

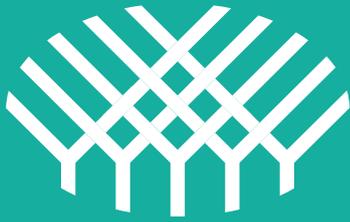
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Te Kāhui Tika Tangata  
Human Rights Commission

# Inquiry into the Support of Disabled People and Whānau During Omicron

FINAL REPORT

20 April 2022



**NZ  
Human  
Rights.**

Te Kāhui Tika Tangata  
Human Rights Commission

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Baker Consulting Ltd (Gabrielle Baker and Dr Paula Toko King) contributed to the data collection, analysis and writing of this report.

An advisory panel consisting of Dr Tristram Ingham, on behalf of Te Aō Marama and Nathan Bond, Disabled Persons Assembly NZ on behalf of the Disabled People's Organisations Coalition, supported the Commission in this phase of the Inquiry. Advice included contributions on the development of the questionnaire, recommendations, as well as additional advice and review.

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# Foreword / Introduction from Disability Rights Commissioner

The emergence of COVID-19 has brought extraordinary challenges that continue to affect the disability community in Aotearoa. COVID-19 exacerbated existing inequities for disabled people and tāngata whaikaha Māori<sup>1</sup> and their whānau.

In my view, these inequities should result in a much more concerted effort to meet the needs of this population to ensure disabled people don't fall further behind.

A fundamental human rights duty on States is to *protect*.

The full extent of the impact of COVID-19 on disabled people and tāngata whaikaha Māori is unlikely to ever be fully known due to not having quality data and evidence and robust monitoring mechanisms in place across the system. This in of itself is of grave concern to me and it is imperative this is addressed for the future.

I launched this Inquiry in March this year because I was hearing a lot of worrying anecdotes and having serious concerns raised with me. I also attended many meetings with government agencies where suggestions were made about how to better support disabled people and plan for widespread community transmission of Covid 19. These suggestions were not acted on or, if they were, there were extensive delays, which put disabled people and their whānau at risk and caused considerable distress.

I wanted to find an opportunity to give voice to disabled people, tāngata whaikaha Māori and their whānau, and to bring an evidence-base to further advocacy and preparations for the future. Thank you to the organisations and networks that provided input to this Inquiry.

Since launching my Inquiry, the government has responded positively and with urgency to some of the issues I and others were raising. I applaud their efforts. This must be sustained and pivot the way governments respond to the needs of disabled people and tāngata whaikaha Māori now and in the future.

In my view, Aotearoa New Zealand's COVID-19 elimination strategy was incredibly successful at protecting disabled people and was highly effective for 18 months. The elimination strategy undoubtedly saved countless lives, particularly before New Zealand's vaccination programme could advance significantly.

Some of the missteps and gaps in a comprehensive COVID-19 strategy for disabled people during 2020 can be understood in the context of an unprecedented global situation. However, missteps and gaps in a comprehensive COVID-19 strategy for disabled people are less understandable or tolerable at this point.

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<sup>1</sup> The Human Rights Commission recognise that there are various terms used by Māori communities. For example, some submissions used the terms Whanau Hauā, Tāngata Turi, disabled Māori, or Māori with lived experience of disability.

The move from alert levels (which allowed for widespread lockdowns) to the COVID-19 Protection Framework, saw a reduction in public health measures. In combination with the emergence of the Omicron variant and widespread transmission, risks to disabled people, tāngata whaikaha Māori and their whānau have increased.

The risks were in relation to contracting COVID-19 (noting that some people in the disability community are at significantly increased risk of adverse outcomes from COVID-19), combined with risks related to disruptions in services, exacerbation of inequitable access to health care and essential services, and needing to quickly and easily access bespoke information tailored to the needs of disabled people, tāngata whaikaha Māori and their whānau.

A whole of government mitigation strategy was needed to immediately respond to these risks. What people have told us during this Inquiry is that these mitigations were not successfully in place. This has caused considerable stress, confusion and put the well-being of disabled people at risk.

The purpose of this Inquiry is not to comment on the Government's move away from the elimination strategy, but to highlight the criticality of putting appropriate mitigations in place to address the increased risks for disabled people, tāngata whaikaha Māori and their whānau.

And most importantly, to have their voices central to the ongoing response to COVID-19.

**Paula Tesoriero MNZM, Disability Rights Commissioner**



# Executive summary

The Inquiry into the support of disabled people during the Omicron outbreak<sup>2</sup> (the Inquiry) was launched on 11 March 2022 and operates under Section 5(2)(h) of the Human Rights Act 1993. The Inquiry is in response to a number of questions raised in media, and in correspondence or other communication with the Disability Rights Commissioner (the Commissioner), about whether the rights of disabled people are being protected during the Omicron phase of Aotearoa's COVID-19 pandemic response.

This first phase of the Inquiry aimed to rapidly gather information from disabled people's community groups, networks, organisations or rōpū around their understandings of the current experiences of disabled people and their whānau, during the Omicron outbreak.<sup>3</sup> The Human Rights Commission (the Commission) approached around 35 organisations and received 30 submissions, for a response rate of over 80%. While the focus of the Inquiry is on the period since Omicron arrived in Aotearoa, information provided in these submissions has, in some instances, related to earlier stages of the pandemic response, including where the impact on disabled people and their whānau has been amplified during the Omicron outbreak.

Te Tiriti o Waitangi considerations and the international human rights framework have underpinned all stages of this Inquiry. A close analysis of the submissions received has confirmed the rights of disabled people throughout the Omicron outbreak warrant attention. It suggests that a rights-based approach can help both the current Omicron response, and any future stages of our COVID-19 pandemic response, meet the needs and aspirations of disabled people and their whānau.

## Submissions made to this phase of the Inquiry

Disabled people, tāngata whaikaha Māori, disabled Pacific peoples<sup>4</sup> and their whānau and communities have been navigating the shifting challenges of Omicron remarkably. Throughout the submissions made to phase one of the Inquiry, were numerous examples of how disabled people have come together, as whānau, as communities, as rōpū, as networks, and as organisations to share information and resources to support each other. This community response served to highlight the need for tailored information for disabled people, which has not been met by government agencies.

Naturally, each submission brought unique perspectives on the Omicron outbreak and on the impacts government action and inaction had on the rights of disabled people. Combined, these submissions shine a light on the need for Te Tiriti o Waitangi consistent, rights-based, approaches in government planning, the absence of which is shown in a perceived lack of participation, partnership

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<sup>2</sup> Since mid-December, when the first case of the Omicron variant was detected in Aotearoa New Zealand.

<sup>3</sup> For the remainder of this report, the term organisation is used to mean community groups, networks, organisations or rōpū

<sup>4</sup> The Human Rights Commission recognise that there are various terms for disabled Māori and disabled Pacific peoples used by Māori and Pacific communities. For example, some submissions used the terms Whanau Hauā, Tāngata Turi, disabled Māori, Māori with lived experience of disability, or Tagata Sa'ilimalo. Tāngata whaikaha Māori is the term used throughout this report to refer to Māori with a disability — whaikaha means 'to have ability' or 'to be enabled'. Throughout the information gathering process, submitters were encouraged to use whichever terms resonated most with them.

and engagement with disabled people and their whānau, and a lack of transparency in government decision-making.

Concerns were also raised in submissions about the need for stronger commitment to Te Tiriti o Waitangi by government agencies, in a way that creates conditions for tāngata whaikaha Māori and their whānau to express mana motuhake, and to ensure that government services and funding meet their aspirations and needs.

## Summary of themes

The aspirations and needs of disabled people and their whānau do not appear to have been given prominence in government policy and decision making throughout the pandemic. This has been amplified during the Omicron outbreak. The pre-Omicron experiences of disabled people and their whānau have also reduced their level of trust and engagement during the Omicron phase.

Many submissions shared experiences of their attempts to be heard during the earlier stages of Aotearoa's COVID-19 response. Some organisations talked of being involved on disability advisory groups, but this did not guarantee that the views and concerns of disabled people and their whānau were listened to or acted upon.

Submissions also emphasise the worry and stress that came with the shift from 'Alert Levels', to the introduction of the COVID-19 Protection Framework (also known as the Traffic Light System), and that many of the issues disabled people identified in the first two years of the COVID-19 response have worsened, while at the same time COVID-19 restrictions (and the protections they offered disabled people and their whānau, and communities) have lessened.

Across the submissions made to the first phase of the Inquiry, six main areas of concern are apparent, and point to disability appearing to be an afterthought in the government's Omicron response.

### Significant concerns with communications

While many disabled people, their whānau, and organisations have worked extremely hard to find and disseminate accessible information about Omicron and COVID-19, official communications have been considerably lacking, particularly since the start of 2022.

- Specific concerns about communications raised involve:
- Accurate and timely disability-specific information has been hard to find.
- Information has not been available in a full range of accessible formats.
- 0800 lines and websites don't work for everyone.
- Official messages keep changing, causing confusion, without an effective strategy to remedy this confusion.

While disabled people, their whānau, and organisations have plugged many of these information gaps themselves, concerns remain that critical information is not being shared in accessible ways with people who need it to make informed choices about how to stay safe and supported during Omicron. There was a sense that participatory approaches involving disabled people and their whānau as part of decision-making and design, if widely used, would ensure that key messages would be better implemented and communicated in more appropriate ways.



## **Staying safe during the pandemic**

Throughout changing restrictions and public health measures, disabled people and their whānau have experienced barriers to accessing many of the supports the government has put in place to keep Aotearoa safe during the pandemic. These include accessing vaccinations, masks, COVID-19 testing, and accessible information (for example, about exemptions or alternatives to vaccinations and/or face coverings). Even before the pandemic, disabled people and their whānau were facing inequalities, including in access to health services and inadequate income. Since the pandemic, these existing inequalities have combined with additional barriers to cause further worry and stress for disabled people. The reduction of COVID-19 protections during the Omicron outbreak has made them feel even more unsafe. As a result, many disabled people and their whānau have decided that the safest option is to effectively self-isolate from the wider community to reduce their risks of COVID-19.

## **Support to isolate safely**

As Omicron has spread, it is likely that greater numbers of disabled people and their whānau have tested positive for the virus and have been required to isolate. While much of the public messaging has encouraged households to prepare for isolation by stocking up on essentials, this requires both financial resources or savings and access to logistical support (such as arranging people to deliver groceries or medications). Expectations that people isolate in their homes also assumes housing is warm and dry and safe, which is not the case for all disabled people and their whānau.

Limited access to information has been especially stressful for disabled people and their whānau looking for support during isolation, including home care. Throughout this phase of the Inquiry a number of examples were shared of disabled people ordinarily living with flatmates, or in supported living situations, having to move in with whānau members to isolate just to be confident that their basic care needs would be met.

## **Disrupted disability support services**

On 8 February 2022, a letter was sent from the Ministry of Health, ACC and all district health boards (DHBs) advising people that, if Omicron cases were to increase, there could be staff shortages and home and community support services may need to scale back temporarily. Many disabled people and their whānau were deeply unsettled by this news as they felt they were left on their own with no means of being able to have their basic needs met. On 1 March 2022 an apology was issued for the “deep distress” caused to disabled people and their whānau, but this was sent only to providers to disseminate. For many disabled people and whānau, the damage had already been done. Significant concerns have arisen about the ability of government agencies to plan for the impacts of Omicron (or any future significant variants of COVID-19) in a way that ensures the rights of disabled people and their whānau are upheld.

