

# **My Experiences, My Rights:**

## **A Monitoring Report on Disabled People's Experiences of Health and Wellbeing in Aotearoa New Zealand**

**Disabled Person-Led Monitoring of the United Nations Convention on the Rights of Persons with Disabilities**

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**E rua tau ruru, e rua tau wehe, e rua tau mutu, e rua tau kai  
Persevere, keep at it, and success will follow**

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# 1 Acknowledgements

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## 2 Acronyms Used in this Monitoring Report

ACC - Accident Compensation Corporation

ADHD - Attention Deficit Hyperactivity Disorder

A&E - Accident and Emergency

CBD - Cannabidiol

DBI - Donald Beasley Institute

DPO Coalition - Disabled People's Organisation Coalition

DRPI - Disability Rights Promotion International

DHBs - District Health Boards

DSS - Disability Support Services

EDS - Ehlers-Danlos syndromes

FASD - Fetal Alcohol Spectrum Disorder

GP - General Practitioner

HLFS - Household Labour Force Survey

HPV - Human Papillomavirus

IMM - International Monitoring Mechanism

MoE - Ministry of Education

MoH - Ministry of Health

MoJ - Ministry of Justice

MSD - Ministry of Social Development

NASCs - Needs Assessment and Service Coordination services

NZSL - New Zealand Sign Language

ODI - Office for Disability Issues

OT - Occupational Therapist

PAP smear - Papanicolaou test

PHARMAC - Pharmaceutical Management Agency

PPE - Personal Protective Equipment

Te Tiriti - Te Tiriti o Waitangi (Treaty of Waitangi)

UNCRPD - United Nations Convention on the Rights of Persons with Disabilities

UNDRIP - United Nations Declaration on the Rights of Indigenous Peoples

WINZ - Work and Income New Zealand

## 3 Foreword

As a signatory to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), Aotearoa New Zealand has a responsibility to monitor and critically examine our progress toward implementing this international human rights convention. Article 33.3 requires disabled people and their representative organisations to be centrally involved in monitoring disabled New Zealanders' human rights in crucial areas of their lives. In 2018, The Disabled People's Organisations (DPO) Coalition commissioned the Donald Beasley Institute to undertake a three-year monitoring research project responsive to Article 33.3. The research was conducted exclusively by a disabled person-led research team and has involved many disabled people and their whānau and close supporters from across Aotearoa. This report details findings related to the second cycle of monitoring, which focused on Article 25 of the UNCRPD – Health.

As evidenced by their poor health status, the health system has not always served disabled people well. Therefore, the DPO Coalition recognised it was crucial to explore human rights breaches experienced by disabled New Zealanders in the area of health and wellbeing. The monitoring research detailed in this report provides an authentic and accurate snapshot of the myriad ways the health system has let disabled people down. It highlights how rights breaches in health and wellbeing intersect with rights breaches in other areas of disabled peoples' lives to create complex and multiple impacts. The report also identifies the strategies identified by the research participants that would make a real difference to our health and wellbeing and have a flow-on effect into other parts of our lives.

We are excited to release this comprehensive research on disabled people's health and wellbeing experiences at this critical point in history for disabled people and the health and disability sector. On Friday 29th of October, 2021, the New Zealand government announced plans for a new Ministry for Disabled People and several other initiatives to ensure greater choice and control for disabled people and their whānau. This announcement came on the back of sweeping reforms planned for the health system. As you read this report, you will see that a number of the recommendations made by disabled people and the disabled person-led research team appear to be underway already - this is good news. However, other health and wellbeing experiences and associated recommendations outlined in this report remain invisible in the current disability- and health-systems reforms.

For this reason, the DPO Coalition encourages you to engage with this comprehensive monitoring research. It has multiple uses. It can underpin our reporting to the United Nations Disability Committee planned at this stage to occur in late 2022. It also provides evidence to inform policy and practice as the disability and health system reforms are embedded in Aotearoa New Zealand, over the coming months and years. Perhaps most importantly though, the report gives priority to the voices of disabled people. Monitoring health and

wellbeing experiences has reminded us we still have a long way to go before we can truly be said to be exercising our right to enjoy the highest attainable standard of health without discrimination.



Anton Sammons

Chair

Disabled People's Organisations Coalition



## 4 Key Principles of this Monitoring Report

This monitoring research is based on the principles and values outlined in the following key documents:

1. Te Tiriti o Waitangi
2. United Nations Convention on the Rights of Persons with Disabilities
3. New Zealand Disability Strategy and Disability Action Plan

## 5 Introduction

In December 2018, the Donald Beasley Institute (DBI) was appointed by the DPO Coalition as the research provider to lead the Disabled Person-Led Monitoring of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in Aotearoa New Zealand.<sup>1</sup> The DBI is a national, independent, non-profit organisation based in Ōtepoti Dunedin, Aotearoa, whose aim is to advance the health and wellbeing of disabled New Zealanders through applied research, evaluation and education. With a 36-year history, and a strong commitment to the UNCRPD and research pertaining to disabled people and their families, whānau and supporters, the DBI was well placed to undertake this monitoring research.

The aim of this research project was to document the health and wellbeing experiences of disabled people in Aotearoa, and whether the health and disability system is fit for disabled people, according to disabled people themselves. During initial cycles of monitoring in 2019 and 2020, data contributed by 72 disabled people and their family, whānau and close supporters formed the basis of two reports investigating disabled people's right to housing, including an adequate standard of living and other interlinking issues (Donald Beasley Institute, 2021a in print, 2021b in print). Findings from these two earlier monitoring reports identified health and wellbeing as an important and interlinking issue with housing, and therefore was selected as the subject for the current cycle of monitoring.

<sup>1</sup> Hereafter referred to as 'Aotearoa'.

## 6 Disabled Person-Led Monitoring in Aotearoa

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, or Convention) is an international agreement that sets out what governments must do to ensure that disabled people have the same rights as everyone else (United Nations, 2006). In 2008, the New Zealand Government became one of the first countries to ratify the UNCRPD, before further indicating its commitment by ratifying the Convention's Optional Protocol in 2016.

Under Article 33.3 of the Convention, the New Zealand Government is obligated to ensure that “civil society (persons with disabilities and their representative organisations) must be involved and participating fully in monitoring the UNCRPD” (United Nations, 2006).

Therefore, the purpose of this monitoring research was to investigate disabled people's experiences of health and wellbeing in Aotearoa in relation to the national health and disability system, policies, and disability rights as outlined in the Convention. This monitoring report summarises the findings.

## 7 Methodology

### 7.1 Phase One

Health and wellbeing is a broad and diverse subject affecting disabled people in different ways. Therefore, the most ethical way to ensure this cycle of monitoring research was relevant, current, and driven by the disability community, was to begin by consulting with disabled people themselves. Phase One involved consulting with 157 disabled people (134 disabled people and 23 family, whānau, and close supporters) through an online survey and focus groups on what health and wellbeing violations they would like to see investigated. The findings from Phase One were then used to inform the research framework of Phase Two.

### 7.2 Phase Two

The second phase took a more traditional approach to monitoring, using the Disability Rights Promotion International (DRPI) methodology. Mandated by the DPO Coalition<sup>2</sup> as their monitoring methodology of choice, DRPI is a research method that:

- Provides a voice to marginalised populations;
- Enhances public awareness by documenting abuses and violations;
- Reinforces a collective identity amongst the disability community;
- Supports efforts to achieve social justice (DRPI, n.d.).

After recruiting and training disabled Monitors (researchers), monitoring interviews were conducted remotely using Zoom or alternative forms of technology. This ensured that COVID-19 physical distancing protocols could be maintained at all times throughout the monitoring.

### 7.3 Interviewee Recruitment

Maximum variation sampling was used to recruit potential Interviewees (participants) for Phase Two qualitative interviews (Patton, 2002). All research information was available in official languages and accessible formats (plain English, Te Reo Māori, New Zealand Sign Language, Easy Read, Braille, large print, and audio).

To participate in a monitoring interview, Interviewees needed to be over the age of 18, identify as disabled or as a family, whānau member or close supporter of someone with multiple and complex disabilities, and also be able to provide full and informed consent.

For Māori Interviewees who indicated they felt more comfortable participating in the focus groups or interviews with facilitators and Monitors who were familiar with tikanga Māori and Te Reo Māori, this was arranged. Further to this, the training of all Monitors was guided by the research team's consultation with Māori researchers and tāngata whaikaha/ whānau hauā (Māori people who identify as disabled).

<sup>2</sup> The DPO Coalition is made up of the Association of Blind Citizens New Zealand (Blind Citizens NZ), Balance Aotearoa, Deaf Aotearoa, Disabled Persons Assembly NZ (DPA), Kāpo Māori Aotearoa, Muscular Dystrophy Association of New Zealand Inc., and People First New Zealand Ngā Tāngata Tuatahi. For more information, see Office for Disability Issues (2019).

## 7.4 Interviewee Demographics

During Phase Two of the monitoring, 100 disabled people and their family, whānau and close supporters were interviewed over a period of six months. Of these, 87 Interviewees identified as disabled, and 13 as family, whānau, or close supporters of people with multiple and complex disabilities. Sixty-eight Interviewees identified as female, 28 as male, four as non-binary, and one as transmasculine. Ethnically, 77 Interviewees identified as Pākehā, 13 as Māori, eight as Pacifica, seven as Asian, seven as European, four as South African, and one identified as South American.

Interviewees were located throughout Aotearoa, from Kaitia to Invercargill. The youngest Interviewee was 20-years-old, and the oldest Interviewee was 77-years-old, with a median age of 45-years. The types of disabilities included physical disabilities; sensory disabilities (including, but not limited to, deafblind, blind, low vision, Deaf, deaf, and hard of hearing); people with learning disability and neurodiversity; and people with psychosocial disabilities. Many participants identified as living with multiple disabilities.

## 8 Findings

The opening text of Article 25 (Health) of the UNCRPD states that the New Zealand Government must:

[R]ecognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties [the New Zealand Government] shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation.

