.

Access to justice and disabled people in places of detention

Custody

One of our members simply didn't understand lockdown, and walks about five or six kilometres each day. During lockdown, they were stopped by Police and became very agitated. Subsequently they were taken into custody for six hours. Eventually, the situation was sorted out, but it was a very distressing time for them.

Introduction

The importance of disabled people having access to justice, including reviews of decisions and redress for errors, was particularly evident during the COVID-19 emergency. The rights and needs of disabled people in places of detention must also receive concerted attention when restrictions or reduced oversight are put in place to stop the spread of infection.

New Zealand has an international human rights obligation under the United Nations Optional Protocol to the Convention against Torture (OPCAT) to prevent torture and other cruel, inhuman, or degrading treatment or punishment for those in places of detention. Article 13 of the Disability Convention affirms disabled people's right to equal access to justice, while Article 14 recognises that disabled people should have their freedoms protected by law on an equal basis with others.

What happened?

Courts were deemed an essential service and continued to operate, at reduced capacity, during the COVID-19 emergency.

Disabled people's access to legal advice and lawyers was limited due to restrictions put in place around face-to-face visits and communication. Some disabled people found they could not access appropriate legal advice or support online, and had services deferred. Physical isolation from whānau and support networks also meant that some disabled people could not call on these supports to access services.

While some facilities took steps to reduce occupancy in places of detention, people who did remain in these facilities experienced increased restrictions aimed at preventing the risk of COVID-19 infection. These restrictions meant that COVID-19 did not enter any prisons or secure mental health or intellectual disability services during the COVID-19 emergency. However, the restrictions also affected the wellbeing of some detainees. Visits from whānau or friends were stopped, and there were changes to daily routines. These steps were unsettling and confusing, particularly in the transition between Alert Levels.

Under OPCAT, the Ombudsman conducted inspections in secure aged-care facilities, prisons, and mental health facilities during various Alert Levels in the COVID-19 emergency.

What did inspections and monitoring reveal?

Secure aged-care facilities (psychogeriatric and dementia units)

- Disabled residents' ability to raise issues or concerns in private was reduced during COVID-19 Alert Levels 3 and 4. Whānau were unable to visit, and communication using digital means often relied on the assistance of staff. Complaints boxes were frequently in reception areas of secure aged-care facilities, not commonly accessible to residents.
- Facilities inspected were physically accessible for residents of all mobility levels. Residents were usually able to access fresh air at a time of their own choosing.
- The majority of facilities ensured that residents with hearing impairments were supported to have hearing aids. One facility advised inspectors that it was not practicable to provide residents in a dementia unit with hearing aids, as these were often lost or required ongoing repairs.
- Some residents who rely on lip-reading or experienced communication difficulties found it more challenging during the COVID-19 emergency, due to physical distancing and staff wearing masks.
- Some disabled people felt safer in their aged-care facility due to the lack of physical contact with the outside world. These residents often worried about the health and wellbeing of whānau members living in the community. Other disabled people, however, felt lonely and isolated without regular visits from whānau and friends.

Prisons

- Prisoners considered by the Ministry of Health to be particularly vulnerable to COVID-19 were placed in 'medical isolation', including older people (generally over 70 years old), and those with pre-existing chronic health conditions, including dementia-related presentations.
- One prison took additional measures to develop a list of prisoners who might be particularly vulnerable to COVID-19 infection, and tailored their regime and contact with health services accordingly. Another prison had a system whereby any prisoners who reported cold or flu symptoms or mental health concerns would be seen by a medical professional the same day.
- Disabled prisoners were housed in cells appropriate to their needs, including some being located on ground floor units to accommodate accessibility needs.

Secure mental health services

- There were low occupancy rates at acute mental health facilities during COVID-19 Alert Levels 3 and 4, compared to before the COVID-19 emergency when there was a shortage of beds. This reflects an increase in transfers to community-based services.
- Contact with the outside world is critical for the psychological wellbeing of mental health service users. Restricting visitor access to facilities was one of the most significant changes introduced by the Government's alert level system. While visiting practices were disrupted, particularly during COVID-19 Alert Levels 3 and 4, some facilities allowed additional communication avenues such as video conferencing with whānau, District Inspectors, and professional services.
- Information and resources on complaints processes was not always visible or available in the facilities for service users.