Homecare support services during Omicron have in fact been disrupted for many disabled people and their whānau. The need for better systemic responses from government agencies such as the Ministry of Health, ACC and DHBs, is shared across many submissions. Submissions also highlighted the ongoing impacts on other disability support services, such as day programmes, caused by COVID-19 restrictions and the resulting impacts that these disruptions have had for disabled people and their whānau.

## Unavailable health services

Concerns around upholding the right of disabled people to enjoy the highest attainable standards of health have been raised in many submissions. Some of these concerns relate specifically to providing care to people who have tested positive for the virus, and others relate to wider issues with access to high quality health services for disabled people and their whānau during the pandemic response.

Numerous submissions highlighted the positive contributions of Māori and Pacific providers. However, there have been considerable difficulties for disabled people and their whānau in accessing support through mainstream general practice services despite reliance on these for essential COVID-19 information. In addition, access to mental health supports has been limited, concerns have been raised about accessing essential hospital-based services, and messaging and approaches between DHBs throughout the country has varied.

## Lack of support in education settings

This phase of the Inquiry has heard several concerns about education settings ranging from Early Childhood Education (ECE), to schools, and to Tertiary Education Organisations (TEOs). Issues were raised about education settings for disabled people and their whānau, especially where they have not been included in planning. Submissions cite a disconnect between policies and directions issued from the Ministry of Education and how these are implemented in schools. Each setting appears to interpret the rules differently, and at times in ways that impact negatively on disabled students and their whānau. The variable ways that schools and TEOs support (or do not support) online learning for disabled students who feel unsafe in education settings due to Omicron, featured in many submissions.

Lastly, submissions emphasised the importance of school-based supports for many disabled people and their whānau. Many of these supports have reduced or disappeared in the past few months, or are inaccessible to students who need to stay at home to avoid the serious risks of COVID-19. A systemic approach to ensuring that as many of these supports can continue to be available to disabled students and their whānau is missing.

## Recommendations and observations

Since this Inquiry was launched on 11 March 2022, increased attention has been paid to disability in the government's COVID-19 response. This includes initiatives such as working to make it easier to locate disability information, a greater number of stakeholder meetings with the community to gather feedback, and the Ministry of Health contracting resource to assist in rapidly addressing gaps. However, the wide range of concerns shared through submissions reinforce the need for further attention to ensuring the rights of disabled people and their whānau are protected throughout the government's COVID-19 response. This must be done in a way that honours Te Tiriti o Waitangi.

In advance of this Report release, and recognising the urgent need for action, the Commissioner has shared the high-level recommendations with Government. Some recommendations have already been partially or fully actioned. All recommendations are set out here for completeness.



This report has organised recommendations into four domains:<sup>5</sup>

- Taking immediate action
- Preparing for the continued responses to COVID-19
- Designing systems and policies for disability inclusiveness
- Transforming society's cultural assumptions about disability.

After considering the submissions to this phase of the Inquiry, the Commission recommends that:

### **Taking immediate action**

1. Government agencies with COVID-19 responsibilities work in partnership with disabled people and their whānau, and disabled peoples' organisations, to establish a coordinated approach to sharing COVID-19 accessible information, support (including access to masks and testing), and service navigation, developed especially for disabled people and their whānau. While this might involve a one-stop-shop, it cannot assume one size fits all. It is essential that information is provided in alternate formats and that low- or no-tech options are available for all disabled people and their whānau. This also requires:
  - a. Revamping the COVID-19 website to ensure specific information, designed for disabled people and produced in a range of alternate formats, is easily available.
  - b. Ensuring information designed for disabled people takes into account the needs of tāngata whaikaha Māori, disabled Pacific peoples and their whānau.
  - c. The contributions already made by disabled people and their whānau, and disabled peoples' organisations to produce accessible and tailored information for disabled people about COVID-19 and Omicron, be acknowledged, built on, and appropriately funded.
2. The Government's COVID-19 response immediately provide improved support to disabled people and their whānau so they can access specific Omicron supports, including:
  - a. Increasing access to free Rapid Antigen Test (RAT) kits for disabled people, to use at their discretion (for example for whānau and support workers to use when coming into the homes of disabled people).
  - b. Providing in-home support for disabled people and their whānau undertaking RATs where required.
  - c. Providing free access to P2/N95 masks for disabled people and their whānau.
  - d. Providing details on vaccination centres, including low-sensory vaccination clinic and at-home vaccination options.
3. Government agencies with disability support responsibilities (particularly the Ministry of Health, ACC and DHBs across the country):
  - a. Create a network for emergency, 24-hour, 7-days a week, caregiver support when carers are not available. This is an essential backstop for disabled people and their whānau when the usual avenues are not necessarily working.

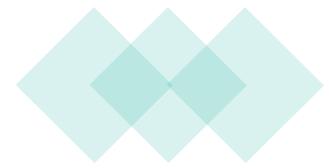
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<sup>5</sup> These recommendations have been further informed by the "practical and moral compass for action" put forward by Jones et al., (2021), and the "framework for disability-inclusive pandemic responses and systemic inequities reduction for disabled people" described in the evidence-base by Jesus et al., (2022).

- b. Make care and support available to disabled people and their whānau who are opting for self-isolation as a protection against COVID-19. The specific care and support must be determined in partnership with disabled people and their whānau.
  - c. Explore support packages for all disabled people and their whānau to provide respite care, with a focus on flexibility in use and location, that works even when COVID-19 restrictions are in place. Accessing this support needs to be as simple as possible, with minimal bureaucratic hoops.
4. Government agencies increase supports to disabled people and their whānau in education settings, especially as disabled children and young people return to in-person learning. This includes:
- a. Exploring whether teacher aide supports (funding, available hours) are sufficient.
  - b. Ensuring disabled students in schools and tertiary education have access to the technology required to continue distance learning if they choose to self-isolate to protect from the risks of COVID-19.
  - c. Supporting consistent rights-based communication of key education messages across Aotearoa, and reducing the possibility of misinterpretation of crucial education policies, to ensure schools uphold the rights of disabled people.

### **Preparing for the continued responses to COVID-19**

5. Government agencies with COVID-19 responsibilities must ensure the rights of disabled people and their whānau are protected throughout all stages of the pandemic response. This requires:
- a. A commitment to ongoing planning for disability support service disruptions and providing workable alternatives and mitigations.
  - b. An assurance that a disability lens be applied across all work. This needs to be at the whole-of-government level as well as within specific sectors (such as Health, Social Development, Education). As Cabinet has already directed government agencies to include consideration of the impacts of policy proposals on disabled people in all Cabinet papers where relevant, this recommendation relates to improving the quality of this advice and ensuring that the perspectives of disabled people and their whānau have been incorporated into advice.
  - c. Participatory approaches to ensure disabled people and their whānau are part of COVID-19 decision-making both in central government and in regional or local decision-making.
6. Government agencies should give further consideration to the findings of the Waitangi Tribunal in its 2021 *Haumarū* report into aspects of the COVID-19 response including:
- a. Funding and resourcing Māori service providers to reach communities, particularly in providing targeted support in rural areas and with the continued vaccination programme.
  - b. Providing targeted support for tāngata whaikaha Māori, including through self-isolation and caring for Māori with COVID-19.
  - c. Prioritising work to improve the quality of quantitative and qualitative data on tāngata whaikaha Māori, in partnership with Māori disability care providers and community groups.
7. Government agencies ensure that public health measures, including those around vaccinations, are applied in a way that does not disproportionately impact disabled people and their whānau.



8. Health agencies give further consideration to providing financial support to Māori providers, Pacific providers, mental health and addiction services, and other community providers delivering high quality care to disabled people, in recognition of the additional care and support they provide disabled people, many of whom feel ignored or let down by health care services during the pandemic response.

### **Designing systems and policies for disability inclusiveness (medium-term)**

9. All government agencies undertake work with disabled people to improve real-time data collection, modelling, monitoring and rapid analysis using high quality ethnicity and disability data across multiple levels including case numbers and rates, transmission, severity and access to and quality of care (including the performance of public health responses) to inform and assess strategies for disabled people.
10. All government agencies consider how best to invest in whānau as natural supports for disabled people. This includes understanding the best way to support particular communities, such as Māori and Pacific peoples.
11. All government agencies explore the impacts and possible solutions to the digital divide in Aotearoa, including its impacts on disabled people and their whānau.
12. The health sector continues work to increase availability and accessibility of mental health and addiction services for disabled people and their whānau, and ensuring services are able to respond to increased demands in the wake of the COVID-19 pandemic and its responses.

### **Transforming society's cultural assumptions about disability (medium-term)**

13. Government ensures disabled people can fully participate in all levels of the COVID-19 response, from governance and advisory roles, to supporting on the ground responses as professionals or educators.
14. Government agencies with disability support responsibilities to ensure *Mahi Aroha – the Carers' Strategy Action Plan 2019-2023* is fully implemented and that there are actions that:
  - a. Recognise the value of carers and other disability support workers.
  - b. Provide professional development for carers and other disability support workers.
  - c. Appropriately remunerate carers and other disability support workers.

### **Areas for further consideration**

A number of observations from this phase of the Inquiry require consideration by government agencies, with a view to taking action in the short to medium term. These include:

- Applying lessons learnt from the unique Māori and Pacific peoples' community approaches first highlighted during the Delta outbreak, and continuing throughout Omicron, so that tailored responses to the pandemic are not seen as a 'one-off' but as a way of working.

- Exploring financial supports and benefits for disabled people and their whānau, to recognise the ongoing costs of the COVID-19 pandemic for disabled people and their whānau, particularly as many continue to effectively self-isolate to protect themselves, despite reduced restrictions. This includes:
  - > Support to tertiary students, including through the Student Loan Scheme
  - > Extending the flexibility for Total Mobility card users accessing subsidised taxis during the earlier stages of the COVID-19 response to the current Omicron outbreak through to the end of the pandemic response.
- Undertaking further research into the longer-term society-wide impacts of disabled people and their whānau choosing to self-isolate for an extended period of time to protect themselves and their whānau.
- Ensuring that any inequities between ACC and Ministry of Health/Disability Support Services funding are identified and removed.
- Recognising the imbalance of power and risks experienced by disabled people, as set out in the two reports *Acting now for a violence and abuse free future*<sup>6</sup> and *Whakamanahia Te Tiriti, Whakahaumarutia te Tangata: Honour the Treaty, Protect the person*<sup>7</sup> released by the Human Rights Commission in December 2021, as relevant in the context of pandemic restrictions. These reports can be used as tools to advocate for changes to protect the human rights of disabled people and tāngata whaikaha Māori, and to ensure their experiences of violence that have been marginalised and ignored for many years are addressed.
- Ensuring that people experiencing long term health and disability impacts of COVID-19, including 'Long COVID'<sup>8</sup> and adverse events from vaccinations,<sup>9</sup> are responded to and supported appropriately by the whole health and disability system.
- Ensuring the health and disability system reforms currently underway prioritise better health and wellbeing outcomes for disabled people and their whānau. This includes ensuring:
  - > Disabled people and their whānau can participate in locality planning in the restructured health system from 1 July 2022.
  - > Regional variation that leads to differences between rural and urban service availability and quality is addressed.
  - > Ensuring Te Tiriti o Waitangi commitments are embedded throughout the health and disability sectors.

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<sup>6</sup> Human Rights Commission(a) (2021).

<sup>7</sup> Human Rights Commission(b) (2021).

<sup>8</sup> Akbarialiabad et al., (2021).