With this in mind, once the data had been collected, transcribed, and coded according to predetermined and emergent themes, it was then grouped under the relevant sub-articles of Article 25 (Health) of the UNCRPD. At the end of each sub-article is a summary of how the findings relate to the progressive realisation of the obligations contained within the sub-article, followed by a list of agencies and organisations (duty bearers) who should be concerned with these findings.

Throughout the findings, quotes are structured to reflect the verbatim response of the Interviewee, and when content was removed by the Monitoring Team, this is indicated by square brackets and three periods (for example, [...]). When two voices are included in a quote, such as the Monitor (researcher) and the Interviewee (participant), this is represented by M: and I: to indicate the change in narrator. When direct quotes have been edited for grammar purposes or clarifying details added then square brackets have been used. To ensure that Interviewee responses remain anonymous, quotes have been coded as (Interview #1), (Interview #2) and so on, with identifying details removed.

For the sake of succinctness, only a small number of quotes have been included in the findings as examples and evidence. However, the DBI acknowledges the magnitude of experiences reported by Interviewees that have not been included in this report, and the importance of those experiences.

## 8.1 Article 25.a

In particular, the New Zealand Government shall:

a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes.

Outlined below are findings that directly relate to the progressive realisation (or lack thereof) of Article 25.a of the UNCRPD.

### 8.1.1 Funding

In Aotearoa, essential health care<sup>3</sup> is provided free for those who qualify through the public health system. Free or subsidised health care includes hospital treatment, 24-hour accident and emergency, prescriptions, most immunisations, out-patient hospital care, and care for the chronically ill and elderly (Medical Council of New Zealand, n.d.a).

While recent Government budgets have indicated a strong commitment to the health and wellbeing of all New Zealanders, findings from this monitoring research revealed funding to be one of the most common barriers to disabled people's engagement in the health and disability system.

The most widely referenced factor relating to funding was which Crown agency an Interviewee was funded by - Accident Compensation Corporation (ACC) or the Ministry of Health (MoH), which was determined by the cause of their disability or condition (injury or congenital/health). Interviewees reported:

- The perception of a two-tiered health system, resulting in different classes of health amongst the disability community:

“[...] I also found that it's very hard to sometimes get services between ACC and MoH, if you got your disability because of an accident, I find that my friends, who, who've done it that way get much more support, and much more funding, and much more housing modifications, and much more employment support, and computer equipment, and everything. Whereas if you're a health [MoH] client it's sort of like a second-class citizen really.” (Interview #14)

- Inadequate funding for Interviewees under the MoH system, which impacted on the type, timeliness, quality, and length of treatment and services they received:

“[...] The amount of care is completely different, and I'm always dumbfounded at the disparity between MoH and ACC and it, it's just, it makes me think something that, ya know, like I can get say, 15 hours caregiving time off ACC, yet someone else in a very, very similar situation would only get like, three hours from MoH, and it's purely funding. Same with the equipment and

<sup>3</sup> Throughout this report, “healthcare” has been used to refer to the “system”, and “health care” to refer to the specific actions and things that people do.

supplies. I've got someone else that's got a, the same, you know, suprapubic catheter that I do, but is MoH because it's a medical issue, and the supplies that she gets is just so substandard, really, compared to what I get. And it's just sad that that's the case, so she's getting constant infections and stuff like that because she hasn't got access to some of the bits and pieces [...]."

(Interview #18)

- A lack of funding for disability-specific services (for example, services for people with Foetal Alcohol Spectrum Disorder, or FASD):

"M: What's the barrier?"

"I: Funding I reckon. They don't want to fund it because they know so many people. If they do fund it they've then got to find the money from somewhere. I think they know because like [specialist name removed] always used to say when he gives talks that it's a tsunami. I think Government aren't... because, like, FASD-CAN do a lot of advocacy work for government with the state. They've said that they know, but you know... it's funding." (Interview #2, Family Member)

- A lack of consistency, coordination and communication was reported by Interviewees who were funded by both the MoH and ACC:

"What I would love is the DHB [District Health Board] and the funding that I'm entitled to through them for my chronic condition, and ACC and the funding that I should be entitled through them for the injuries that I'm carrying, should literally be talking to each other and come up with a finance plan to do the stuff that needs to be done in my kitchen. They won't talk to each other, so they just deny anything." (Interview #63)

"When they listed my injuries, they did not list my bowel injury from the incomplete spinal injury. Only my bladder is covered. So I get different coverings and I have to deal with injuries differently depending on whether they are ACC covered or not." (Interview #96)

## CASE STUDY:

The funding issues outlined above can be found in the experience of one Interviewee, whose adult family member had recently experienced a significant medical injury during childbirth. After an initial attempt to access ACC funding was declined, the funding for the family member's intensive rehabilitation services were withdrawn, forcing her to move into an ill-equipped MoH-funded aged care facility. As highlighted by the Interviewee, had her family member been able to access ACC funding, she would have not only been able to continue her specialised and intensive rehabilitation, but also been able to remain at home with her new baby and family, as articulated under Article 23 of the UNCRPD (Respect for Home and Family):



“Initially when she was in the rehab, she still can talk a little bit. She had been in rehab for ten and a half months. So, she was moved to the facility, actually in the aged care facility now - it’s not suitable for her, it’s for elderly people. [...] We are not happy with that facility, the care that she had been given. [...] The one registered nurse is looking after 34 residents. [...] It’s horrible and we were there, we were always there before the lockdown. I was there for her throughout the day, so most of the care, I helped her. At the time we didn’t say anything. I think, that facility, that’s okay, I will take care of her. But out of the lockdown, we see the gaps, it’s just her needs are not met. [...] Some days, I went there, they just leave her in the room with a few others, elderly people, she cries, because she needs to be wheeled around or stretched. [...] And, also, we claimed ACC and they didn’t approve it. They declined her claim, you know. It’s just horrible and they decline her claim and it’s now under review. We have asked a solicitor to fight for her because this is the minimum that can help to have, provide care for [name removed], for her family, you know.”  
(Interview #31, Family Member)

On a practical level, inconsistent and inadequate funding systems affected Interviewee’s engagement with what is supposed to be free and/or affordable health care. For example:

- In line with the findings of the 2020 New Zealand Health Survey (Ministry of Health, 2021a), Interviewees reported being unable to afford the cost of primary health care, mental health services, and allied health services. This was a result of fees, the financial cost of taking time off paid employment, and low benefit levels:

“[...] I’ve had to cut down my [General Practitioner, GP] visits, because it’s subsidised, but it’s still \$20, you know. Other people pay \$38 I know or something like that. And I am told WINZ [Work and Income New Zealand] wasn’t paying for my prescription because I found a place where you know you could get your prescriptions for free and of course that meant my disability allowance went down, but you know that’s just the way it is because they only pay for what you are applying for.” (Interview #86)

- The cost of prescriptions, transport and parking at primary and tertiary health care services was identified as being prohibitive:

“M: So, your medical costs, your doctors’ costs and everything, that’s what’s taking you over being able to live on that benefit?”

“I: Yep. I can’t even afford to get prescriptions, a lot of them. I’ve got about three pages of scripts to get done from the doctor a couple of weeks ago and I could only get two things off it.”

“M: And there is no additional help that you can get for those costs?”

“I: No because apparently, with the benefit, I’m getting money for that and the doctor included in it.”

“M: But it’s not enough?”

“I: No. I’m basically left with \$10 a week. That’s it. With all the bills coming out [...]” (Interview #9)

“I had to go to [hospital name removed] cause I couldn’t go to [hospital name removed]. That’s now changed but that was the significant cost for me to get there and find a park that was free.” (Interview #48)

- Some Interviewees felt at a financial disadvantage by the length of appointments offered by free and/or affordable health care services. For example, some Interviewees reported disabled people being charged for double appointments because they had a greater number of complex issues to discuss with health professionals, or because they communicated using an alternative form of communication:

“I: [...] I know some people with communication devices are charged more because they need longer to communicate.

“M: Wow, so they’re, basically you wouldn’t be charged so much if you didn’t have your disability?”

“I: Yeah.” (Interview #21)

As summarised by one Interviewee with a physical disability, “I think that poverty and health go hand-in-hand. I think that a lot of disabled people are in poverty more than the average able-bodied counterpart.” (Interview #26)

### 8.1.2 Sexual and Reproductive Health

Another key aspect of Article 25.a is a disabled person’s right to sexual and reproductive health care. Research shows that globally, disabled people experience multiple health disparities and challenges when accessing the health care they need (Casebolt, 2020). Sexual and reproductive health is no exception, with barriers including a lack of knowledge around sexual and reproductive health; limited educational opportunities; inaccessible population-based sexual and reproductive health public programmes; disability-specific barriers; and perhaps one of the most prevalent factors being the attitudes, training, and experience of health care providers (Agaronnik et al., 2020).