Access to legal services/justice

- Some disabled people struggled to access legal advice through their usual channels (generally face-to-face) in a time of great uncertainty. This resulted in increased anxiety, and many disabled people spent a significant amount of time learning about their rights under different COVID-19 Alert Levels.
- Many disabled people reported that members of their respective communities wore 'multiple hats' in order to provide legal guidance or direction.
- Some disabled people expressed concerns about domestic violence during COVID-19 Alert Levels 3 and 4, and were unsure about where to seek support or raise concerns.

Disabled People's Organisations

Some disabled people told us that their representative DPO took on additional responsibilities in locating or summarising key information about their legal rights during the COVID-19 emergency. A number of disabled people asked a DPO to help them locate information on their rights in the absence of their usual support networks. One DPO actively advocated with the Ministry of Health to discharge all patients in secure mental health facilities who had a safe place to go, and sought evidence of what protocols were in place to prevent the spread of infection among those who remained in secure facilities.

What needs to change?

Article 14(2) of the Disability Convention states that if disabled people are deprived of their liberty through any process, they are entitled to be treated on an equal basis with others, in compliance with the objectives and principles of the Disability Convention. During the COVID-19 emergency, disabled people in places of detention experienced some barriers, particularly around accessing appropriate complaints mechanisms, and having information given to them in a clear and reliable way. Some disabled people in aged-care facilities were also denied aids to assist their understanding of key information about the pandemic. Places of detention need to ensure that they provide disabled people with reasonable accommodation, particularly during a humanitarian emergency.

According to Article 13(2), governments should ensure effective access to justice for disabled people and promote training for those working in administration of justice. Disabled people said that, due to the closure of many community-based services, they did not always know where or to whom to turn with concerns about the safeguarding of their rights. Many disabled people felt they could not easily find key information about their rights on the internet. Further work needs to be done to ensure that appropriate training on disability rights (including access to information) is provided to those working in the justice sector. This should be achieved by engaging directly with disabled people.

Recommendations

In addition to the recommendations made in the *Making Disability Rights Real 2014–2019* report, and the published reports of the Chief Ombudsman regarding secure facilities that were inspected during the COVID-19 emergency, the IMM recommends that the Government:

21. ensures that reasonable accommodation, particularly, disability support aids, is provided to disabled people in places of detention to allow them to effectively communicate in emergency situations;
22. ensures information on complaints processes and mechanisms is accessible and available to all disabled people in places of detention at all times without intermediary involvement of staff, and that disabled people feel supported to express their needs or concerns;

23. engages with disabled people and their representative organisations to better facilitate disabled people's access to legal advice and information during emergency situations; and
24. strengthens intersectional collection and analysis of data about disabled people at risk of violence in order to accurately record, monitor, and reduce violence towards them, including in situations of risk and emergency.

Acknowledgements

The IMM would like to acknowledge and thank all those who contributed to our report — sharing stories, time, and a commitment to making rights a reality for disabled New Zealanders. Your input has provided us with valuable insight into this difficult time. It will help to inform government responses and preparation for future emergency events, and help ensure that disabled people are at the decision-making table and disability rights are placed at the forefront.

We would also like to thank Life Unlimited and all those involved in the production of their book *Life in a Pandemic* for allowing us to use images in this report.⁴⁸

Contact information

Human Rights Commission

Tel: 0800 496 877 (free phone)
Email: infoline@hrc.co.nz
Website: www.hrc.co.nz
Fax: 09 377 3593 (attn: InfoLine)
TXT: 0210 236 4253
PO Box 10424, The Terrace,
Wellington 6143

Ombudsman

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

Disabled People's Organisations Coalition (DPO Coalition)