<sup>9</sup> Medsafe, (2022). COVID-19: Vaccine Safety Monitoring Process.



# Discussion

## Human rights and Te Tiriti framework

In Aotearoa New Zealand, Te Tiriti o Waitangi (Te Tiriti) provides a constitutional foundation upon which the Crown's human rights obligations rest. Together, te Tiriti and human rights are essential in building an inclusive and legitimate response to national crises and ensuring the health and wellbeing of disabled people and their whānau.

Te Tiriti establishes a continual and ongoing relationship between Tangata Whenua and the Crown. It affirms the status of whānau, hapū and iwi as tangata whenua and recognises their pre-existing rangatiratanga. It envisages a sharing of power and authority and a partnership of equals. Te Tiriti requires the government to act in partnership with tāngata whenua (article 1), protect tino rangatiratanga (article 2), advance equity for Māori (article 3) and enable Māori customary practices and beliefs (oral article 4). Experience shows that when Crown authority (kāwanatanga) and iwi, hapū and whānau tino rangatiratanga authority co-exist and work in partnership, effective responses can be rolled out that protect all of us, including our most at risk communities.

A Tiriti-based approach is required when developing policy that impacts disabled people – an approach that prioritises equity and ensures tāngata whaikaha Māori, as part of whānau, hapū and iwi, are resourced and supported to participate in decision-making and to develop and implement their own solutions.

In addition to its Te Tiriti commitments, the New Zealand government is bound in international law to protect human rights. The Universal Declaration of Human Rights (UDHR), the International Covenant on Economic Social and Cultural Rights (ICESR) and the International Covenant on Civil and Political Rights and associated Optional Protocols (ICCPR) – collectively known as the International Bill of Human Rights – provide the framework for the other international human rights treaties that protect and affirm ensure the rights of particular population groups. These United Nations treaties include the following, all of which have been ratified by the New Zealand Government:

- Convention on the Rights of Persons with Disabilities (CRPD)
- Convention on the Elimination of all Forms of Racial Discrimination (CERD)
- Convention on the Elimination of Discrimination Against Women (CEDAW)
- Convention on the Rights of the Child (CRC).

Domestically, the New Zealand Bill of Rights Act 1990 and the Human Rights Act 1993 give effect to many of these rights.

The New Zealand Government also supports the UN Declaration on the Rights of Indigenous People (UNDRIP). The UNDRIP is the foremost international statement on the human rights of indigenous peoples, affirming their rights to self-determination, participation in decision-making, equality and

non-discrimination, and distinct identity, culture and way of life. In its implementation, the Declaration requires States to give particular attention to the rights and special needs of indigenous persons with disabilities (Articles 22 and 23).

The CRPD is aimed at promoting, protecting and ensuring the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and promoting respect for their inherent dignity. It states that disabled people have the same civil, political, economic, social and cultural rights as all other people and acknowledges the need for a specific focus on the rights of disabled people. It must be read in conjunction with all other human rights covenants and declarations.

The CRPD sets out what is required for disabled people to attain equal enjoyment of all human rights. In particular, it recognizes that disabled people have a right of accessibility, on an equal basis with others, to enable them to live independently and participate fully in all aspects of life (Article 9), the right to live independently and be included in the community (Article 10), and the right to enjoyment of the highest attainable standard of health without discrimination on the basis of disability (Article 25).

A central feature of the CRPD is that disabled people must be involved in its implementation and monitoring. It emphasises the importance of the autonomy and active involvement of disabled people in decision-making processes about policies and programmes, including those directly concerning them (preamble and Article 3). For tāngata whaikaha Māori, tino rangatiratanga is also implicit in Articles 3, 4 and 18 of UNDRIP.

## Background to this report

The Inquiry into the support of disabled people during the Omicron outbreak<sup>10</sup> was launched on 11 March 2022 by the Disability Rights Commissioner (the Commissioner). The Inquiry operates under Section 5(2)(h) of the Human Rights Act 1993.<sup>11</sup>

The Inquiry is a response to several questions raised in media and correspondence or communication with the Commissioner, about whether the rights of disabled people are being protected during the Omicron phase of Aotearoa's COVID-19 pandemic response.

This first stage of the Inquiry aimed to gather views rapidly from organisations<sup>12</sup> on what they know about the impact of the Omicron outbreak and the easing of public health measures, on disabled people, their whānau and communities. The speed at which the Inquiry gathered information was necessary both to:

- Identify some areas for immediate action to improve the government response to Omicron, so that the rights of disabled people can be protected

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<sup>10</sup> Since mid-December, when the first case of the Omicron variant was detected in Aotearoa New Zealand.

<sup>11</sup> Section 5(2)(h) of the Human Rights Act 1993 provides for the Human Rights Commission to inquire into matters that may involve the infringement of human rights.

<sup>12</sup> In this report, the term organisation means community groups, networks, organisations or rōpū around their understandings of the current experiences of disabled people and their whānau, and community groups, networks, organisations or rōpū.



- Help shape the second phase<sup>13</sup> of the Inquiry, which will take a deeper look at the impacts of the pandemic on disabled people, whānau and communities.

The focus for phase one related to: the information available to disabled people; the adequacy of national and local planning to meet the needs of disabled people during the Omicron outbreak; the implications of new testing arrangements; and how disruptions to disability support services, in particular home-based support services, were being managed to ensure disabled people and their whānau continued to have access to essential supports during this most recent stage of the pandemic. While the focus has been clearly on the period since Omicron arrived in Aotearoa, the information provided naturally related to earlier stages of the pandemic response where the impact was amplified during the Omicron outbreak.

## Submissions and analysis

The information gathering stage was planned for between 11 March and 23 March 2022 and was extended to 4 April 2022 in response to specific requests. The Commissioner approached a range of organisations for their submissions via email and publicised the Inquiry through public media statements – leading to other organisations providing submissions. Around 35 organisations were approached and 30 submissions were received (over an 80% response rate), mostly in writing, with some audio and video recorded<sup>14</sup> (with informed consent). Submissions generally responded to a set of questions<sup>15</sup> developed by the Commissioner with the support of Baker Consulting Ltd. (an independent consultancy, engaged to support phase one of the Inquiry) and the Chair of Te Ao Mārama, a Māori Disability Advisory Group.<sup>16</sup> A small number of submissions provided information that was outside of the scope of the first phase of the Inquiry as guided by the questionnaire. All 30 submissions have been included in the analysis where appropriate.

The submissions received from these organisations have been thoughtful and compelling, and it has been important to analyse them appropriately. For phase one, analysis has been informed by Te Tiriti o Waitangi and the human rights framework. An intersectional lens was used to analyse the mechanisms by which “intersecting power relations influence social relations across diverse societies as well as individual experiences in everyday life”.<sup>17</sup> Māori scholars, including tāngata whaikaha, observe how “intersectionality has been declared an essential requisite for an equitable public health approach to the COVID-19 pandemic”.<sup>18</sup> More information on the approach to ethics and thematic analysis is provided in the Appendices.<sup>19</sup>

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<sup>13</sup> The second phase of this Inquiry is subject to resourcing decisions.

<sup>14</sup> Audio and video recordings of submissions (obtained with informed consent) of video meetings between organisations and the Disability Rights Commissioner were transcribed. NZSL interpreters were made available as requested in video meetings.

<sup>15</sup> Refer to Appendix 1.

<sup>16</sup> Te Ao Mārama is an expert Māori disability advisory group to the Ministry of Health.

<sup>17</sup> Collins and Bilge (2020), p.2.

<sup>18</sup> Jones et al., (2021), p.73.

<sup>19</sup> Refer to Appendix 2.

## Findings of this report

“Omicron not only brought a whole host of new challenges, but put additional pressures on pre-existing issues and inequalities, especially when it comes to areas such as caregiving availability and accessing non-COVID related health services. However, it’s important to note that our [disabled people and] their whānau demonstrate remarkable resilience at this time.” (Submission)

Disabled people, whānau and communities have been navigating the varying challenges of Omicron remarkably. Throughout the submissions made to this phase of the Inquiry are many examples of how disabled people have come together, as whānau, as communities, as rōpū, as networks, and as organisations to share information and resources:

“[We] are resilient, we are strong, they are resourceful, but we are exhausted, we are stressed, and they are trying to manage with fewer tools for safety than we had before we had the Omicron outbreak.” (Māori submission)

While these incredible efforts have done a lot to make sure disabled people and their whānau stay as safe as possible during Omicron, this adds to the existing impacts of ongoing ableism.

A close analysis of the submissions received from organisations has confirmed the rights of disabled people throughout the Omicron outbreak warrants attention and suggests that a rights-based approach can help both the current Omicron response and any future stages of our COVID-19 pandemic response meet the needs and aspirations of disabled people.

Submissions shared a range of concerns about the lived experiences of disabled people and their whānau during Omicron, many of which relate to the lack of rights-based approaches in government planning. This includes the lack of participation and engagement with disabled people and their whānau, advice provided but not taken, and a lack of transparency around why decisions are made.

Concerns were also raised around a perceived lack of commitment to Te Tiriti o Waitangi by government agencies in a way that creates conditions for tāngata whaikaha Māori and their whānau to express mana motuhake and ensures government services and funding meet their aspirations and needs.



## A lack of partnership with disabled people and their whānau in the government response to COVID-19

“We don’t think we have seen partnership opportunities for disabled people and their whānau.” (Submission)

The aspirations and needs of disabled people and their whānau do not appear to have been given prominence in government policy and decision making throughout the pandemic, and this has been amplified during the Omicron outbreak. Disability appears to have been an ‘afterthought’ in the pandemic planning around Omicron:

“We don’t know of any inclusion in Omicron planning at these levels. There is nothing to show that the government response to Omicron used a disability evidence base for their Protection Framework or that agencies subsequently involved or considered a disability lens in any Omicron planning or interventions.” (Māori submission)

“I think the government’s response and planning regarding Omicron has been generally incompetent and as usual the voices of [disabled people] have been the last to be heard.” (Submission)

“We weren’t given the opportunity to consult in this rapid moving space. We could have...We could have moved at speed. If somebody had rung us up and said, ‘Can you drop everything and consult on these?’ We would have done it. The whole team would have mobilised and I would speak confidently for a lot of other organisations too. We weren’t given that opportunity because it wasn’t really seen as important.” (Submission)

While this has impacted most disabled people and their whānau in some way, this ableist approach compounds with the impacts of racism for some communities:

“It’s an overarching systemic thing that the system recognises disabled people as an afterthought and then parents and family and whānau, including Māori and Pasifika within that are left out altogether. As a result there are huge equity issues coming up.” (Submission)

“Māori in general seem to always be forgotten, always grouped with Pākehā and other Pākehā groups when we should be talked to separately, not being clumped with everybody all at once I guess. It gets hard when you have one set of voices that are bigger than a majority and then you have a minority voice there as well that doesn’t usually get listened to sometimes I guess.” (Māori submission)

“The absence of an effective Te Tiriti o Waitangi partnership for tāngata whaikaha Māori and their whānau nationally has contributed to overall health and wellbeing inequities for our people compounded by the existing inequities that Māori suffer at an individual and population level.” (Māori submission)

Concerns were also expressed in the submissions that the Omicron response failed to recognise the differential impacts of the pandemic and therefore that a range of different approaches was needed to ensure equitable outcomes for disabled people:

“The Omicron response has been entirely ‘whole of population’ or a one-size-fits-all, that further contributes to inequities for disabled people. There has been NO specific targeted plan to protect or safeguard this at-risk population. This directly contravenes the Crown’s obligations under Te Tiriti o Waitangi, the United Nations Convention on the Rights of Persons with Disability and the United Nations Declaration on the Rights of Indigenous Peoples.” (Māori submission)

Many submissions shared experiences of trying to be heard during the earlier stages of the COVID-19 response, such as through participation in Ministry of Health advisory groups. However, several submissions raised concerns that disabled people on advisory groups were not listened to or acted on:

“While in theory the groups provide opportunity for organisations to share the challenges that the disabled community face during this pandemic, our representatives have felt that despite repeatedly highlighting issues, concerns were left unaddressed...In March 2020, several groups formed as a response to the pandemic, including groups focused on disability issues. The plans put in place and advice given at that time do not appear to have been carried through to present day. For example, official communications continue to be in inaccessible formats and disabled people continue to experience barriers to accessing key health responses such as vaccinations and testing.” (Submission)

“I’ve been on two [Ministry of Health] groups – I don’t think any of our suggestions were ever followed, especially with regard for the needs of Māori and Pasifika in South Auckland.” (Submission)

These concerns have grown with the introduction of the COVID-19 Protection Framework (known as the Traffic Light System) as many of the issues disabled people identified in the first two years of the COVID-19 response have become worse, while at the same time COVID-19 restrictions (and the protections they offered disabled people, whānau, and communities) have lessened:

“They were often being told by non-disabled both in person and via the media, in particular business interests, that we should just be getting on with getting back to normal. [We are] being made to feel like we are overreacting, fearful, instead of the fact we are making sensible decisions based on our health and risk factors.” (Submission)



“We feel that the voice of tagata sa’ilimalo, tāngata whaikaha and disabled people more widely, has not been given a sufficient profile to influence the public conversation that surrounds the pandemic policy.” (Pacific peoples submission)

Across the submissions made to the first phase of this Inquiry, six main areas of concern are apparent, stemming from disability appearing to be an afterthought in the government’s Omicron response. These six areas are outlined in the following sections:

- Significant concerns with communications
- Staying safe during the pandemic
- Support to isolate safely
- Disrupted disability support services
- Unavailable health services
- Lack of support in education settings.

## Significant concerns with communications

While many groups of disabled people have worked tirelessly to find, produce, and disseminate accessible information about Omicron and COVID-19, many submissions to phase one of the Inquiry described a lack of clear and concise official communications targeted to disabled people and their whānau, particularly since the start of 2022:

“Early in the pandemic, disability support services advised their communities of support services available during different alert levels... Since moving to the traffic light system, disability-specific information such as accessing disability support services has been received in a more sporadic nature.” (Submission)

Specific concerns about communications raised throughout this phase of the Inquiry are set out below.

### **Accurate and appropriate information is hard to find**

Information about Omicron, specifically prepared for disabled people, is either unavailable or hard to find. This includes information on masks, how to undertake rapid antigen tests (RATs), and where to access supports.

When information is available it is often confusing or repetitive, making it hard to identify the most important messages:

“Quite often... what we have received is just a barrage of information and it’s not answering the questions that are top of mind for our families and whānau.”  
(Submission)

“There is no ‘one stop shop’ for all COVID-19 related information and the COVID-19 website does not have enough disability specific information.” (Submission)

Many concerns were also raised around how the information that was available was not actually designed for disabled people:

“The communications side of things is really important... it was easy to find what to do if I test positive but what do I do if I test positive AND I have a disability?... The biggest communication breakdown is that there is nowhere to go if you’re slightly outside the box.” (Submission)

Often the lack of appropriate information from government sources (such as the Ministry of Health) designed for disabled people meant that community groups, networks, organisations or rōpū, and whānau and individuals had to look for, and share information themselves:

“We have had to source information from outside the Ministry of Health as they could only provide generic information and even this was very delayed.” (Submission)

Several submissions highlighted that the lack of accurate and clear information designed for disabled people and their whānau created unnecessary worry and stress, on top of the already heavy demands of the pandemic:

“Disabled people and whānau reported that information about managing COVID was in many cases variable, inconsistent, misleading and in some cases created stigmatisation and disadvantage.” (Submission)

## **Information is not in accessible formats**

Information is not always available in accessible formats, which limits the ability of disabled people to make fully informed decisions during the Omicron outbreak:

“Despite obligations under the UNCRPD and repeated requests, many government communications continue to remain inaccessible. For example, images without descriptions and videos without captioning.” (Submission)

Significant effort has gone into producing information in a range of accessible formats (including New Zealand Sign Language (NZSL) translations) often led by disabled peoples’ organisations and other disability groups. Information shared as part of this Inquiry outlined the growing workload of people skilled in producing Easy Read material as they aimed to provide accessible versions of complex messages around COVID-19 as quickly as possible. Submissions highlighted disappointment around material being developed that was not disseminated in a way that was user-friendly for disabled people, specifically, the lack of printed copies of Easy Read material produced for the Department of Prime Minister and Cabinet.



A number of submissions also noted that, even when accessible formats were produced, they were not shared with disabled people quickly:

“The different disability groups dealing with the district health boards made sure that information was accessible and that the advice was correct. We worked with the Pandemic COVID Disability team. However, while it was made accessible, it has not gone out in a timely manner, and it hasn’t been easy to access or for some to even understand because some of the providers don’t know what they’re doing either.”  
(Māori submission)

### **0800 lines and websites do not work for everyone**

As many submissions noted, information about the pandemic response during Omicron is mostly shared online. While for some disabled people this works well, for others it remains inaccessible.

Numerous submissions highlighted issues with the use of 0800 numbers. It is unsurprising that some people would prefer to be able to call and talk to someone over the phone when they have queries or concerns, while others would prefer to have text message responses. The health system should be able to accommodate both styles of communication. What these submissions had in common was the sense that when they asked for solutions that would work for disabled people, they felt dismissed or ignored:

“The response has been that there is already a COVID healthline and people can use that service, we again explained the accessibility issues that raises, which was disappointing.” (Submission)

Many submissions raised the issue of the digital divide in Aotearoa – where not everyone has access to computers, tablets or smartphones. Even if they do not everyone has access to internet or data that allows them to find the information they need:

“Often a case of ‘no cell phone, no communication’.” (Submission)

“Systems and processes devised to provide information or access to healthcare (or any government services) that rely on the presumption of access to a smartphone or computer and a reliable connection will always leave a significant proportion of our communities out. For many, phones are available but not the funds needed to access a connection.” (Submission)

## Official messages keep changing, causing confusion

Official messages are changing rapidly, as are restriction levels during the Omicron outbreak. This has made most of the communication issues for many disabled people and their whānau worse:

“We get Omicron’s changing by the week but we have members that are multi-impaired so they might also have an intellectual disability as well and they find it difficult to actually process the first lot of information and the next minute you get a whole lot of new information that comes through afterwards like a week later.” (Māori submission)

Rapidly changing information and advice, for example, on different Traffic Light settings, means that disabled people and their whānau, and community groups, networks, organisations or rōpū often hear about changes from media before they hear about it from any official source. This adds to confusion about what the rules are, what advice to follow, and how to get support:

“At times we have accessed information from our members or journalists before receiving it from government agencies.” (Māori submission)

While there is a tension for any government trying to make sure their citizens have the most up to date advice, the submissions highlighted that if participatory approaches that ensured disabled people were part of the decision-making and design, these changes would be implemented and communicated in more appropriate ways.

## Disabled people and their whānau have plugged information gaps themselves

Across the submissions to the first stage of this Inquiry, there were numerous examples of how the gaps created by inaccurate, confusing, and slow official information for disabled people were being plugged by disabled people and their whānau themselves. Examples include:

- Supplementing official Ministry of Health information with additional research.
- Using different group’s websites and social media to disseminate information more quickly.
- Producing accessible formats/versions of official advice or information so it is appropriate for disabled people.
- Running online forum or discussions, including with health professionals, to get accurate clinical information out to disabled people and their whānau.
- Running targeted discussions for, Pasifika disabled people and their whānau access the information they need during Omicron.

“We have had to source information from outside the Ministry of Health as they could only provide generic information and even this was very delayed.” (Submission)



## Staying safe during the pandemic

“There have been multiple accessibility issues, particularly around testing and face masks, and a general feeling that these could have been addressed before they became problematic if disabled voices had been heard at any stage in the planning process.” (Submission)

“Access to everything COVID-19 and Omicron related, vaccinations, tests, accessible information, none of it has come to our community when it needed to come out, which was right at the beginning. It has come after, when we dig for it, find it, and send it out, but it doesn’t go to everybody. But what can I say? We’re denied treatment in any case.” (Māori submission)

“In this Omicron phase we are especially conscious of the higher level of risk that tagata sa’ilimalo face with the easing of public health restrictions. The high transmissibility of the Omicron virus, the extent of underlying health issues in the Pacific community, and the socio-economic pressures, place our community at higher risk when current safeguards are removed.” (Pacific peoples submission)

Throughout the COVID-19 pandemic, the government has used a range of public health measures to keep us all safe and reduce COVID-19 spread. However, three of the main tools used during Omicron – vaccination, RATs and masks – have often been inaccessible to disabled people and their whānau. Submissions highlighted that the impacts of this fell most heavily on tāngata whaikaha Māori and disabled Pacific peoples:

“It should come as no surprise that the ones whose needs weren’t being met were Māori or Pasifika disabled, while Pākehā disabled I know had their needs met very well.” (Māori submission)

“Tāngata whaikaha Māori or other disabled people who are unemployed often said they didn’t have the funds to prepare or stock their pantry, or to get extra medications, thermometers etc for if/when they had COVID. Some couldn’t use technology e.g. to report they were sick.” (Māori submission)

## Vaccination

Although this Inquiry is focused on the Omicron stage within Aotearoa's overall pandemic response, several submissions highlighted that, although many of the accessibility issues around vaccinations started 12 months ago or more, their impacts are still being felt today.

Submissions identified that the roll-out approach used in the early stages of the COVID-19 vaccination programme, which placed many disabled people in Group 3, was difficult to implement because of the lack of good quality data about disability within the health and disability system. The roll-out effectively relied on general practices having records about who on their registers had disabilities and how to reach them. As a result, some disabled people missed out on the benefits of early vaccinations and still have not caught up – meaning more disabled people have yet to have the benefit of being fully vaccinated:

“Rates of vaccination among tāngata whai ora remain at least 10% lower than the rest of the population (more than 10% for Māori and people who have experienced harm from substance use). While the rest of the country has moved focus to boosters and opening up the community, many tāngata whai ora have yet to have their first or second vaccinations.” (Submission)

“Despite many years of requesting data and information, the absence of disability data at DHB, Primary Health Care and Ministry levels has an enormous impact on trying to identify and mitigate the effects of COVID on this population.” (Māori submission)

A lack of trust in government was also raised as a barrier, specifically with regard to trusting in the safety of vaccines. This was considered a reason for why there was lower vaccination uptake amongst some disabled people:

“Lack of trust in the government, health and justice systems due to past trauma, including forced treatment, colonisation and disinformation... has contributed to our lower vaccination rates.” (Submission)

Many submissions discussed the need for a variety of options for vaccinations, including having them available at a range of accessible venues. A number of submissions noted that the booking system was difficult for some disabled people to navigate (for many of the reasons mentioned in the findings around communication), and that moves to having pop-up clinics were welcomed. There was criticism from some that vaccinations were offered in inaccessible sites for many disabled people. An example given was that of drive-through clinics, which required people to have access to private transport:

“Has been easier with pop-up centres, but often disabled people still rely on someone to transport them and the wait required can be difficult. Therefore, access has not been straightforward.” (Submission)



For disabled people with sensory impairments, there remains a demand for low sensory vaccination clinics. While it seems that it was common for district health boards (DHBs) and providers throughout the country to offer low sensory vaccination clinics, these were not always well advertised, and some disabled people missed out on the opportunity to have a vaccination in a way that suited them best.