Reflecting international research, several Interviewees reported barriers and challenges when seeking access to sexual and reproductive health care in Aotearoa, such as:

- Inaccessible fertility services:

“I know my choice to have children or not was at least partially impacted by the struggle (caused by my disabilities) of getting to a fertility clinic hours away in an unfamiliar place. Poor public transport is also an aspect.” (Survey Participant)

- A lack of knowledge around intersex bodies and reproductive health:

“I remember this particular day I went in for something else and she said, “You haven’t had your Pap smear.” And I assumed it would come up on her computer as a bad thing because of my age and because she saw me as a woman so this day I said, “You can’t do it.” And then she said, “Oh well, let’s see if we can try.” So, you know I was angry and really embarrassed and got up on the table and she got what she called a [audio unclear] speculum. So, my variance is such that I don’t have an external vagina - it’s inside of my body, and I have something called urogenital sinus it’s sort of like a U-bend but it’s not flexible so when she tried to go inside, one you can’t, and that’s incredibly painful. I mean I can stand [it] now. It could be hilarious, but it wasn’t hilarious at the time. So, I was embarrassed, and she didn’t know what to do and she just kind of backed away and I got off the table and it was afterwards that I decided to fire her.” (Interview #95)

- A lack of knowledge around gender affirming health care and disability:

“I was quite scared to disclose that I also had a disability because I had heard that a lot of other disabled people who had tried to access gender affirming health care [were] being prevented because they were told that their situation was too complex and things like that. But disability isn’t related to gender, so I didn’t, you know, I was hesitant to discuss that at all.” (Interview #101)

- Assumed parental incompetence:

“[I] got the referral and it said [...] on the referral that it was, “Disabled woman shouldn’t have a baby but has had one and needs help.” [...] The maternity nurses were very rude. So, they would often kind of make comments like, “Oh why is she having a baby?” Yeah. Again, the notion of being selfish for being a Mum.” (Interview #45)

## CASE STUDY:

As is demonstrated in the following example, the negative attitudes of health professionals towards a disabled person’s desire to form a family is a barrier to not only Article 25.a, but also Article 23 of the UNCRPD. In this example, the Interviewee’s physical disabilities were the result of a mismanaged mental health crisis that had occurred when she was younger. More than a decade on, she had become pregnant, recalling that it was a complex pregnancy due to her disabilities:

“I had strong encouragement not to try for a second baby because of the complex problems I’ve had [...] I understand that I potentially will have more damage or increase in my disabilities from having another baby, but I am happy to have a second one and that’s probably all I am willing to do to my body.” (Interview #96)

However, when asked how medical professionals responded to her desire to have a second child, the Interviewee responded:

“It was surprising to a lot of doctors that I wanted to have a baby in my body. To be honest, I’ve changed physiotherapists and occupational therapists because I am sick of the negativity around me having a baby. I consider it ignorance towards the experience of infertility because pain in my opinion is perceptive; yes, I do have horrific physical pain and a lot of physical consequences from having a baby, but I also know the emotional pain of not having a baby or emotional pain of losing children, so I feel I have more autonomy over making a decision. So, I avoid practitioners who aren’t helping. My pregnancy pain specialist was joking last week that after this baby he would make me sign a contract that I never tried again. But I just laughed it off and said, “You watch out, I’ve got three more embryos in the freezer.” I deal with attitudes better now. When I was under the chronic pain team in [hospital name removed], it was terrible. [...] It was terrible because I was completely medicalised, and I felt dehumanised. He pretty much put his pen down and said, “Why do you want to have a child?” The way he said it was clear he meant, “Why the hell are you doing this to yourself and to the system? Look at all of us trying to help you just manage until now, and now there is going to be more of us helping you because you are making this selfish decision. You shouldn’t have the right to have a child because you are disabled.” (Interview #96)

### 8.1.3 Population-Based Public Health Programmes

Population-based public health programmes refer to preventative and holistic health programmes that aim to improve the health status of a population as a whole (Shahzad et al., 2019). In Aotearoa, these include bowel screening, breast screening, human papillomavirus (HPV) screening, Smokefree 2025, immunisations, and so on (Ministry of Health, 2021b).

However, when a health programme is targeted at a wider population, the needs of specific populations can sometimes be dismissed or ignored. The findings of this monitoring research showed that in some circumstances, population-based public health programmes in Aotearoa do not consider the rights, needs, will and preferences of disabled people. Take, for example, the public health response to the COVID-19 pandemic in Aotearoa.

#### CASE STUDY:

First reported in China in 2019, COVID-19 quickly turned into a global pandemic with significant social, health, psychological, and economic consequences (Bandyopadhyay & Meltzer, 2020). In March 2020, Aotearoa moved into a strict Level 4 lockdown, and has since moved in and out of lower lockdown levels. Notably, the country’s rapid response to COVID-19 led to significant disruptions to the delivery of health and disability services during these periods.

The Government's response to COVID-19 was formulated as a public health programme. However, as highlighted by Interviewees, the response did not appear to initially consider the needs of the disability community. The combined impact of COVID-19 as a potentially life-threatening illness, the lockdowns, together with the public health response, exacerbated disabled people's existing poor health outcomes. This was primarily due to the compounding challenges associated with accessing health and disability services (Perry et al., 2020) - findings that were also reflected in New Zealand's International Monitoring Mechanisms (IMM's) report, 'Making Disability Rights Real in a Pandemic' (IMM, 2021).

In order to understand disabled people's experiences of the Government's public health response to COVID-19, all Interviewees were asked to share how COVID-19 had affected them personally, with many highlighting the adverse impact it had on their health and wellbeing. Common issues included:

- Disruptions to Individualised Funding, which enables disabled people to have choice and control over their health and wellbeing supports:

“[...] Over Covid... we were left alone. There were hundreds and hundreds of people out on Individualised Funding. [...] There was no system to trace where we lived, how to contact us. Now that's got to change.” (Interview #73)

- Restricted or delayed access to Personal Protective Equipment (PPE) during the earlier stages of the COVID-19 public response:

“[...] the time to get PPE to [location removed] would be two, if not three days. And we [disabled people] are not important. So, I don't understand why people with disabilities, how they're gonna cope. Because Covid, we're living with Covid in the world.” (Interview #73)

- Delivery of public health information in inaccessible formats:

“Where it affected me really was - luckily I've got a sighted wife. But if I was by myself it really affected a lot of people who are totally blind because of course everything was visual out there.” (Interview #20)

- Physical and social isolation:

“And just like clear discrimination and just that total sense of isolation because I'm responsible for getting my own groceries and I don't have a credit card or an online presence to order those things online and I'm not over 65 so I don't fit in, or over 70, that target group that they said stay home blah blah, those services will help you. Well not sure who? And it was just really isolating and really concerning.” (Interview #69)

## 8.1.4 Access

A further group of findings relevant to Article 25.a was ‘access’. Access was referred to in a variety of contexts, including financial access (as discussed in the Section 8.1.1), as well as physical access, mental access, communication access and sensory access. This was particularly relevant when discussing free and/or affordable health care and programmes.

### 8.1.4.1 Physical Access

While many Interviewees acknowledged that improvements had been made to physical accessibility in health settings - such as primary, secondary and tertiary health care services, as well as allied health services - examples of inaccessibility were still common. This included:

- Inaccessible buildings (for example, GPs located in residential villas and old buildings):

“I’ve really struggled to find a GP that has an accessible office. There are just so many out there that are in these converted houses or even new built commercial buildings that don’t have elevators or ramps or anything like that. It’s bizarre. [...]” (Interview #6)

- Healthcare providers neglecting Universal Design principles during construction and building upgrades:

“[...] Like walking into the hospitals... um... polished floors, things like that, they’re not good.” (Interview #4)

- Inaccessible in-patient care:

“[...] I can’t wheel and then they’d be like, “Oh you can go to the waiting room.” I can’t wheel. Like I’ve got one hand to wheel. And then they’re like, “Oh ok. We’ll just leave you here then.” It was like well you can actually move me out. You don’t have to leave me here.” (Interview #93)

### 8.1.4.2 Mental Access

Several Interviewees also indicated they felt a lack of ‘mental access’ due to anxiety, and/or past trauma relating to the health system itself. Coined by a survey participant during Phase One of this monitoring cycle, ‘mental access’ refers to an individual’s ability to access a health setting with a sense of mental wellbeing and safety. However, Interviewees felt triggered by past negative experiences when attempting to engage with the health and disability system:

“Probably the biggest thing for me, that I have had to get over, is the anxiety and sometimes near panic attacks if I need to have a hospital admission. Because it is the only time I am afraid for my life.” (Interview #96)

### 8.1.4.3 Communication Access

Another widely cited issue were the efforts required to communicate with medical administrative staff, practitioners and specialists. This included:

- Confusion around booking New Zealand Sign Language (NZSL) Interpreters in different health settings:

“M: Are you aware that you don’t have to be the one who books that interpreter? Actually, doctors should be doing that, not yourself.”

“I: I’ve always done for myself where I can.”

“M: Why? You don’t actually have to? It’s actually their responsibility to book an interpreter for you. And you can tell them I would like you to book interpreters. It is really their responsibility to do that. You can ask them to do that. Were you aware of that?”

“I: I did not know that. I have never put that onto them. It would have been nice if they did.” (Interview #67)

- A shortage of NZSL interpreters, particularly during emergencies:

“M: So, you didn’t have that information? You had no interpreter to communicate with?”

“I: None, nothing, no none.”

“M: They should’ve provided one.”

“I: It was urgent, it was an emergency and I didn’t know what was going on. It was my first-time experiencing epilepsy so yeah.” (Interview #59)

- Health service providers relying on children and family members to interpret when NZSL interpreters were not provided, or were unavailable:

“I need an interpreter, I don’t want my daughter to be interpreting in those [medical] spaces, you know. She’s not a professional, she shouldn’t be signing in that context. You want a professional interpreter there.” (Interview #67)

“Can I just say in terms of New Zealand health services for Deaf people there are not enough interpreters you know. I’m always having to rely on pen and paper or family to interpret you know and you know sometimes it’s personal stuff you don’t really want your family getting involved with. I think it would be nice to have interpreters because I don’t necessarily want to have family involved or actually any other people involved in my personal stuff.” (Interview #28)

- Limited modes of accessible communication (for example, phone call only):

“And yeah, yeah so it is sometimes that for example, everything is about “call Healthline, call Healthline, call 0800” blah blah blah whatever it is, and I’m just



- like no, is there an email address? Because that would be my preference or being able to text for example would be preferred.” (Interview #98)
- Complex medical information being communicated by practitioners through interpreters, leading to confusion and low comprehension:

“[...] They [medical practitioners] need to provide pictures so that people know what they mean. Like they write a lot of things down. There are a lot of words they use that just go past me. They have this really sort of high register language that I just don’t understand.” (Interview #29)
- A lack of mental health support in NZSL:

“I mean, in the past I’ve definitely felt like I’ve been treading water with that kind of thing. Counselling often feels like that’s not something that’s very accessible.” (Interview #60)
- Limited methods of accessible communication for people who are blind or low vision:

“Barriers were not providing an email address for direct communication between patient and hospital departments [...]” (Interview #43)

“My GP uses Manage My Health. Which is an app and the app is not accessible.” (Interview #14)
- A lack of accessible communication, procedures, and documents for people with learning disabilities and who are neurodiverse:

“I’m a highly visual person and I understand better when people use visual aids and simple explanations with me, such as Easy Read. Except I kept on getting these big reading materials on the surgery, nothing was ever in Easy Read or using visual aids.” (Interview #41)

“I: [...] The forms are not easy to understand. The paper work surely is not easy to understand. All the letters. They need to make this into another way, building understanding in different ways because we’ve got different needs. So, they need to look at all options and be flexible on the needs. Yeah. They need to really make this short, simpler and get to the core, don’t put extra words you don’t need, or you don’t understand, for people to understand.”