Email: us-dpo@groups.io

Endnotes

- 1 New Zealand was in a nationwide state of national emergency from 25 March to 13 May 2020, and during the immediate period after this (National Transition Period) which lasted until 8 June 2020, when the country moved to Alert Level 1.
- 2 For further information, see: <https://www.rnz.co.nz/national/programmes/afternoons/audio/2018753426/the-creator-of-the-bubble>, accessed November 2020.
- 3 Unite against COVID-19, *History of the COVID-19 alert system*. See <https://covid19.govt.nz/alert-system/history-of-the-covid-19-alert-system/>, accessed November 2020.
- 4 Civil Defence, *Declared States of Emergency*. See <https://www.civildefence.govt.nz/resources/previous-emergencies/declared-states-of-emergency/>, accessed November 2020.
- 5 An elimination approach is defined as reducing the cases of COVID-19 to zero by seeking to eliminate transmission within the community. Suppression and mitigation involve reducing the spread and burden of COVID-19. For further information on the Government's elimination strategy, see Michael G Baker et al, 'New Zealand's COVID-19 elimination strategy', *The Medical Journal of Australia*, 13 August 2020, doi:10.5694/mja2.50735.
- 6 See <https://covid19.govt.nz/alert-system/about-the-alert-system/>, <https://shorthand.radionz.co.nz/coronavirus-timeline/index.html>, <https://www.civildefence.govt.nz/resources/previous-emergencies/declared-states-of-emergency/>, and <https://covid19.govt.nz/alert-system/history-of-the-covid-19-alert-system/#timeline>, accessed November 2020.
- 7 See <https://covid19.govt.nz/assets/resources/tables/COVID-19-alert-levels-summary.pdf>, accessed November 2020.
- 8 See further information about inequality statistics for disabled people: <https://www.stats.govt.nz/infographics/the-disability-gap-2018> and <https://www.stats.govt.nz/information-releases/disability-survey-2013>, accessed November 2020.
- 9 United Nations Convention on the Rights of Persons with Disabilities, *General comment No. 6 (2018) on equality and non-discrimination*. See <https://www.ohchr.org/en/hrbodies/crpd/pages/gc.aspx>, accessed November 2020.
- 10 World Health Organization, *Rio Political Declaration on Social Determinants of Health*. See https://www.who.int/sdhconference/declaration/Rio_political_declaration.pdf?ua=1, accessed November 2020.
- 11 See <https://www.ombudsman.parliament.nz/resources/making-disability-rights-real-2014-2019-0>, accessed November 2020.
- 12 Human Rights Commission, *Human Rights and Te Tiriti o Waitangi: COVID-19 and Alert Level 4 in Aotearoa New Zealand*. See https://www.hrc.co.nz/files/6615/8819/4763/Human_Rights_and_Te_Tiriti_o_Waitangi-COVID-19_and_Alert_Level_4_FINAL.pdf, accessed November 2020.

- 13 See <https://covid19.govt.nz/updates-and-resources/translations/te-reo-maori/>, accessed November 2020.
- 14 See <https://www.uruta.maori.nz/>, accessed November 2020.
- 15 See <https://covid19.govt.nz/alert-system/alert-system-overview/#alert-level-4---lockdown>, accessed November 2020.
- 16 See <https://kauwhatareo.govt.nz/en/news-holder/ki-te-ao-marama-learning-packs/#>, accessed November 2020.
- 17 Independent Monitoring Mechanism, *Making Disability Rights Real 2014–2019*, p 44.
- 18 Civil Defence, *COVID-19 Foodbank FAQs*. See <https://www.civildefence.govt.nz/cdem-sector/guidelines/claims-factsheets/covid-19-welfare-response-and-costs-eligible-for-reimbursement/covid-19-foodbank-faqs/>, accessed November 2020.
- 19 Civil Defence, *COVID-19 Welfare Response and Costs Eligible for Reimbursement*. See <https://www.civildefence.govt.nz/cdem-sector/guidelines/claims-factsheets/covid-19-welfare-response-and-costs-eligible-for-reimbursement/>, accessed November 2020.
- 20 Deaf Aotearoa, *Total Mobility Subsidy to 30 June 2020*. See <https://www.deaf.org.nz/2020/05/total-mobility-subsidy-to-30-june-2020/>, accessed November 2020.
- 21 See <https://www.beehive.govt.nz/release/27-million-ngos-and-community-groups-continue-providing-essential-services>, accessed November 2020.
- 22 For further information, see: <https://www.ombudsman.parliament.nz/resources/making-disability-rights-real-2014-2019-0> , accessed November 2020.
- 23 The Office for Disability Issues is the designated Government focal point under Article 33(1) of the Disability Convention.
- 24 See <https://www.hrc.co.nz/news/human-rights-and-te-tiriti-need-be-part-covid-19-response/>, accessed November 2020.
- 25 See <https://www.odi.govt.nz/guidance-and-resources/how-life-is-going-for-the-disability-co/>, accessed November 2020.
- 26 PRovoke Media, *COVID-19 PR Industry Survey, second wave*. See <https://www.provokemedia.com/latest/article/covid-19-comms-us-government-worst-new-zealand-germany-best-say-pr-pros>, accessed November 2020.
- 27 A Finset, H Bosworth, P Butow et al, 'Effective health communication – a key factor in fighting the COVID-19 pandemic', 103(5), *Patient Education and Counseling*, 2020, pp 873–876.
- 28 See <https://www.stuff.co.nz/national/health/coronavirus/122074593/coronavirus-world-health-organisation-praises-nzs-covid19-response>, accessed November 2020.
- 29 New Zealand Digital Government, *Web Accessibility Standard 1.1*. See <https://www.digital.govt.nz/standards-and-guidance/nz-government-web-standards/web-accessibility-standard-1-1/>, accessed November 2020.