A solution offered by several submissions was to increase the number of in-home vaccinations offered, and to make them more widely known. One submitter organisation has raised this directly with the Ministry of Health but at the time they wrote to the Inquiry they had yet to receive a response.

There was, however, plenty of praise in the way aspects of the vaccine programme had been run, and particularly regarding the hard work of Māori and Pasifika providers to ensure their communities were supported. This came with the recognition that such vaccination efforts relied on volunteers, or on providing services over and above what they were contracted for:

“During the vaccine drives, vaccine centres that were accessible or culturally appropriate were organised by community groups and students (especially Pasifika, Māori, and disabled community groups). While this mahi is extremely commendable... it is not fair for this critical work to fall on community members and voluntary student leaders when it should be the responsibility of TEOs [Tertiary Education Organisations] and government.” (Submission)

## Masks and exemptions

During the Omicron wave of the COVID-19 pandemic, masks have become mandatory in many situations, such as public transport and public indoor spaces, unless there are grounds for an exemption. They are considered an important tool in preventing the spread of Omicron in the community. While official advice doesn't specify which face coverings should be used as masks, government messaging has indicated some masks (such as medical masks and P2/N95 particulate respirators) to be more effective than others.

For some disabled people, having the ability to use masks and require others to wear masks around them provides a great deal of comfort, while others are unable to use masks or find masks a source of stress, anxiety and discomfort. Submissions provided a range of views on masks, with three main themes emerging around issues in accessing masks, in finding masks that work, and applying mask exemptions:

“Many tāngata whai ora cannot afford things like N95 masks and so are reliant on accessing free masks where available and may retain and reuse masks more than the recommended amount.” (Submission)

Cost remained a significant barrier to disabled people and their whānau being able to access high quality masks and submissions highlighted the reliance many disabled people have on free masks. But, as with RAT kits, access varied by location/district, and thus still relied on available transportation, or on whānau or friends picking up masks on their behalf.

Other submissions highlighted that face masks exacerbate many of the ableist attitudes in society around communicating with Deaf or hard of hearing people. Face coverings that completely obscure mouths further reduce effective communication for some disabled people, and within submissions there are calls to make clear face shields more common and easily accessible:

“People are facing ableist and audist attitudes when it comes to other people communicating with us Deaf. People (general society) need to learn basic NZSL and learn how to communicate with Deaf people (there are a range of ways). There also needs to be an infrastructure in place for scenarios where it really is good to be able to see someone’s face and lipread and for facial expressions, e.g. more plexiglass shields, more face shielding.” (Submission)

The right to a mask exemption is important for many disabled people. Some submissions highlighted that navigating the process for mask exemptions was unnecessarily difficult and stigmatising, particularly in education settings (such as schools):

“Families were scrambling for information and applying for exemptions before term one started as there had been no communication from schools specifically for families of children with additional needs... [they were] grouped with the concerns raised by families wishing for freedom to not wear masks (for a variety of reasons) which is distressing and unfair.” (Submission)

Some submissions also highlighted issues around navigating processes for vaccine exemptions:

“This is an area where I think the space is really difficult. There is not a lot of knowledge around that mask and vaccine and other exemptions do exist for a reason...there’s not a lot of acknowledgement that genuine exemptions exist and that people are not just being anti-maskers or anti-vaxxers.” (Submission)

“People who have suffered an adverse reaction after a medical treatment need special consideration to assess the risks of them having further treatment with the same medicine, or whether another approach should be adopted. The very narrow approach to exemptions creates extreme difficulties for those who have suffered vaccine injuries or post vaccine injuries which may have been caused or contributed to by the vaccine... The government’s ‘one size fits all’ approach towards management of COVID, accordingly discriminates against and has particularly serious adverse effects for people with disabilities, vaccine injuries or other special needs.” (Submission)



## Isolating to protect from COVID-19 in the community

“The preference is to encourage vaccination and retain vaccine mandates as the best approach to reducing COVID-19 risks and ensuring they do not continue to live in isolation.” (Submission)

Despite requirements around both vaccination and masks in certain settings during the Omicron response, some submissions shared concerns that the lessening restrictions overall have led some disabled people to choose to effectively isolate themselves either with whānau, the people they live with, or a small bubble of close contacts. Submissions likened this to home detention, leading to feelings of isolation and stress and a restriction on their own freedoms for the benefits of others:

“The difference between a nationwide lockdown and a community needing to use self-imposed lockdown to mitigate risk means that supports that should be in place are not in place and life becomes even more challenging and isolating for disabled people in contrast to the increased freedom and community participation others are enjoying.” (Submission)

In some settings, particularly workplaces and schools, the decisions made by disabled people to stay home attracted unwelcomed scrutiny, leading (in the case of schools) to parents feeling frustrated and as if their concerns for their children were not being taken seriously:

“We have every right to stay at home if school doesn’t feel safe. Parents feel like schools are not taking disabled students or their whānau rights to keep themselves safe from Omicron as a valid response.” (Submission)

## Access to and use of Rapid Antigen Tests (RATs)

As part of the Omicron response, testing has moved from primarily PCR testing to RATs, which can be self-administered at home. There was general support for a move to less invasive and quicker testing, as offered by RAT kits, but there were still issues in accessing the kits. They were either too expensive for people who paid out of pocket (to have them delivered from an online supplier), or (earlier during the outbreak) could only be accessed through a collection site, which could be hard to find and required travel:

“Testing should allow for reasonable accommodations, but these things are not happening.” (Submission)

Some submissions referred to DHBs regularly changing the locations to pick up RATs. This exacerbated worry and stress for disabled people for whom transport is already an issue, and people who are reliant on whānau and friends to drive them places:

“It was a marathon... to get where you needed to go, which is highly exclusionary.”  
(Submission)

Where RAT kits have been available for disabled people, limitations remain on the kit numbers meaning carers and family members who provide support are not able to be tested before coming into homes – leaving disabled people feeling vulnerable and unprotected:

“A few of our members have had COVID-19 and have been well supported by friends and family. However, many with carers or family members who care for them, the ability to get free RAT kits was impossible to ensure their safety.” (Submission)

Even when disabled people received RAT kits, there were concerns that they were difficult to administer at home. Some submissions shared experiences of disabled people trying to get health professional support to administer in-home testing. Despite the needs of the disabled people involved, this support did not happen:

“For example, [we were] contacted by a support worker...unable to find any services for in-home supervised testing and had explored multiple avenues of enquiry with a variety of government agencies and support services without any result. Nobody they contacted was able to give a clear answer on whether this was, or was not, possible.”  
(Submission)

For some submitters, there were concerns that by only offering PCR and RAT kits, the health and disability system had not responded to a range of disabled people’s needs. Exploring different testing options (such as the lollipop test) was suggested, so that such options could be made available to disabled people who found taking either a PCR or RAT difficult or distressing.

## Support to isolate safely

As Omicron has spread, greater numbers of disabled people and their whānau have tested positive for COVID-19 and have been required to isolate for seven days, along with anyone else who lives in the same household. For some, the requirement to isolate is distressing, either because they do not believe their needs will be met during isolation or because of previous experiences of having seclusion used on them by mental health services:



“Some are concerned that what is seen as ‘isolation’ will in fact be solitary confinement (seclusion) and that their prior experiences and trauma from solitary confinement will not be considered. These fears may be leading people to not seek help from mental health services when they need to, adding to their distress.”  
(Submission)

While public messaging has encouraged households to prepare for isolation by stocking up on essentials, this requires financial reserves that many New Zealanders do not have. Such messages have caused distress for disabled people and their whānau, who do not have disposable income or savings to purchase essentials, like food, cleaning products or medicines, weeks ahead of when they are needed:

“Many of the people in our communities live week to week, and do not have the financial means to stock up on groceries, or the essential supplies needed to get through COVID-19.” (Submission)

Once isolating, submissions noted that disabled people are often left to rely on whānau or friends to deliver groceries or deliver other essentials:

“Many relied on whānau and friends to donate or access food, medication, information, transport. Many of our community are still struggling, especially those on benefits – Omicron just seems to have enhanced the divide and feelings of separation and being on our own.” (Submission)

For those who had the means to purchase groceries online, delivery services have been helpful, but submissions note that even with some supermarkets offering priority spaces for disabled people, the spaces are very limited. Furthermore, grocery delivery to the door only, rather than inside to the kitchen, may not be helpful for all disabled people and their whānau:

“With changes to groceries being carried into the house disabled people told us they had to try and drag their groceries in from outside in the rain while sitting in their wheelchair or using their walking frames. This was very difficult and resulted in some hurting themselves. Some tried calling MSD for assistance but either the person answering didn’t know about disability assistance or there was no response to their call.” (Māori submission)

Expectations that people isolate in their homes also assumes housing is warm and dry and safe, which is not the case for all disabled people and their whānau:

“We have heard that people are under immense stress and pressure in many avenues of their life from employment to support, to housing – both disabled people and their whānau.” (Submission)

Not everyone's living situation makes it easy to isolate either. Throughout this phase of the Inquiry several examples were shared of people living with flatmates, or in supported living situations, having to then move in with whānau members during isolation to ensure their basic care needs were met.

Submissions shared examples of community groups, non-governmental organisations, Māori providers, Pacific providers and disability providers making sure disabled people and their whānau had what they needed during periods of isolation:

“We have always made it clear for the whānau we support that we will provide whatever they require to keep them safe in the first instance and to access information and support such as kai. Our whānau relied heavily on us to provide them with whatever they needed.” (Māori submission)

“We have been told that some Māori providers have not been paid for their pandemic services and that they supported whānau in need with food packages because of the challenges faced with Pākehā services who were funded to do this.” (Māori submission)

In contrast, government support for disabled people and their whānau has, according to many submissions, been limited. Although some talked about disabled people and their whānau feeling fairly well supported or having no problems while isolating, others were critical of the lack of support from the Ministry of Social Development (MSD) in particular:

“Don't rely on MSD, they let you down. We were promised access to food grants and other entitlements. Some get it, some don't. Again, inconsistency, this time from Case Managers means some disabled receiving all they need while others are missing out completely. So it definitely hasn't been working for some.” (Māori submission)

Many submissions were especially concerned about the lack of disability support services during periods of isolation, in particular home-based care. This is further discussed in the following section on disability support services.