“M: Can you give me an example of when you couldn’t understand the information?”

“I: Um when they send you a letter, ah about what you need to do before the operation. This is not easy to understand at all. Because this letter gives you more questions compared to answers. [...] so when they give you a letter for an operation, your brain goes haaaa? I wish they’d make this in a way I can understand, easy words, it sounds like this but big words you never saw ever before in your life. It’s a bit confusing and no one had to explain to you about it.” (Interview #35)



#### 8.1.4.4 Sensory Access

A final aspect of access was shared by Interviewees who experience auditory and sensory overload within public health settings:

“What I find so hard and difficult is the spaces I may have to go to are inaccessible. Um, if I have to spend six hours waiting in a hospital waiting room under these big fluorescent lights in a place that is so noisy that will make me more sick. And it puts me off going to get help when I am sick. And that means I wait even longer and then the situations that I might be needing help for is further away [...] it takes me longer to get what I need because I avoid getting help sooner. Yeah because often the places I have to go to are not designed for people who experience any auditory or sensory overload.”  
(Interview #51)

#### 8.1.5 Formal Complaints Procedures

An important aspect of free or affordable health care, as well as population-based public health programmes, is the ability to raise and resolve issues in a timely, respectful, and rights-based manner. However, when discussing complaints procedures most Interviewees recalled negative and traumatic experiences, such as:

- Unsatisfactory resolutions and a lack of accountability by people in positions of power:
  - “No, I feel like it’s a waste of time trying to complain.” (Interview #4)
- Falling through the cracks of different systems such as the Human Rights Commission, Ombudsman’s Office, different government departments, District Health Boards (DHBs), and hospital departments:
  - “We went to the Ombudsman over a year ago. So, there’s been no action. Falling through the gaps. Ombudsman saying no thank you and the Health and Disability [Commission] haven’t done anything. [...] I just... beggars’ belief!” (Interview #19, Family Member)
- Fear for the consequences of making a complaint:
  - “I feel kinda stuck that even though it was a crap outcome he’s [specialist’s name removed] still one of the best in New Zealand and I wouldn’t want to make a complaint because he might not want to work with me and then what? We’re screwed.” (Interview #82)
- Being ‘blacklisted’ after making a complaint:
  - “I was asked to give [hospital name removed] some feedback and I did. It was polite, but it was direct. I said I felt that I had been failed completely. Then the Health and Disability Commissioner got on board and they said, “You’ve been failed completely.” [Hospital name removed] didn’t take it very well. I’ve been blacklisted.” (Interview #5)

- Trauma and/or fatigue from prolonged and complex complaints procedures:
  - “I don’t want to go back and complain and have flashbacks. I just, I don’t want that, I want to move on.” (Interview #68)
  - “The emotional strain of complaining and pushing, it’s just too much. I would rather spend the emotional energy and the physical energy that I have on things that make me happy. Rather than butting heads with a person who doesn’t really care. And that’s the bottom line. They don’t care, they don’t see it and until the Government actually puts really strong laws in place, until they actually start taking it absolutely seriously, and not just lip service, and not just saying, this is what we want to do.” (Interview #16)
- A preference for seeking out an alternative health care provider rather than making a formal complaint:
  - “I was feeling a bit stuck. Communication just hadn’t been going well and then I transferred to another doctor.” (Interview #59)

Furthermore, while all people are entitled to submit a complaint to health authorities, the complaints processes themselves were not always accessible to everyone. For example, many processes required verbal or written evidence in English, which was identified as being inaccessible and a deterrent to NZSL users:

- “M: Did you make a complaint about that particular incident?”
- “I: I was not going to type it up. My English is not the best. I have got some skill in English, but I did not feel comfortable to send anything through really. I just let it go.” (Interview #67)

### 8.1.6 Article 25.a Summary

Article 25.a states that disabled people should have the same range, quality and standard of free or affordable health care and programmes as is provided to the general population of Aotearoa, including population-based public health programmes.

However, findings revealed that as prolonged and frequent users of the public health and disability system, the costs of accessing primary health care were prohibitive; that free or affordable systems were often physically, and mentally inaccessible; and that communication and sensory barriers were common. This resulted in many Interviewees either actively avoiding engaging with the health system, or feeling that engagement was detrimental to their health and wellbeing. These experiences were also heightened when accessing sexual and reproductive health, and other population-based public health programmes, such as the Government’s response to COVID-19.

### 8.1.7 Duty Bearers Who Should be Concerned

- Accident Compensation Corporation (ACC)
- Allied health services
- Contracted architects, builders and designers
- Disability Support Services (DSS)
- District Health Boards (DHBs) and their successor organisations<sup>4</sup>
- Health NZ
- Māori Health Authority
- Medical practitioners
- Mental Health and Wellbeing Commission
- Mental health services
- Ministry of Health (MoH)
- Relevant Ministers

<sup>4</sup> When this report was written, Aotearoa New Zealand's Health and Disability Systems were undergoing reform in response to the Health and Disability System Review. DHBs were going to be replaced by another organisation, which was yet to be established at this point. For the purpose of this report, successor organisations means the organisations that would replace DHBs. For more information about the reform, visit <https://dpmc.govt.nz/our-business-units/transition-unit>

## 8.2 Article 25.b

In particular, the New Zealand Government shall:

b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons.

Outlined below are findings that directly relate to the progressive realisation (or lack thereof) of Article 25.b of the UNCRPD.<sup>5</sup>

### 8.2.1 Choice and Control: Services, Treatment and Medication

In order to maintain the highest attainable health, it is crucial to have access to preventative health as well as ongoing health care support. A key issue raised by Interviewees was the lack of access to non-funded and non-subsidised health care that would enable them to maintain a high standard of health. For example:

- Many Interviewees reported not being able to access gym memberships, non-subsidised allied health care (such as physiotherapy), interventions outside of primary health care (such as chiropractic) and non-subsidised medicines:

“I: There’s no support to get treatment.”

“M: No support... you mean no funding? Or are there no ways of treatment?”

“I: [Shakes her head and mouth downturned] funding for me to get physio.”

“M: Umm because it’s part of your congenital condition?”

“I: [nods]”

“M: Aye, that’s so bad. So, your physio would be able to help you but you can’t access it because it’s too expensive?”

“I: Yeah, yeah [nods].” (Interview #97)

- Interviewees with psychosocial disabilities shared how easy it was to access prescribed medications, but not non-medicalised treatments such as counselling:

“[...] My GP has only suggested antidepressants. I have been turned away from counselling services because nobody wants to deal with somebody who is so complicated.” (Interview #21)

Another important issue relating to choice and control was access to NZSL interpreters. Many Deaf interviewees experienced difficulties when trying to access interpreters in general, let alone an interpreter of their choice. The main factors being the limited availability of interpreters and a lack of awareness by health services around how interpreter booking systems work:

<sup>5</sup> In Aotearoa, health and disability issues are often discussed together. While these two components are equally important, they are distinct aspects of disabled people’s health and wellbeing. The first half of this section relates to disability specific health services, with the latter half relating to disability support services (DSS).

“I wanted to access an interpreter both that I felt I would be able to understand, and also that I just felt comfortable with because it was personal. But it was really, really difficult because the hospital wanted to choose the interpreter for me.” (Interview #30)

### 8.2.2 Service Coordination

In Aotearoa, health care is provided by different levels of systems and providers. As frequent and prolonged users of the health and disability system, Interviewees felt frustrated by the lack of collaboration and coordination between services and providers. This included:

- A lack of consistency between different DHBs.
- Needing to repeat lengthy and complex medical histories at each medical interaction.
- A lack of communication between DHBs (MoH) and ACC.
- ‘Falling through the cracks’ of different systems and services.
- Exhaustion from the extra time and effort required to navigate systems and services.
- A lack of communication and coordination between departments within a single service provider (for example, hospital departments).
- A lack of consistency in supports and services across a disabled person’s lifetime.

As summarised by one Interviewee with a physical disability, “I’m under the care of different departments. It’s very hard kind of keeping an overview of all of those areas and generally what’s happening for me. That should be my doctor’s responsibility but that doesn’t work so well for me.” (Interview #63)

### 8.2.3 Disability Services and Coexisting Disabilities

Also referred to as ‘comorbidity’, coexisting disabilities refers to circumstances where an individual has more than one condition or illness at the same time (Australian Department of Health, 2020). While disability-specific services provide for the needs of a target disability population, Interviewees reported that services often failed to consider the interlinking nature of the various coexisting disabilities they lived with.

The most commonly cited example was the lack of physical, communication and sensory access within mental health services. This often meant that Interviewee’s mental health and wellbeing needs were considered in isolation, rather than holistically, as people who also experienced other physical, neuro, learning, and sensory disabilities.