- 30 Statistics New Zealand, *Social and economic outcomes for disabled people: Findings from the 2013 Disability Survey*, 2014. See http://archive.stats.govt.nz/browse_for_stats/health/disabilities/social-economic-outcomes-13.aspx#gsc.tab=0, accessed November 2020.
- 31 Ministry of Education, *Guidance for schools for Alert Levels 1 – 4*. See <https://www.education.govt.nz/covid-19/advice-for-schoolskura/guidance-for-schools-for-alert-levels-1-4/#:~:text=At%20Alert%20Level%203%20a,from%20or%20stay%20at%20home>, accessed November 2020.
- 32 Tertiary Education Commission, *COVID-19 (coronavirus) information*. See <https://www.tec.govt.nz/about-us/covid-19-coronavirus-information/>, accessed November 2020.
- 33 See <https://www.education.govt.nz/news/boost-for-students-with-highest-learning-support-needs/#:~:text=Students%20with%20high%20and%20complex,a%20result%20of%20COVID%2D19.&text=This%20funding%20starts%20in%20Term,the%20end%20of%20June%2C%202021.>, accessed November 2020.
- 34 Ministry of Education, *COVID-19 and wellbeing*. See <https://www.education.govt.nz/covid-19/covid-19-and-wellbeing/>, accessed November 2020.
- 35 Ministry of Social Development, *Working Matters*, July 2020. See <https://www.msd.govt.nz/what-we-can-do/disability-services/disability-employment-action-plan/working-matters/index.html>, accessed November 2020.
- 36 Statistics New Zealand, *Labour market statistics (disability): June 2020 quarter*. See <https://www.stats.govt.nz/information-releases/labour-market-statistics-disability-june-2020-quarter>, accessed November 2020.
- 37 Ministry of Business, Innovation and Employment, *Māori labour market trends*. See [https://www.mbie.govt.nz/business-and-employment/employment-and-skills/labour-market-reports-data-and-analysis/other-labour-market-reports/maori-labour-market-trends/#:~:text=In%202017%2C%20the%20labour%20force,workers\)%20higher%20than%20in%202012](https://www.mbie.govt.nz/business-and-employment/employment-and-skills/labour-market-reports-data-and-analysis/other-labour-market-reports/maori-labour-market-trends/#:~:text=In%202017%2C%20the%20labour%20force,workers)%20higher%20than%20in%202012), accessed November 2020.
- 38 Ministry of Business, Innovation and Employment, *Pacific Peoples labour market trends*. See <https://www.mbie.govt.nz/business-and-employment/employment-and-skills/labour-market-reports-data-and-analysis/other-labour-market-reports/pacific-peoples-labour-market-trends/>, accessed November 2020.
- 39 Work and Income, *COVID-19 Wage Subsidy Extension*. See <https://www.workandincome.govt.nz/covid-19/wage-subsidy-extension/index.html>, accessed November 2020.
- 40 Work and Income, *COVID-19 Income Relief Payment*. See <https://workandincome.govt.nz/covid-19/income-relief-payment/index.html>, accessed November 2020.
- 41 Work and Income, *COVID-19 Leave Support Scheme*. See <https://workandincome.govt.nz/covid-19/leave-support-scheme/index.html>, accessed November 2020.
- 42 The 2014 concluding observations of the Committee on the United Nations Convention of the Rights of Persons with Disabilities in New Zealand was to abolish the MWEP, and these permits are currently under review.

- 43 Work and Income, *COVID-19 Income Relief Payment or a benefit*. See <https://www.workandincome.govt.nz/covid-19/income-relief-payment/better-off.html>, accessed November 2020.
- 44 Employment New Zealand, *The personal grievance process*. See <https://www.employment.govt.nz/resolving-problems/steps-to-resolve/personal-grievance/the-personal-grievance-process/>, accessed November 2020.
- 45 See <https://www.hrc.co.nz/news/new-data-shows-covid-recovery-needs-focus-disabled-people/>, accessed November 2020.
- 46 Ibid.
- 47 Ibid.
- 48 For more information, see <https://www.lifeunlimited.net.nz/home/life-in-a-pandemic/>, accessed November 2020.

**DPO
COALITION**

 **Ombudsman**
Tuia kia ōrite • Fairness for all

 **NZ
Human
Rights.**
Human Rights Commission
Te Kāhui Tika Tangata