## Disrupted disability support services

On 8 February 2022, a letter was sent from the Ministry of Health, ACC and all DHBs advising people that, if Omicron cases were to increase, there could be staff shortages and home and community support services would need to scale back temporarily. The letter gave no indication that appropriate contingency plans were in place. Many disabled people and their whānau were deeply unsettled by this news, which was viewed as reinforcing that disability support services are not a priority for government agencies or officials:

“Sufficient time had passed for agencies to anticipate this situation, yet this communication indicated that the labour of care would fall on disabled people and their whānau, which was confusing and distressing for many who received it.” (Submission)



“Where clients have received letters to inform them their services might have to be reduced this was concerning for the clients and they worried about what might happen, especially when no alternative arrangements were discussed with clients.”  
(Submission)

On 1 March 2022 an apology was issued for the “deep distress” caused to disabled people and their whānau by this letter but this was only sent to providers to disseminate. But many submissions highlighted that the damage had already been done. Concerns remain about the ability for government agencies to plan for the impacts of Omicron in a way that ensures the rights of disabled people and their whānau are protected:

“The intention to communicate high-level information to manage the impact of critical workforce shortages overlooked the nuance and detail required in preparation of support for disabled people at this time.” (Submission)

“This situation especially exposed disabled people that were not able to draw on family and community supports to compensate for these gaps.” (Pacific peoples submission)

Home and community support services during Omicron have in fact been disrupted for many disabled people and their whānau, often without discussions on existing alternative arrangements:

“Home support services have been regularly disrupted with no prior notification, and often no follow up either. Family are not informed that the service cannot or has not been provided until well after the agreed time, if at all. For many personal home support services that can have serious implications – missed medications, not checking food and nutrition intake.” (Submission)

“For some tāngata whaikaha Māori and their whānau their regular services have been reduced without consultation or untrained, unsuitable support workers have been provided. Disabled people have declined those unsuitable support workers as they are unsafe to have in their homes but no suitable replacement staff have been provided.” (Māori submission)

Views were also expressed in submissions that COVID-19 was being blamed for a wide range of disruptions:

“Caregiving agencies [are] blaming everything on COVID.” (Submission)

Submissions talked about how important home-based care was in the day to day lives of many disabled people and their whānau. When carers were away, for example, due to having tested positive for the virus, not all disabled people and their whānau were able to find people to cover their usual carer, or they were not able to find carers with suitable expertise, for example, where replacement carers were not able to communicate with Deaf people using basic NZSL. This caused added worry and stress:

“DHB disability services: we had many reports of poor quality of services, lack of any communications from providers prior to changes in services, untrained support workers unable to carry out services safely, and long delays in services that impacted on disabled people being able to get out of bed when need to access the bathroom, get a meal or get ready on time to attend studies or work.” (Māori submission)

Access to personal protective equipment (PPE) for support workers and carers was raised as an issue by numerous submissions. A number reported that some disabled people and their whānau were unable to access PPE for support workers until they or their support worker tested positive for COVID-19. Even after testing positive, there appeared to be no guarantee that PPE would be supplied to ensure disability supports could continue safely for disabled people:

“The biggest challenge for our members has been delivering full PPE to COVID-19 positive disabled people to continue their support.” (Submission)

In amongst frustrations about a lack of consistent and reliable disability support services, submissions highlighted the need to value carers more highly, including through remunerating the workforce on a par with Australia (where submissions stated carers are said to be paid almost \$20 per hour more for similar jobs).

Workforce shortages have also had impacts on other types of disability support services. One submission talked specifically about residential support being moved between facilities with little notice, and inadequate consultation:

“We understand there has been statements such as ‘people will need to sleep on the floor.’” (Submission)

Concerns were raised about the reduction or closure of community-based support services and programmes such as day services or Special Olympics as a result of Omicron. The reduction in these services is connected, by many submissions, to increasing feelings of isolation for disabled people:

“Regular routines (all community contact) has been shut down because of Omicron.” (Māori submission)



As highlighted previously, disabled people and their whānau have been experiencing issues with transport and accessing vaccination and RAT kits. The risk of Omicron in the community also has many disabled people and their whānau avoiding public transport. Although in the earlier stages of the pandemic response Total Mobility cards allowed card holders to have free taxi fare use up to the regional fare subsidy cap, this has not continued in Omicron, despite transport needs increasing:

“Total mobility cards provide a discounted taxi or other provider fares but given people with intellectual disability are high health users in non-COVID times, increased frequency of visits to doctors, to hospitals, will impact on household budgets with limited amounts being available for food and other household essentials.”  
(Submission)

Several submissions also gave examples of disabled people and their whānau testing positive for COVID-19 and being left without disability support services during their isolation periods. This in turn meant that disabled people are left with little support, or requiring support from whānau members who themselves are unwell:

“Many families and whānau have been isolated at home, sick and unable to look after their family member with the disability. There is little support for people in this situation, especially when people have to reduce their bubbles and continue to provide care (sometimes in the absence of a support worker) meaning ongoing exhaustion for family members.” (Submission)

Submissions highlighted differences in the experiences of disabled people on Individualised Funding (IF) or receiving personalised budgets, or those with ACC, compared to those without:

“What we’re genuinely worried about is, for lack of a better term, a class system occurring between those who have IF and those who don’t, those who have ACC and those who don’t. It’s a real class system that’s coming up. You’re touching on stuff there like the inequities with ACC and non-ACC and individualised funding and non-[IF]. That’s a massive issue at the best of times and COVID just illuminates that even more so with the inequities.” (Submission)

“IF users have more flexibility to employ their own workers. Personal budget holders have an even greater flexibility to use their funds to provide suitable supports. DHB funded services (for over 65 years)... are very prescriptive and some users who queried the services were told ‘take it or leave it’, no attempt was made to meet the needs of the clients.” (Māori submission)

Overall, there was the sense that IF left disabled people and their whānau in more control over the services and how they are delivered:

“The beauty of IF funding and personalised budgets is that we employ our own, we don't go through agencies... I cannot emphasise enough how important it is for us or our whānau to be in charge of our own funding support.” (Māori submission)

Some submissions noted that people with IF arrangements had more flexibility, for example, in finding replacement support workers. Other submissions noted that IF arrangements came with additional administrative requirements (that go hand in hand with being an employer). For example, according to some submissions, ACC has taken the view that it isn't their role to provide PPE to people who (through IF) are employers of carers. When these are being supplied to other providers for free this appears to create unjustifiable inequities for disabled people based on the types of funding arrangements they have with government agencies:

“People on IF are not being treated as providers, therefore what they are entitled in the form of support to keep themselves protected is different i.e. access to RAT tests for staff.” (Submission)

“Some users of these services have said they provide more flexibility in that they can use IF to pay for whānau and friends but most are using these supports regularly anyway. People have been left with support workers due to no replacement workforce for IF users and no one to support them with alternative arrangements for home care.” (Māori submission)

## Health services availability

The right of disabled people to the highest attainable standards of health remains a concern for many who have raised issues around access to high quality health services for disabled people and their whānau during the pandemic response. For some submissions, this translated to a concern that a disproportionate effort was going into COVID-19 measures, rather than other priority health issues for disabled people and their whānau:

“Sometimes [there has been] too much information/focus on COVID-19 vaccines, particularly by GPs, to the detriment of other health issues.” (Submission)

For some, there was considerable concern that COVID-19 related health issues would not be picked up by health professionals, particularly so where there was no face-to-face contact with disabled people because of COVID-19 restrictions, and that this would result in disabled people becoming very unwell:

“Very concerned that no community support checks for people with Down syndrome reporting positive results... We know that people with Down syndrome do not always report feeling unwell, so they could be extremely unwell and need treatment hospitalisation and will be needing to navigate this on their own.” (Submission)



Some health services have, however, been able to show expertise in serving disabled people and their whānau throughout COVID-19. Several submissions singled out Māori and Pacific healthcare providers in this regard:

*“Feedback from our staff supporting whānau in Northland, Auckland, Tairāwhiti and Waikato talk of the immense support from Māori and Iwi providers. This was also the story of Pasifika providers in Auckland.” (Submission)*

*“The four Māori providers in South Auckland have done everything they can to assist disabled people as have [Pacific providers]. They have offered food, wellness support, everything in their powers often well beyond any contract they have with the DHBs.” (Submission)*

*“Māori providers are doing everything they can while they’re underfunded. Pasifika providers have been amazing.” (Māori submission)*

Many submissions also highlighted the significant role played by general practice throughout COVID-19 in providing essential information and support around COVID-19 when a disabled person or whānau member tested positive for COVID-19. However, difficulties in accessing general practice services were a common theme amongst submissions. Specific concerns include problems with:

- Booking appointments with a general practitioner (GP)
- Enrolling with or changing GPs, largely due to ‘closed books’ in many general practices
- Long waits to receive follow up calls for GPs
- Relying on telephone consults or video calls rather than face-to-face appointments, which makes GP care inaccessible for some disabled people and their whānau.

*“The lack of understanding by medical practices that phone consultations do not work for some people with disabilities. They need the face-to-face in person, as most of us do not have access or ability to use [Microsoft] Teams for an appointment.” (Submission)*

Submissions also noted that often disabled people were told to talk to their GPs about COVID-19 related health and disability issues, for example by ACC or DHBs, but many GPs were not aware of this and were not able to answer their questions. This was considered an extension of poor communication and information issues discussed earlier.

Several submissions highlighted the worry and stress that was worsened through Omicron and the ongoing pandemic response. However, there are limited mental health supports available to disabled people and their whānau:

*“[There has been] lesser access to mental health and addiction supports, particularly peer groups. For people supporting whānau members with high substance dependency, no access to support programs has been problematic.” (Submission)*

Issues were also raised around health services overall – from diagnostic services, specialist care and appointments, surgery, mental health and addictions services, physiotherapy to the running of hospitals during the pandemic. This is added to by the lack of input by disabled people and their whānau into hospital design and decision-making. This has had flow on impacts for disabled people and their whānau, creating the impression that hospitals are unsafe places for disabled people:

“The message to us as disabled people and our whānau is that we are on our own. We have no defence and no one to protect us. If we go into a hospital, there is no protection from COVID-19 at triage or even in the hospital itself. So, the overall experience has been one where we have been relatively safe, but now we are no longer.” (Māori submission)

This negative experiences around hospitals has had a long term impact for some disabled people and their whānau, with some submissions suggesting it creates a barrier to people seeking health professional advice and assistance.

Specific COVID-19 issues raised by submissions included serious concerns that health professionals were being told to return to work in hospitals seven days after first testing positive for COVID-19, raising questions about how the risk to disabled people and their whānau is being factored into health and disability system decision-making:

“A problem of serious and significant note is that our government is telling nurses, doctors, and carer supporters they can go back to work after 7 days, even if they are still testing positive. To me, that is a contradiction, and for the immune-compromised and disabled, it presents an unacceptable risk.” (Māori submission)

Specialist services in hospitals have also been postponed, causing concern for disabled people who rely on regular hospital treatment to stay well. Others have had to move to online consultations with specialists – which may not work for all disabled people and their whānau:

“People who have had their appointments for mental health and addiction services, as well as medical treatment, cancelled with little to no notice. This has been quite distressing for people especially those who have waited a long time for surgery, have arranged time off work, care for their kids etc and then it has been cancelled the day before or the day of.” (Submission)

Cancellation or delays of some health services was also raised by submitters as contributing to decreased functioning or ‘flare ups’ of some conditions:

“Patients who received medications via infusions had their appointments cancelled, risking a flare of their disease.” (Submission)

A final area of concern raised was the variation amongst DHBs for the services they offer and the view that there is a ‘post code lottery’. Many of the issues raised highlighted different levels of service for people living in urban areas compared to those in rural areas, not only in health care.