“They don’t have suitable mental health services. In fact, my experience, a big part of my life, I mean my life has been ruined [starts crying] really because of my experiences in mental health services as an Autistic person.” (Interview #10)

“I didn’t want to have an interpreter in the [counselling] sessions so I got her to type on a laptop and for me to talk, sort of similar to how we’re doing this I guess. It was hard, it took more time. I sort of felt like we were only starting to

become more comfortable with each other sort of by about session five, and there was one more session, six, and then you're finished. And so, it took all that extra time to get to the point that, if I had been hearing you know, I would have been at, from the beginning." (Interview #30)

## 8.2.4 Diagnosis

Diagnosis was identified as being a barrier to health and wellbeing. Accurate diagnosis is crucial for identifying appropriate health treatments and interventions. A diagnosis can also act as a bridge between health services and disability support services and is often the first step towards funding. However, Interviewees reported that financial access, diagnostic overshadowing, and misdiagnosis, were issues that prevented them from having the highest attainable standard of health.

### 8.2.4.1 Financial Access

One of the main challenges associated with diagnosis was the cost of qualified specialists. For example, several Interviewees shared that they had to go through private health care services in order to receive a diagnosis, as public health care services did not have the capacity. Other Interviewees, however, did not have financial ability to see a specialist privately:

"I know it's still incredibly difficult [to get] assessed. I know there's a massive waiting list to get it funded. So, I think that's why my family went private in the end. But they got hit with a big bill. But I think it's even more high and the wait list is even more high in the rural areas like [regional location name removed] and [regional location name removed] and places like that because there's, I guess, more demand and less assessors." (Interview #7)

Interviewees with a family member with FASD shared openly about the lack of resources for a FASD diagnosis. Furthermore, even when a person receives a diagnosis of FASD, it is yet to be recognised as a disability by the New Zealand Government. Therefore, specialised services are almost non-existent, leaving people with FASD and their families and whānau in dire, and often unsafe, situations.

"We pushed for a diagnosis but the DHB doesn't have a diagnostic capacity. This is in [location removed]. We paid privately for a diagnosis of our daughter and she did have Foetal Alcohol Spectrum Disorder. She's got a lot of secondary disabilities from that as well." (Interview #2, Family Member)

Without a diagnosis, Interviewees were unable to receive the support and funding they needed, which in some circumstances led to serious health consequences. The importance of early diagnosis was highlighted by one Interviewee who lives with a psychosocial disability:

“[...] If I look back, if I had had the right things and the right, you know, like stuff put in place, like from a very early age, because my first presentation for mental health issues was when I was five. As soon as I hit the school system, they were like [expletive removed], you know, what’s going on here? So, if I had had an intervention and help and support that was adequate at that stage, not only would I have not cost the country - I’m [in my 50s] now and I’m still costing the country and I’m a burden on society. If I hadn’t been... if I had had that early on, I would have been an asset to the country.” (Interview #10)

#### 8.2.4.2 Diagnostic Overshadowing

Another common experience was diagnostic overshadowing. That is, a health professional’s bias that leads them to over-attribute certain symptoms to an individual’s disability, while ignoring the potential existence of other co-existing health conditions unrelated to disability (Javaid et al., 2019). While diagnostic overshadowing is a term that has commonly been used to describe the experiences of people with learning disabilities and psychosocial disabilities (Jamieson & Mason, 2019), the findings of this monitoring research indicates that it is an experience also shared by the wider disability community:

“[...] It’s like they think, “Mm, ok, that person’s got that,” and it’s immediately... you’re put into another category or a lesser category and all that overshadows whatever else you’re seeing them there for.” (Interview #13)

#### 8.2.4.3 Misdiagnosis

Misdiagnosis, or the incorrect diagnosis of a disability or health condition, had prevented Interviewees from accessing treatment, which had often led to adverse health effects. Interviewees also shared the difficulties they had had when attempting to correct the misdiagnosis they had received:

“[...]But I was ignored and told I was bipolar because it fit with their narrative. But it was only a year ago? No, two years ago that I finally got that removed from my medical records!” (Interview #17)

#### 8.2.5 Wait Times

Another issue relating to Article 25.b were the extended periods of time between a health event, making contact with primary and tertiary health providers, diagnosis, referral, appointments, and follow up. While wait times within the public health system are a well-documented problem (Ansell et al., 2017; Ministry of Health, 2013), the impact on disabled people’s health and wellbeing was noted by Interviewees as being compounded. For example, several Interviewees reported a deterioration in their condition due to prolonged wait times:

“M: So, when did you get that formal diagnosis?”  
“I: It was last year.”



“M: So, you’ve had 10 years of undiagnosed pain?”

“I: Yeah, over 10 years. It started when I was 20 and has been gradually getting worse.” (Interview #9)

Interviewees also experienced long wait times when trying to access mental health services. As highlighted by one Interviewee with a psychosocial disability:

“I went to the [hospital name removed] and again it took about I’d say six to seven weeks to see someone and I was in quite a crisis state and I thought that was terrible. Thought that was really hard.” (Interviewee #50)

This point was also noted in the context of mental health services that are inclusive of, and accessible to, people with learning and sensory disabilities:

“But I do realise there is a long waiting list and there’s very few therapists qualified to do it [mental health services for people with learning disabilities and multiple/complex disabilities].” (Interview #22, Family Member)

### 8.2.6 Unpaid and Paid Supports

In addition to Article 25, Article 19 of the UNCRPD requires the New Zealand Government to recognise the right of disabled people to have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community. Both Articles 19 and 25 reflect the importance of Disability Support Services (DSS) for disabled people.

Natural support, on the other hand, refers to the relationships disabled people have in their lives – that is, unpaid, informal, and ordinary relationships (Field, 2012). However, Interviewees reported experiences where people in positions of power had pressured them to rely on their natural supports as a substitute for formal and paid disability support:

“Natural support is the same, pushing parents to care... My parents are getting on in age and shouldn’t have to help. They [MoH] say, “Your partner should take you.” But why? I’m not a child, I want to be independent.” (Interview #66)

DSS is the MoH agency tasked with planning and funding disability support services in Aotearoa (Ministry of Health, 2016). Despite attempts at improving support services, many Interviewees indicated there are gaps in the current system, particularly for specific disabilities and long-term conditions:

“I’m always doing stuff on my own. Yeah. They talk about natural support but I don’t believe that. There are no natural supports.” (Interview #83, Family Member)



Along with accessing diagnosis, family members of people with FASD experienced significant challenges with attempting to access formal disability support. As stated by one parent:

“It’s just all been an absolute uphill battle and because it’s not funded by the government; it’s not recognised as a fundable disability; no one’s trained in it and specialised in it. So, it’s an absolute abuse of human rights for any child and family with Foetal Alcohol. It’s shocking what I’ve been through; absolutely shocking.” (Interview #57, Family Member)

And as highlighted by another Interviewee:

“We’ve begged and begged for support. [...]. We go round and round in circles asking for help. [...]. And I’ve been begging for nine years, “Please give us help. Please give us support.” But none of it was the correct support or help. [...] FASD is not recognised by our government as a disability. There’s no funding attached to it.” (Interview #2, Family Member)

Finally, the lack of accountability and low quality of services provided by DSS were amongst the most frequently cited issues:

“But the problem is, all the support workers through... they all run from one job to the next. Or... they don’t have a lot of in between time. So, I’m happy when it’s my regular person, but I’m not so happy when I have to wait around. But it’s not the fault of the support workers, it’s the fault of the system they work under.” (Interview #71)

### **8.2.7 People with Multiple and Complex Disabilities and their Family, Whānau and Close Supporters**

For Interviewees with a family member with multiple and complex disabilities, acquiring appropriate carer and support funding under DSS was reported as being a barrier to their family member’s health and wellbeing. Funding for the care of people with multiple and complex disabilities is a service that is designed to minimize and prevent further disabilities, both for the disabled person, and their close supporters. Reported issues included:

- Inconsistent pay rates for carer and support hours (depending on the funding provider - ACC or MoH), as well as funding packages that, when broken down into hourly rates, were well below the minimum wage.
- Families being unable to offer an acceptable level of pay to external support workers and being forced to work for the low pay rate themselves.
- Family members of people with multiple and complex disabilities reported acquiring physical and psychosocial disabilities themselves due to the lack of funding and support.

“So, the MoH provides Carer Support at a rate of \$75.00 a day and for me to go to work, I need eight hours, that doesn’t cost \$75.00. It costs eight times about \$20.00. So, Carer Support funding is unrealistic and woefully inadequate. If I wanted a respite facility, there isn’t one when she’s a child

(there is now). So, I could not send her anywhere, there was no care for someone like her when she was a child, unless she came under Oranga Tamariki or there was a care and protection concern, and even then, it would be hard to find a facility. [...] There's no respite, I mean they can give me \$75 a day to pay somebody but nobody works for \$75 a day in this day and age.”<sup>6</sup>  
(Interview #34, Family Member)

Another component of DSS is respite, which exists to provide people with multiple and complex disabilities and their primary carers (often family members) periods of time away from each other (Ministry of Health, 2018a). The need for respite is stated under Article 28 of UNCRPD and is a requirement for disabled people to have an adequate standard of living (United Nations, 2006). Whilst a small number of Interviewees shared positive experiences of respite, the majority of Interviewees who had interacted with respite services within the past five years were not so complimentary:

“No, it [funding] wasn't adequate but I needed respite. So, um, I had to access it but the level of care wasn't high enough, [disabled family member's name removed] sustained quite severe injuries while in respite care and also in residential care, like what he's in now, because the support provided wasn't high enough and he got quite severe injuries due to a lack of supervision.”  
(Interview #44, Family Member)

### 8.2.8 Needs Assessment and Service Coordination services (NASCs)

Funding for disability-specific services was also linked to Needs Assessment and Service Coordination services (NASCs). According to the MoH website, if someone needs support because of a disability, they or their family/whānau must be assessed by a NASC service, who then allocate MoH-funded disability support services and help with accessing other supports (Ministry of Health, 2021c).

However, many MoH-funded Interviewees reported adverse NASC experiences, noting that NASC staff often had a lack of training in disability rights, health and wellbeing; were inconsistent; took a deficit-based approach to disability; did not engage with disabled people in a meaningful way; and were the gatekeepers to much-needed funding. As such, Interviewees reported feeling misunderstood by NASC staff, with little to no control, and as if they had to fit into a box, leading to anxiety around the process of the needs assessment itself:

“Yeah a needs assessment which are very... actually quite traumatising for me.” (Interview #75)

<sup>6</sup> \$9.38 per hour before tax. For comparison, the minimum wage in New Zealand was \$20 per hour at the time of writing this report.

### 8.2.9 Article 25.b Summary

Article 25.b articulates the need for disability-specific care and treatment as well as disability support services in order for disabled people to achieve the highest attainable standard of health. However, during the monitoring interviews Interviewees recalled many challenges regarding the lack of funding and resources required for preventative health and wellbeing care; limited choice and control over services, treatment and medication; poor service coordination; restricted and delayed access to diagnosis; extended healthcare wait times; an over-reliance on ‘natural supports’; inadequate Disability Support Services (DSS) and Needs Assessments and Service Coordination Services (NASCs); and a lack of safe and affordable respite options. These complex layers of disability-specific provisions prevented Interviewees from maintaining the highest attainable standard of health.

### 8.2.10 Duty Bearers Who Should Be Concerned

- Accident Compensation Corporation (ACC)
- Disability Support Services (DSS)
- District Health Boards (DHBs) and their successor organisations
- Health NZ
- Māori Health Authority
- Mental Health and Wellbeing Commission
- Health educators
- Health practitioners
- Mental health services
- Ministry of Health (MoH)
- Relevant Ministers

## 8.3 Article 25.c

In particular, the New Zealand Government shall:

c) Provide these health services as close as possible to people's own communities, including in rural areas

Outlined below are findings that directly relate to the progressive realisation (or lack thereof) of Article 25.c of the UNCRPD.

### 8.3.1 Post-Code Health Care

Currently, health care and DSS are provided by the MoH through regional DHBs. As highlighted in national reviews and reports,<sup>7</sup> inconsistencies amongst different DHBs regarding the types of services that are provided, funding, and procedures for accessing those services, are common; points that were also reported by the Interviewees of this monitoring research. This is known as 'postcode health care' - that is, the availability, provision, and/or quality of health care being dependent on a geographical location. In particular, Interviewees noted:

- Differences in services, supports, and funding that are available to disabled people depending on which DHB they come under:

“There's nobody here in [regional location name removed] that I can talk to because there are no counsellors trained in the trauma that I've been through. So, I'm just kind of thinking I'm tired of falling through the [system's] cracks.”  
(Interview #5)

- Interviewees living rurally often experienced financial, physical, and mental barriers when trying to access essential and allied healthcare services:

“There was one doctor who I was really uncomfortable with, and I wanted to see someone else, but I couldn't find someone else in the area, so I felt really stuck there then.” (Interview #53)

- A lack of specialist care was also mentioned frequently by Interviewees who require specialist disability support outside of their region:

“So, in nine years I haven't been seen by a specialist who knows about my disability. I think this is quite bad, nobody can answer the questions I have about my disability.” (Interview #21)

“The problem is again with Foetal Alcohol, there's not enough awareness. There's no education. No one's trained in Foetal Alcohol. They're not experienced in Foetal Alcohol.” (Interview #57, Family Member)

- Additional challenges included long wait lists; being required to commute to larger cities; and Interviewees feeling like they had to pay for private health care because public health care was not easily accessed:

<sup>7</sup> For example see *Health and Disability Review (2020)* and *Health and Disability Commissioner (2019)*.

“[In other regions] you’ve got people in your hospital left, right and centre. We don’t have that here. Our specialist, who retired, and our board says they won’t replace the specialist. They’ll only bring the specialist from [location removed] as consultants. So, when we need specialists, you either have to wait on the specialist to fly down, or you have to travel to [location removed].” (Interview #73)

- Deaf Interviewees also expressed concern about the availability of professional NZSL interpreters in regional settings:

“[...] We’ve only got the one [NZSL interpreter] in [regional location removed]. Just one interpreter so that’s not enough to provide support to all of the Deaf people who need communication.” (Interview #33)

### CASE STUDY:

The limited general and specialist services offered in rural areas had left many Interviewees feeling disadvantaged when accessing their right to the highest attainable standard of health. Often, this feeling of disadvantage was related to access. For example, one Interviewee shared that when they were required to seek specialist services in a nearby city, there was no accessible transport option. In this case, the specialist service was the only one in the region, leaving the Interviewee with no other options:

“[...] I’m in a wheelchair. [...]. There’s no public transport between [rural town name removed] and [city name removed] [...]. There’s supposed to be the national travel scheme but the way [location name removed] runs it is you’ve got to pay all the costs and then ask to be reimbursed and they may or may not accept that. In my case I was supposed to go up for an MRI [magnetic resonance imaging] at one stage. I went to [hospital name removed] and said, “I have got no way of getting there.” [...]. They said, “Well, take the health shuttle.” So, I called [health shuttle name removed] [...]. They go, “We can’t take you because you’re in a wheelchair.” [...]. So, I went back to [hospital name removed] and said, “I can’t get there.” They said, “Well you could hire a car and go and do it.” I said, “Would I get reimbursed?” “No.” So I can’t do that. I can’t get there unless I can find the resources. [...]. You’ve got to have functional body parts. You’ve got to be able to get yourself in and out. You’ve got to be capable of full communication. Communication’s not a problem but I can’t load my own wheelchair and I can’t get into the health shuttle because it’s a van.” (Interview #5)

### 8.3.2 Article 25.c Summary

While Article 25.c guarantees health services as close as possible to a disabled person’s own community, Interviewees who were living rurally shared that postcode health care meant they had limited access to transport, specialist services, and often experienced inconsistencies

in the support, funding and procedures provided by the different DHBs. The quality and standard of health care was therefore reliant on where they lived.

### **8.3.3 Duty Bearers Who Should be Concerned**

- District Health Boards (DHBs) and their successor organisations
- Health NZ
- Māori Health Authority
- Mental Health and Wellbeing Commission
- Ministry of Health (MoH)
- Ministry of Social Development (MSD)
- Ministry of Transport
- Relevant Ministers

## 8.4 Article 25.d

In particular, the New Zealand Government shall:

d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care

Outlined below are findings that directly relate to progressive realisation [or lack thereof] of Article 25.d of the UNCRPD.

### 8.4.1 Attitudes

When considering Article 25.d of the UNCRPD, key issues concerned the attitudes of health practitioners, including doctors, nurses, occupational therapists, administrators, pharmacists and support workers. For example, Interviewees routinely experienced:

- Assumptions that disabled people lack competency:

“[...] And attitude – assuming that because my ears don’t work, that my brain doesn’t either. [...] It’s hard to say what other people are thinking, but it shows ignorance, prejudice and discrimination as well as lack of respect for me as a person.” (Interview #43)

- Medical professionals failing to listen to, or take seriously, medical issues:

“The doctor was like, “Oh what’s wrong?” And I tried to say I have a sore ear and he checked and was like, “Oh it’s fine.” But I was trying to still say it was sore and he just wasn’t believing me.” (Interview #46)

- The assumption that disability is a negative life experience:

“[...] It was obvious he thought having a disability or being in a wheelchair was something people didn’t want... or weren’t happy with.” (Interview #72)

- Failure to thoroughly investigate medical issues, leading to misdiagnosis and diagnostic overshadowing:

“[...] They just expect that you are not as healthy as non-disabled people and that’s just normal and I feel like they understand it as additional barriers.” (Interview #101)

“I saw lots of different people. And I was having just lots of different episodes and I was just being told it was in my head and it was anxiety and mental health was just as important as physical health and just felt really minimised. Like I knew my body and I’ve had mental issues my whole life. Like I’ve had anxiety and mild depression and I know what that is. Like you know when you’re not ok. And it was just always ignored and minimised.” (Interview #17)

Further to this, Interviewees who identified as having intersecting identities reported compounding negative attitudes from the health professionals, including

- Racial discrimination:

“[...] He was white, and he just didn’t like me, thought I was in a gang, that sort of stuff. I was going in for pills for epilepsy and he thought I was out of it because I was on drugs, he just made that assumption. That was racist, so I was like no, we’re not going in there.” (Interview #59)

- Denial of identity on the basis of disability:

“Anyway, I did have one doctor tell me that I wasn’t really trans, I just didn’t like my body because I was disabled.” (Interview #101)

## 8.4.2 Training

In many cases, Interviewees attributed negative attitudes to health practitioners’ training and awareness. Under Article 25.d, it is the Government’s responsibility to ensure health professionals have necessary training and awareness of “the human rights, dignity, autonomy and needs of persons with disabilities” (United Nations, 2006).

In Aotearoa, the Medical Council of New Zealand is responsible for setting the curriculums for medical schools (Medical Council of New Zealand, n.d.b).<sup>8</sup> While some individual educators have incorporated disability content into their teachings, inclusion of disability from human rights and critical disability studies perspectives is rarely included as part of the official curriculum (Peiris-John et al., 2021).

The Medical Council is also responsible for setting the standards for medical registration (Medical Council of New Zealand n.d.b). One standard in particular relates to Article 25.d of the UNCRPD, stating that: “Cultural safety requires doctors to reflect on how their own views and biases impact on their clinical interactions and the care they provide to patients” (Medical Council of New Zealand, 2019, p.1).<sup>9</sup> Even so, Interviewee’ experiences highlighted that health professionals lack training and awareness, particularly in the following areas:

- Disability, disability rights, disability culture, disability justice, models of disability and ableism:

“Not so much about the service but more about how they relate to people and their lack of experience of working with different people with disabilities. In my case, blindness. You know I’ve been in situations where they sort of put something in front of you and you don’t know it’s there and that sort of thing. So, it’s about that awareness thing.” (Interview #20)

- Neurodiversity, particularly within the mental health sector:

“Not for those of us who have an invisible disability such as Autism, ADHD or something like Fetal Alcohol Spectrum Disorder etc. It’s really hard to get our needs met when mental health services haven’t had the training in our needs.” (Interview #41)

<sup>8</sup> There are two medical schools in Aotearoa, the University of Auckland and the University of Otago.