## Lack of support in education settings

Several submissions have raised concerns about education settings ranging from Early Childhood Education (ECE) to schools and Tertiary Education Organisations (TEOs):

*“Disabled students and their families/whānau continue to face challenges in understanding, navigating and accessing their rights within the education system in light of the complexities and challenges created by the recent Omicron outbreak.”  
(Submission)*

Issues were raised about the safety of education settings for disabled people and their whānau, especially where they have not been included in planning:

*“People are making decisions without any consultation, or care regarding the impact these decisions will have on their whānau.” (Submission)*

This was made even harder by government decisions during Omicron, such as the decisions not to publish locations of interest, or to release specific COVID-19 positive numbers in the same way that occurred during the earlier stages of the pandemic:

*“The removal of COVID numbers actually made it exponentially harder for our community to assess the risk, e.g., of sending our children to school – with no accurate numbers or locations available, it has meant increased uncertainty and inability to make accurate risk assessments. We were left unable to make informed choices about our safety.” (Submission)*

Other government decisions, like the removal of vaccine pass requirements in education settings, also cause concern for disabled people and their whānau. Some have decided to stay at home and not return to school in term one, a decision not always supported by schools:

*“In some cases, schools were understanding, but in many, they were not due to the schools’ interpretation of the MOE [Ministry of Education’s] instructions.” (Submission)*

Several submissions noted that Omicron has been fast paced and that schools themselves are under considerable stress across the board and have not been resourced to cope with the changing risks and advice:

*“We are aware of how under resourced this sector is, also aware that many experienced educators have stepped away because of the high stress involved in educating during Omicron.” (Submission)*

Submissions cite a disconnect between policies and directions issued from the Ministry of Education and schools, with each school interpreting the rules differently, and often in ways that impact on disabled students and their whānau:

“[Some schools said] they didn’t want to single out a group (disabled and neurodivergent students) as being exempt from wearing masks as it would create division and other parents who chose to not wear masks would be angry that they didn’t have the same freedom. This was a very awkward situation for families of disabled children and made them feel very unwelcome in their own school.”  
(Submission)

The variable ways that schools and TEOs support (or do not support) online learning for disabled students who feel unsafe in education settings due to Omicron, was also a feature of many submissions:

“Some have been advised by a health professional to remove children/young people from schools, but many schools were not really set up for successful distance learning.” (Submission)

In situations where schools or TEOs offer online learning options during Omicron, not all disabled people and their whānau were able to access these due to lack of resources:

“For many disabled children the lack of technology and connectivity in their homes has meant that they are unable to carry on learning at home.” (Submission)

For disabled students in TEOs, the supports that were available for earlier stages of the pandemic have disappeared under Omicron. This includes financial support and the ability to borrow an increased amount of course-related costs through the student loan scheme:

“In 2020, the amount that a student could borrow through Student Loan through course-related costs increased. This was in recognition that studying online, or from home, came with extra costs. In line with the assumption that students would return to campus, this has not been continued in 2022. This has caused hardship, especially among disabled students who are still often studying from home due to their heightened vulnerability to COVID-19. This means students may not be able to afford basic study necessities such as access to WIFI, adequate technology, and also utilities such as heating.” (Submission)



Submissions also emphasised the importance of school-based supports for many disabled people and their whānau. Yet, many of these have reduced or disappeared in the past few months or are inaccessible to disabled students who have had to stay at home to avoid the serious risks of COVID-19:

“Some children have support at school but no support at home, so when they have to stay at home they have no support and neither do the families.” (Submission)

Several examples were shared around schools not having contingency plans to ensure that support workers and teachers’ aides were available for disabled students and their whānau. Submissions also highlighted that, for some disabled students, returning to education settings after long periods isolating at home and with limited contact with the wider community was especially difficult and required additional support. This has not been part of planning and schools are generally not resourced to meet the new needs of disabled students caused by the pandemic and its restrictions:

“For children with intellectual disability it is like anyone returning to something after a traumatic event, they will have experienced regression and need time to fill in the gaps before they can move forward. Teachers know this but are not being given the resources or time to meet the learning needs of this population group of students.”  
(Submission)

“There have been no additional learning support resources or topping up of teacher aide hours to allow these students to re-engage with learning. Staff are overwhelmed.” (Submission)

Appropriate forward planning by the Ministry of Education toward ensuring as many supports as possible for disabled children and young people, and their whānau could continue to be available was missing:

“For disabled students the Omicron outbreak hit just as students who were already lagging way behind were starting to feel they might be able to move forward with their learning. This has compromised teachers ability to support and provide for their students. There are concerns that there has been no systemic approach to address these issues or sufficient forward planning on the part of the Ministry of Education. There appears to be no plan within the learning support model to address the gaps experienced by disabled students in their learning due to the COVID pandemic.”  
(Submission)

## Conclusions and cross-cutting themes

In addition to the six main themes outlined in this report, several cross-cutting themes emerged in submissions to this phase of the Inquiry. These include:

- Issues with quality disability data. The lack of real-time data collection, modelling, monitoring, and analysis using high quality ethnicity and disability data was at the root of a number of the concerns raised in submissions. This has limited the ability for government agencies to monitor case numbers and rates, transmission and severity of COVID-19 for disabled people and their whānau, just as it has prevented a closer look at access to and quality of health and disability services. A lack of data has also limited the ability for community groups and organisations to advocate for urgent changes.
- Unacceptable variation in the level or nature of health care or disability supports available to disabled people and their whānau. These variations include issues of differences by location (either by DHB district or by urban or rural setting), which have already been widely canvassed elsewhere, such as the Health and Disability System Review,<sup>20</sup> and differences in the supports funded by ACC compared to the Ministry of Health.
- Concerns that services are not universally accessible to disabled people and that government agencies are not consistently providing information in accessible formats that allow disabled people to be fully informed during the pandemic. This reinforces the need for the proposed new “accelerating accessibility” in Aotearoa<sup>21</sup>, which aims to identify, prevent, and remove barriers to participation for disabled people, tāngata whaikaha Māori and others with accessibility needs.
- Ongoing concerns about structural inequities and recognition of how different types of discrimination, such as ableism and racism, can intersect and add to disadvantage for disabled people. For this reason, areas like violence and abuse remain a concern for the Commission in all work to ensure the rights of disabled people are protected.
- The need to ensure all parts of the health and disability system are playing their roles in ensuring the quality of health care and other services for disabled people. This includes ensuring that people experiencing long term health and disability impacts of COVID-19,<sup>22</sup> including ‘Long COVID’ and adverse events from vaccinations,<sup>23</sup> are responded to and supported appropriately by the whole health and disability system. The future roles of Health New Zealand, the Māori Health Authority and the Public Health Agency should also be considered in any work in this area.

Collectively, the six themes identified throughout this phase of the Inquiry and these cross-cutting themes raise questions around how the rights of disabled people and their whānau have been protected throughout the Omicron outbreak. These questions warrant further attention. Following on from this phase of the Inquiry, the Human Rights Commission will explore the best way to ensure these critical questions are addressed, be that through engagement with government agencies, or a further detailed examination of the government’s COVID-19 response, and its impacts on disabled people and their whānau.

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<sup>20</sup> Department of the Prime Minister and Cabinet. (2022).

<sup>21</sup> Hon Carmel Sepuloni and Hon Andrew Little. (2021).

<sup>22</sup> Akbarialiabad et al., (2021).

<sup>23</sup> Medsafe, (2022). COVID-19: Vaccine Safety Monitoring Process.



## Recommendations and observations

Since this Inquiry was launched on 11 March 2022, increased attention has been paid to disability in the government's COVID-19 response. This includes initiatives such as working to make it easier to locate disability information, a greater number of stakeholder meetings with the community to gather feedback, and the Ministry of Health contracting resource to assist in rapidly addressing gaps. However, the wide range of concerns shared through submissions reinforce the need for further attention to ensuring the rights of disabled people and their whānau are protected throughout the government's COVID-19 response. This must be done in a way that honours Te Tiriti o Waitangi.

In advance of this Report release, and recognising the urgent need for action, the Commissioner has shared the high-level recommendations with Government. Some recommendations have already been partially or fully actioned. All recommendations are set out here for completeness.

This report has organised recommendations into four domains:<sup>24</sup>

- Taking immediate action
- Preparing for the continued responses to COVID-19
- Designing systems and policies for disability inclusiveness
- Transforming society's cultural assumptions about disability.

After considering the submissions to this phase of the Inquiry, the Commission recommends that:

### Taking immediate action

1. Government agencies with COVID-19 responsibilities work in partnership with disabled people and their whānau, and disabled peoples' organisations to establish a coordinated approach to sharing COVID-19 accessible information, support (including access to masks and testing), and service navigation, developed especially for disabled people and their whānau. While this might involve a one-stop-shop, it cannot assume one size fits all. It is essential that information is provided in alternate formats and that low- or no-tech options are available for all disabled people and their whānau. This also requires:
  - a. Revamping the COVID-19 website to ensure specific information, designed for disabled people and produced in a range of alternate formats, is easily available.
  - b. Ensuring information designed for disabled people takes into account the needs of tāngata whaikaha Māori and disabled Pacific peoples and their whānau.
  - c. The contributions already made by disabled people and their whānau, and disabled peoples' organisations to produce accessible and tailored information for disabled people about COVID-19 and Omicron, be acknowledged, built on, and appropriately funded.
2. The Government's COVID-19 response immediately provide improved support to disabled people and their whānau so they can access specific Omicron supports, including:
  - a. Increasing access to free RAT kits for disabled people, to use at their discretion (for example for whānau and support workers to use when coming into the homes of disabled people).

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<sup>24</sup> These recommendations have been further informed by the "practical and moral compass for action" put forward by Jones et al., (2021), and the "framework for disability-inclusive pandemic responses and systemic inequities reduction for disabled people" described in the evidence-base by Jesus et al., (2022).

- b. Providing in-home support for disabled people and their whānau undertaking RATs where required.
  - c. Providing free access to P2/N95 masks for disabled people and their whānau.
  - d. Providing details on vaccination centres, including low-sensory vaccination clinic and at-home vaccination options.
3. Government agencies with disability support responsibilities (particularly the Ministry of Health, ACC and DHBs across the country):
- a. Create a network for emergency, 24-hour, 7-days a week, caregiver support when carers are not available. This is an essential backstop for disabled people and their whānau when the usual avenues are not necessarily working.
  - b. Make care and support available to disabled people and their whānau who are opting for self-isolation as a protection against COVID-19. The specific care and support must be determined in partnership with disabled people and their whānau.
  - c. Explore support packages for all disabled people and their whānau to provide respite care, with a focus on flexibility in use and location, that works even where COVID-19 restrictions are in place. Accessing this support needs to be as simple as possible, with minimal bureaucratic hoops.
4. Increasing supports to disabled people and their whānau in education settings, especially as disabled children and young people return to in-person learning. This includes:
- a. Exploring whether teacher aide supports (funding, available hours) are sufficient.
  - b. Ensuring disabled students in schools and tertiary education have access to the technology required to continue distance learning if they choose to self-isolate to protect from the risks of COVID-19.
  - c. Supporting consistent communication of key education messages across Aotearoa, and reducing the possibility of varied interpretation and misinterpretation of crucial education policies between schools.

### **Preparing for the continued responses to COVID-19**

5. Government agencies with COVID-19 responsibilities must ensure the rights of disabled people and their whānau are protected throughout all stages of the pandemic response. This requires:
- a. A commitment to planning for disability support service disruptions and providing workable alternatives and mitigations.
  - b. An assurance that a disability lens be applied across all work. This needs to be at the whole-of-government level as well as within specific sectors (such as Health, Social Development, Education). As Cabinet has already directed government agencies to include consideration of the impacts of policy proposals on disabled people in all Cabinet papers where relevant, this recommendation relates to improving the quality of this advice and ensuring that the perspectives of disabled people and their whānau have been incorporated into advice.
  - c. Participatory approaches to ensure disabled people and their whānau are part of COVID-19 decision-making both in central government and in regional or local decision-making.