<sup>9</sup> The concept of culture in this statement comes from Papps and Ramsden (1996). It is not confined to ethnicity specific cultures. It refers to culture shared among particular groups with common identity such as disability, class, socialisation, sexual orientation and age.



- Respect for disabled people’s capacity and self-determination:
  - “M: So, your Mum gave you the information and the doctor gave you the options and you felt like you were able to give a decision or did the doctor talk to your Mum and they just ignored you?”
  - “I: Oh, he definitely just talked directly to Mum.” (Interview #55)
- Alternative communication styles and accessible forms of communication:
  - “I blame the system for not training them [medical practitioners] to communicate with people in a way to make sure they understand.” (Interview #35)
- Biases that lead to diagnostic overshadowing:
  - “Before my hospitalisation I had some symptoms, and I feel like doctors just put it down to Irritable Bowel Syndrome or my disability. Because the doctors were not concerned, I just learned to live with the pain. I often wonder if I would have been more persistent or taken more seriously if I didn’t have a disability.” (Interview #21)
- Holistic approaches to health and wellbeing:
  - “They look at one aspect. I call myself a zebra, because doctors are trained to think about horses, the most common things, and I am never that simple.” (Interview #21)
- Training on disability specific conditions and symptoms (particularly chronic health conditions):
  - “But the person that I saw last time, she acknowledges that they don’t even believe that mast cell activation disorder is a real thing. There are doctors who don’t think that EDS [Ehlers-Danlos syndromes] is a real thing when it’s like, there’s a gene that’s been identified.” (Interview #17)

A further aspect of training was Interviewees’ feeling like it was their responsibility to train the health professionals. While this was not necessarily a negative experience, some Interviewees expressed feeling burdened by the responsibility to educate each new health professional they interacted with:

“Am I allowed to say no to the trainee doctor? I like to say I am not actually very comfortable, I know they are learning but, and I understand that we want them to do some training, but I do not always feel comfortable accepting it. Is it fine for me to say no?” (Interview #67)

### 8.4.3 Awareness of Rights and Responsibilities

According to Article 25.d, the New Zealand Government is also responsible for raising awareness of “the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care” (United Nations, 2006).

During monitoring interviews, Interviewees were asked to reflect on how they feel that the New Zealand Government is doing when it comes to raising awareness of disabled people's right to the highest attainable standard of health. While some Interviewees acknowledged that improvements had been made, most Interviewees used the opportunity to reflect on the attitudes of health practitioners. As summarised by an Interviewee with a psychosocial disability, "It's [the CRPD] just a little acronym in our paperwork and it's not actioned." (Interview #3)

Another Interviewee shared the potential that the Convention possesses, if taken seriously and properly actioned:

"The Convention is, like, hope of what it could be and that was really exciting. But it also made me really sad because it's not the reality for many people in New Zealand and I wish, it also makes me angry because that's how it could be, um so it's the problems we have in New Zealand it's not how we know it could be it's just were not doing all the things that we should be." (Interview #51)

Further to Article 25, Article 8 (Awareness Raising) of the UNCRPD also highlights the New Zealand Government's responsibility to promote the Convention to the public and disability community itself (United Nations, 2006). When asked whether they knew about the UNCRPD, 64 Interviewees answered yes, 25 said no, two Interviewees were unsure, and nine Interviewees were not asked or did not respond. Most notably, of the 25 Interviewees who said they did not know about the Convention, 15 identified as Deaf.

These findings highlight the need for greater awareness-raising efforts to be made amongst both health professionals, as well as the disability community - especially amongst specific cohorts such as Deaf people.

#### 8.4.4 Self-Advocacy

When discussing training and awareness of disability rights within the health sector, some Interviewees said they felt like they could not access adequate care and treatment unless they advocated for themselves.

Self-advocacy, however, was often linked to fear and fatigue. Interviewees shared experiences where self-advocacy efforts were perceived as defiance, non-compliance, or as challenging the system. It was reported that at best, this led to lower-quality treatment that failed to improve their health and wellbeing. At worst, it led to a deterioration of their condition. The constant need to self-advocate often took a toll on Interviewee's wellbeing:

"It's hard when you're not feeling well, and they're not listening to you, and you're in hospital, and you're feeling really sick and in pain, and they're talking down to you. It's really hard to stand up for yourself because you just don't have the energy and um, yeah, it's hard but you just have to keep reiterating to these booking clerks that weren't listening to me. Like no, I'm meant to have a follow up appointment. Keep saying it until they listen to what you're saying to them." (Interview #94)

Self-advocacy was also related to a perceived power imbalance between health practitioners and disabled people, as highlighted in the quote below:

“I have to teach up from the position of requiring the services to be delivered, it really is stressful, it stresses me out, you know?” (Interview #69)

Another Interviewee highlighted the power of advocacy provided by a support person during health appointments. While this type of support was valued by Interviewees, it also diminishes the right to self-advocacy, and reflects the preference of health practitioners to engage with non-disabled support people, rather than the disabled person themselves:

“M: So, when your Mum went with you, they took, they took your pain more seriously? And do you think that would’ve happened if you had gone to that emergency room without your mum?”

“I: No, I don’t think it would’ve happened without Mum being there.” (Interview #41)

Another point relating to advocacy was raised by the family, whānau and supporters of people with multiple and complex disabilities, whose health and wellbeing relied on the advocacy of others. Interviewees expressed concerns for their loved one’s health and wellbeing if they were no longer around to advocate for them:

“And I worry because I realise I’m [in my seventies] and I’m not gonna live forever. And I will continue to do what I can for [name removed] but I need to know that she’s somewhere safe and secure that if anything happens to me then she will be well catered for.” (Interview #39, Family Member)

### 8.4.5 Confidentiality and Informed Consent

In order to provide any form of treatment, health practitioners must obtain permission from the service user, which is also known as ‘informed consent’. According to New Zealand’s Code of Health and Disability Services Consumers’ Rights, health professionals must provide patients with information - the risks and benefits of different treatments, for instance - in order to assist them in making an informed decision (Medical Council of New Zealand, 2019). For disabled people, literature indicates that informed consent procedures are often inadequate, especially when providing an individual with all relevant information in a way they understand (Carey & Ryan, 2019; Goldsmith & Skirton, 2015). The findings of this monitoring research confirmed this, with one Interviewee stating:

“I think informed consent is a bit of a joke actually for the disabled community. I think it’s just like neurotypical people thinking we’ve done our job.” (Interview #2, Family Member)

Other Interviewees experienced situations where health practitioners held attitudes or assumptions about the capacity of disabled people to make a valid medical decision. As discussed earlier, for example, the health practitioner in the situation below ignored the Interviewee’s decision, and attempted to continue with the procedure anyway:

[...] this particular day I went in for something else and she [doctor] said, “You haven’t had your PAP smear,” and I assumed it would come up on her computer as a bad thing because of my age and because she saw me as a ‘woman’. So, this day I said, “You can’t do it.” And then she said, “Oh well, let’s see if we can try.” So, you know, I was angry and really embarrassed...” (Interview #95)

### 8.4.6 Dignity

As articulated in Article 25.d, disabled people have a right to inherent dignity. In Aotearoa, the same right to dignity has been recognised in the New Zealand Disability Strategy 2016–2026, as well as the Code of Health and Disability Services Consumers’ Rights, which includes the right to be treated with respect, the right to be treated fairly, and the right to dignity and independence. However, many Interviewees felt their dignity had not been respected by the health and disability system:

“You end up just thinking, “I just don’t want to go there so I’ll just keep quiet because it’s just less painful.” You don’t want to be a burden. That’s the other thing. People say, “Oh no you’re not a burden.” Well actually you are. The truth of it is that when they make it so damn hard they are saying to me, “You’re a burden. Don’t want to know. You’re not equal to everybody else. You don’t have the same rights. You don’t matter the same.” (Interview #5)

- Some Interviewees felt that their experience of disability was the reason why they were not treated with respect:

“Disabled persons are like anybody else, they deserve the dignity to live and to participate in civil society without having to tell their entire medical background. Sometimes it feels to me like the nature of disability is hierarchical.” (Interview #69)

- Other Interviewees reported that the health and disability system did not respect their right to make informed choices about the care and support they receive:

“I felt disrespected. I am a mature, intelligent woman capable of making my own decisions and being involved in discussing my medical condition. I strive to maintain my independence.” (Interview #43)

- Many interviewees reported feeling like they were not being listened to:

“I’ve become paraplegic over a period of sort of three months, it just got worse and worse, and I guess the doctors’ not talking, you know, not listening to what I was doing. [...]. It was a little bit frustrating for me, that they didn’t listen to me right from the start. [...]. I was being treated like this second-rate citizen, and no one was listening to me. I’m going, “There’s something wrong in my body, it’s not right.” But no one was listening. So yeah, I struggled big time.” (Interview #18)

“The thing I think is the biggest is not being seen or heard and so you’re not included. You’re not acknowledged like you’re the expert of your condition. It’s that other people have to speak for you. Other people who have to come in and say what’s best for you.” (Interview #3)

- Interviewees from the Deaf community also shared specific examples from their interactions with the health and disability system, where they felt their dignity was not upheld due to the system being ill-equipped to accommodate their needs, such as accessible communication, choice and control:

“The doctor wanted my son to interpret for me. I said, “No, you should be writing to me.” And the doctor just ignored me and [kept] talking to my son. I felt really stuck in that situation. So, I stopped seeing that doctor now. It’s not like it’s the first time this happened. There have been a few times when I felt frustrated.” (Interview #23)

### 8.4.7 Article 25.d Summary

Under Article 25.d the New Zealand Government is required to uphold disabled people’s right to informed consent, dignity and respect, while increasing awareness of human and disability rights within the health and disability sector and beyond. Most Interviewees shared experiences that contradict the obligations contained within this article. Of the Interviewees who encountered negative attitudes of health practitioners, many attributed these to the lack of disability rights training and awareness. This highlights the need for the inclusion of human/disability rights-based practice through training at tertiary level, as well as in on-going professional development.