6. Government agencies should give further consideration to the findings of the Waitangi Tribunal in its 2021 *Haumaru* report into aspects of the COVID-19 response including:
  - a. Funding and resourcing Māori service providers to reach communities, particularly in providing targeted support in rural areas and with the continued vaccination programme.
  - b. Providing targeted support for tāngata whaikaha Māori, including through self-isolation and caring for Māori with COVID-19.
  - c. Prioritising work to improve the quality of quantitative and qualitative data on tāngata whaikaha Māori, in partnership with Māori disability care providers and community groups.
7. Government agencies ensure that public health measures, including those around vaccinations, are applied in a way that does not disproportionately impact disabled people and their whānau.
8. Health agencies give further consideration to providing financial support to Māori providers, Pacific providers, mental health and addiction services, and other service providers delivering high quality care to disabled people, in recognition of the additional care and support they provide disabled people, many of whom feel ignored or let down by health care services during the pandemic response.

### **Designing systems and policies for disability inclusiveness (medium-term)**

9. All government agencies undertake work with disabled people to improve real-time data collection, modelling, monitoring and rapid analysis using high quality ethnicity and disability data across multiple levels including case numbers and rates, transmission, severity and access to and quality of care (including the performance of public health responses) to inform and assess strategies for disabled people.
10. All government agencies consider how best to invest in whānau as natural supports for disabled people. This includes understanding the best way to support particular communities, such as Māori, and Pacific peoples.
11. All government agencies explore the impacts and possible solutions to the digital divide in Aotearoa, including its impacts on disabled people and their whānau.
12. The health sector continues work to increase availability and accessibility of mental health and addiction services for disabled people and their whānau, and ensuring services are able to respond to increased demands in the wake of the COVID-19 pandemic and its responses.

### **Transforming society's cultural assumptions about disability (medium-term)**

13. Ensure disabled people are able to fully participate in all levels of the COVID-19 response, from governance and advisory roles, to supporting on the ground responses as professionals or educators.
14. Government agencies with disability support responsibilities to ensure *Mahi Aroha – the Carers' Strategy Action Plan 2019-2023* is fully implemented and that there are actions that:
  - a. Recognise the value of carers and other disability support workers.
  - b. Provide professional development for carers and other disability support workers.
  - c. Appropriately remunerate carers and other disability support workers.

## Areas for further consideration

There are also a number of observations from this phase of the Inquiry that require consideration by government agencies, with a view to taking action in the short to medium term. These include:

- Applying learnings from the unique Māori and Pacific peoples' community approaches first highlighted during the Delta outbreak, and continuing throughout Omicron, so that tailored responses to the pandemic are not seen as a 'one-off' but as a way of working.
- Exploring financial supports and benefits for disabled people and their whānau, to recognise the ongoing costs of the COVID-19 pandemic for disabled people and their whānau, particularly as many continue to effectively self-isolate to protect themselves, despite reduced restrictions. This includes:
  - > Support to tertiary students, including through the Student Loan Scheme
  - > Extending the flexibility for Total Mobility card users accessing subsidised taxis during the earlier stages of the COVID-19 response to the current Omicron outbreak through to the end of the pandemic response.
- Undertaking further research into the longer-term society-wide impacts of disabled people and their whānau choosing to self-isolate for an extended period of time to protect themselves and their whānau.
- Ensuring that any inequities between ACC and Ministry of Health/Disability Support Services funding are identified and removed.
- Recognising the imbalance of power and risks experienced by disabled people, as set out in the two reports *Acting now for a violence and abuse free future*<sup>25</sup> and *Whakamanahia Te Tiriti, Whakahaumarutia te Tangata: Honour the Treaty, Protect the person*<sup>26</sup> released by the Human Rights Commission in December 2021, as relevant in the context of pandemic restrictions. These reports can be used as tools to advocate for changes to protect the human rights of disabled people and tāngata whaikaha Māori, and to ensure their experiences of violence that have been marginalised and ignored for many years are addressed.
- Ensuring that people experiencing long term health and disability impacts of COVID-19, including 'Long COVID'<sup>27</sup> and adverse events from vaccinations,<sup>28</sup> are responded to and supported appropriately by the whole health and disability system.
- Ensuring the health and disability system reforms currently underway lead to better health and wellbeing outcomes for disabled people and their whānau. This includes ensuring:
  - > Disabled people and their whānau are able to participate in locality planning in the restructured health system from 1 July 2022.
  - > Regional variation that leads to differences between rural and urban service availability and quality is addressed.
  - > Ensuring Te Tiriti o Waitangi commitments are embedded throughout the health and disability sectors.

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<sup>25</sup> Human Rights Commission(a) (2021).

<sup>26</sup> Human Rights Commission(b) (2021).

<sup>27</sup> Akbarialiabad et al., (2021).

<sup>28</sup> Medsafe, (2022). COVID-19: Vaccine Safety Monitoring Process.



# Appendix 1: Inquiry questionnaire

## Te Kāhui Tika Tangata - Human Rights Commission

### Inquiry into the Support of Disabled People and Whānau During the Omicron Outbreak

#### Introduction

We would like to gather information about the experiences of disabled people<sup>29</sup> and whānau during the Omicron outbreak (since mid-December, when the first case of the Omicron variant was detected in Aotearoa New Zealand).

**We are asking you to please respond to these questions no later than Wednesday 23 March 2022.**

Answer as many of the questions below as you can and wish to.

With your permission we intend to list your community group, network, organisation or rūpū as one we have consulted.

You are welcome to share other information not captured in our questions. We are seeking as much information as possible about the current experiences of disabled people, whānau, community groups, networks, organisations or rūpū during this outbreak. We have some specific questions for Māori and Pasifika providers and rūpū at the end of the survey too.

If it is more convenient for you to meet with us in a video call to provide feedback, we are more than happy to do so. In that event, we would record the meeting – for the purposes of this inquiry only.

We will make NZSL interpreters available as quickly as possible, if requested.

We will use the information you provide to:

- Produce a report on key themes for publication in early April detailing the experiences of disabled people and whānau
- Advocate on common and urgent issues in real time to government
- Work with media to bring awareness to the issues we may find (ahead of the publication of the report)

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<sup>29</sup> We recognise that people use very different language to describe themselves and their community, we have used the term 'disabled people' but please respond to us using any language you prefer.

## Questions

### *General questions*

1. What has been the overall experience of the disabled people and whānau in your community or network during this Omicron phase of COVID-19?
2. How would you describe the community, network, organisation, or membership that you are considering in your responses?

### *Specific questions*

3. Access to relevant information and advice during the Omicron outbreak:
  - a. What do you know about the experiences of disabled people and whānau around accessing information and advice about COVID-19 during the Omicron outbreak?
  - b. What has the experience of your network or organisation been of accessing relevant information and advice?
  - c. How clear, accessible, timely and easy to understand has information and advice been?
  - d. How has information and advice been tailored towards different groups and organisations (including updates over time)?
4. For people who get COVID-19 during the Omicron outbreak:
  - a. What do you know about the experiences of disabled people or someone in their bubble who get COVID-19?
  - b. What do you know about the experiences of disabled people and whānau in seeking assistance when they or someone in their bubble has tested positive for COVID-19 or needs to isolate?
  - c. To what extent has assistance met their needs?

### *Government support*

5. Continuity of care:
  - a. What do you know about the experiences of disabled people and whānau during the Omicron outbreak, who usually receive services, e.g., funded by the Ministry of Health (DSS/Aged Care supports), ACC and DHBs?
  - b. What do you know about the communication that disabled people and whānau have had with their support provider about potential service disruption?
  - c. Have disabled people and whānau had opportunities to have input into revised plans, due to service disruption? If so, how?
  - d. Have disabled people and whānau had services disrupted without any prior communication? If so, how?
  - e. Are experiences different for disabled people on Individualised Funding or receiving personalised budgets? If so, how?

N.B., if possible, please say which government services you are referring to in your responses.



6. Accessing broader government services (e.g., income support and housing):

a. What do you know about what disabled people and whānau experience when seeking assistance with:

- Access to essentials (e.g., food, medication, data / access to communications) if self-isolating
- Testing (incl. RATS, transport etc.)
- Access to PPE
- Access to vaccination, and accessible information on vaccination
- Information about anti-viral medication, if most at risk (e.g., immuno-compromised)
- Access to anti-viral medication, if most at risk (e.g., immuno-compromised)
- If not connected to any service, where to go for disability assistance (e.g., a person to collect food and bring it inside – not drop at door etc.)

N.B., if possible, please say which government services you are referring to in your responses.

7. What do you know about disabled people and whānau experiences of getting assistance from their regular 'go to' places such as Māori providers, Pasifika providers, and GPs? Where have people tried to get assistance – and has it worked?

**Questions for Māori and Pasifika rūpū and providers**

8. Could you please provide any details of any additional Government assistance (including information, funding, other supports) for responding to the Omicron outbreak and meeting the needs of Māori and Pacific people and whānau?
9. Could you please provide any details of how your workload has been impacted by the need to ensure Māori and Pacific peoples have access to vaccination and accessible information on vaccines?

**Final Questions**

10. Do you think the voices of disabled people and whānau have been included in any planning to date about the Omicron outbreak? If yes, could you tell us how?
11. Do you have any recommendations for the Government to help address any issues disabled people and their whānau may have experienced during the Omicron outbreak?
12. Is there anything else you wish to share with us?
13. Can we contact you to clarify any written information you have provided?
14. Do you give us permission to attribute your comments to your community group, network, organisation or rūpū? If no, we will share your comments anonymously.

Many thanks for your time.

Please send your response to: [disabilityinquiry@hrc.co.nz](mailto:disabilityinquiry@hrc.co.nz)

## Appendix 2: Ethical and thematic analysis approaches

Ethical processes, which have been an essential part of phase one, were informed by *Te Ara Tika Guidelines for Māori research ethics: A framework for researchers and ethics committee members*,<sup>30</sup> the *Community Research Code of Practice*,<sup>31</sup> and ethics of care and transformational research practices.<sup>32</sup> This ensured a strong ethic of manaakitanga and regard for the mana of the participants and the information they shared about the experiences of disabled people and their whānau. It also ensured the application of rigorous research ethics processes and practices. All document and video/audio storage and security complied with the Human Rights Commission document management processes.

Baker Consulting undertook a thematic analysis of the evidence submitted during phase one. This involved systematic coding, allowing for the identification and labelling of components of the evidence.<sup>33</sup> Once the initial coding was generated, Baker Consulting undertook analysis wānanga to review the coded evidence to identify commonalities and differences between the various codes, collectively discussing patterns and meanings identified in the coded evidence that demonstrated coalescing characteristics. From here, initial themes and related sub-themes were generated. Following this, an iterative process of quality-checking the developing themes and sub-themes against the coded evidence was undertaken. The final themes were then described with anonymised quotes from the submissions used to illustrate key points. Report recommendations informed by the evidenced findings were developed by the Commissioner and reviewed by the Chair of Te Ao Mārama and the President of the Disabled Persons Assembly on behalf of the Disabled People's Organisations Coalition.

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<sup>30</sup> The Pūtaiora Writing Group (2010).

<sup>31</sup> Community Research (2022).

<sup>32</sup> Brannelly and Boulton (2017).

<sup>33</sup> Braun and Clarke (2012).



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