### 8.4.8 Duty Bearers Who Should be Concerned

- Accident Compensation Corporation (ACC)
- Allied health practitioners
- District Health Boards (DHB) and their successor organisations
- Health NZ
- Māori Health Authority
- Mental Health and Wellbeing Commission
- Disability Support Services (DSS)
- Medical Council of New Zealand
- Ministry of Education (MoE)
- Ministry of Health (MoH)
- Primary, Secondary and Tertiary Health Organisations
- Professional development providers
- Relevant Ministers
- Tertiary Institutions that offer professional medical or health-related training or education including universities and polytechnics

## 8.5 Article 25.e

In particular, the New Zealand Government shall:

e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner.

Outlined below are findings that directly relate to the progressive realisation of Article 25.e (or lack thereof) of the UNCRPD.

### 8.5.1 Private Health and Life Insurance

Most disabled people who were interviewed during this cycle of monitoring accessed health and disability support through the MoH or ACC. Very few Interviewees had private health and life insurance. The three key reasons being the high cost, together with discriminatory policies that mean people with pre-existing conditions are required to pay higher and more unaffordable levies, or that they simply were declined based on their experience of health and disability:

“I: I got health insurance once. I’ve only applied for it once and I was declined because of my mental health. That was back in 2004 I think, a long time ago. But I have twice been able to claim on a loan that I’ve had that I’ve had insurance on. Because they didn’t realise, probably, that it was a pre-existing condition. They make you take insurance, whether you say that you’d be entitled to a payment anyway it feels. So in fact you can’t get a loan [audio unclear] insurance.

“M: So, you’ve been declined insurance once, but have you been able to get insurance in those other cases?”

“I: Yes. I’ve been declined life insurance.” (Interview #1)

“Because of my disability I can’t get good health insurance.” (Interview #21)

While the relevance of Article 25.e to private health insurance providers as a non-State entity requires further discussion, it is important to acknowledge the experiences of Interviewees when attempting to access private health insurance. This is particularly relevant when private insurance is required by other third parties - for example, when acquiring a loan, buying a house, and so on.

For Interviewees who were able to afford and access private insurance, however, they found it to be beneficial to their health and wellbeing.

“I feel incredibly privileged because I have medical insurance.” (Interview #17)

For example, access to private hospitals and treatment ensured a much quicker, more comfortable, dignified, and more accessible experience:

“But the private hospital was very calm, making sure everything was all right, checking in. They made the time for you. It was really lovely! If you were in the public system, they’ve got fifteen minutes for you. It’s a very different situation. You know, like I mean, sure I have to pay, you know, and it costs a bit of money to have health insurance and they cover a certain amount. It’s a subsidy on the treatment that you have. [...] I had something else going on with my leg, with my veins. Yeah. So luckily that was also covered. So they treated me really well for that. So that was great. I got some injections for that maybe four years ago. Yeah. I think if I hadn’t had health insurance I would have been waiting on the public health list for quite a long time. It was pretty pretty quick.” (Interview #8)

### 8.5.2 ACC

ACC provides compulsory insurance cover for personal injury for everyone in Aotearoa, whether as a citizen, resident or visitor. As a no-fault scheme, it applies regardless of who caused the accident, but it also means an individual cannot sue for any costs that relate to the injury or its negative effects (Accident Compensation Corporation, 2020).

In Section 8.1.1, the disparity in funding and support afforded to people with injury-related disabilities and congenital- or medical-related disabilities was discussed, with most Interviewees agreeing that ACC-funded individuals receive more support than MoH-funded individuals. However, as highlighted by one ACC-funded Interviewee,

“People with the MoH, they have their problems. People with ACC, we have our problems. [...] [They think that ACC-funded people are] much better off... no, that’s not the case. If they [ACC] don’t have to spend one extra dollar, they will not spend that extra dollar.” (Interview #16)

Issues reported by ACC-funded Interviewees included:

- Denial of support and funding:

“Putting me through this process of assessment to try and minimise their support. That’s what it feels like. It’s not, “Let’s see what we can do.” I tell them what I need but that doesn’t come under their supports you know. It’s very hard.” (Interview #63)

- A deficit understanding of disability:

“[...] At the moment they, ACC, are kind of like you’ve been on it too long. Even though they awarded permanent impairment. The language they use is like ‘impairment’ and stuff. The whole point is that they deem wellness is like your employability so your ability to make money. So, they are constantly trying to talk about how you should go back to work. And the way they measure that is at the time of your injury, they look at what job you were doing and whether you can do it again. I was sixteen at the time and I worked at [department



store name removed] part time after school. And so, they use that still, even though I'm [in my thirties], as like a methodology like a baseline to see whether I could be a retail person. And I am constantly like, well, I have this whole other life and despite all these physical challenges I've achieved heaps and there's all these other things I'm interested in. And they're like, "Maybe you could work at a call centre cause you sit down for that." So, it's kind of like I'm at the point now where I really just wanna get off it even though it gives me this stability. In a way it feels really controlling and kind of also threatening at the time. So, it's kind of not stable. [...] Cause that's what I always say to them [ACC]. We have a shared goal. You don't want me here, I don't want to be here. You know? So, like if we work together with our visions we could probably achieve that better than me having to follow this very regimented thing." (Interview #99)

- Skewed calculations and assessments:

"Yeah, but it is one of the things that really gets me with ACC at the moment is they only pay 80 per cent of my salary. And that 80 percent of my salary which was based in 2011 and there has been slight increases in the last nine years. There haven't been massive increases [in ACC]." (Interview #16)

- Slow and inconsistent support:

"Yes, I find them absolutely horrific to be honest. But it depends, my treatment, from my perspective, solely depends on my case manager. So, if I have a case manager who is empathetic and caring they use the system and the legislation to be able to help me. Whereas if it is someone who judges me, they make it extremely difficult to get anything." (Interview #96)

"I was under ACC to start with. And they just cut my supports overnight and I got a new case manager and she decided she would because she could. [...] They cut my funding and I ended up in hospital. [...] I spent six weeks in hospital, two months in hospital, four months in sub-acute rehab and it took two years to climb back to my baseline. But I had an ACC case manager while I was in the rehab that said to me, she's like, "I will get you off ACC you mark my word. And I'll do it any which way I have to." (Interview #63)

- ACC-funded Interviewees were also aware of their privileges, with some even articulating a sense of gratitude that their disability was a result of injury:

"Now that I've got into the disabled community I've learned a bit more about other people's situation I would say I'm definitely one of the lucky ones in the sense that I'm covered by ACC and I have an able-bodied husband who is working in a permanent position, so Government funds me through ACC and also he covers other expenses. So, I do not have a financial battle because of my disability." (Interview #96)



“And I’m just really pleased that, you know, I’m in a position and I’m really lucky and grateful because I mean there’s not many people that would, and I’m only saying this flippantly in a way is that it was lucky that I was sexually abused as a child, you know, because it’s actually, ACC’s picking up a lot of the slack. Like a lot of the good service and a lot of the health help that I’ve had over the years has been because of ACC and I can just think, imagine if I hadn’t been sexually abused, and there’s a lot of people out there that are in my situation and that that haven’t got that, you know, and I’ve just been... I’m lucky that I get a liveable wage from ACC [...].” (Interview #10)

### 8.5.3 Article 25.e Summary

Article 25.e clearly states that disabled people must not experience discrimination in the provision of health and life insurance, particularly when provided by national law. Several Interviewees reported being denied private health and life insurance based on their disabilities, while others made a link between their financial status and the cost of private insurance. Even more concerning were the issues reported with the national insurance scheme, ACC. This included denial of claims, or support; a medical model understanding of disability; inconsistent assessments and support; as well as Interviewees’ needing to feel grateful for being injured, simply because they receive ACC support, rather than MoH support.

### 8.5.4 Duty Bearers Who Should be Concerned

- Accident Compensation Corporation (ACC)
- Ministry of Health (MoH)
- Private health and life insurance providers
- Relevant ministers

## 8.6 Article 25.f

In particular, the New Zealand Government shall:

f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability

Outlined below are findings that directly relate to the progressive realisation of Article 25.e (or lack thereof) of the UNCRPD.

### 8.6.1 Denial of Treatment, Services and Medication

Article 25.f is closely linked with Article 25.a, as it encompasses the New Zealand Government's responsibility to prevent discriminatory outcomes where the obligations contained within the other sub-articles of Article 25 have not been met. While there was no evidence of the denial of food or fluid on the basis of disability in the monitoring interviews, there was evidence of the denial of health care and services on the basis of disability.

For example, as outlined in Section 8.2.3, Interviewees who have coexisting and complex conditions had been denied access to diagnosis, and as a result, treatment. Further to this, two Interviewees reported being denied treatment by their local hospital after being blacklisted for making complaints (as detailed in Section 8.1.5):

“Neurology threw me out. The Rheumatologist refused to see me right from the very start at the hospital. The pain clinic won't see me anymore.”  
(Interview #9)

Similarly, two other Interviewees reported being denied access to a mammogram. While one Interviewee managed to advocate for themselves, the other Interviewee had not been so successful.

“I can't get my mammogram appointment because I'm in a wheelchair.”  
(Interview #5)

For family members of people with multiple and complex disabilities there was a sense of fear that their disabled family member would be denied health care due to health care practitioners' prejudice against disability. This fear was echoed by the wider disabled community, especially when discussing issues such as the referendum on the End of Life Choice Act:

“But I'm also worried that they don't treat him and then I think it is because he's got Downs, or is it because you know, there is not anything they can do.”  
(Interview #83, Family Member)

Interviewees with psychosocial disabilities had also experienced the denial of care. This was particularly relevant for Interviewees who identified as neurodiverse:

“[...] With all my medical issues and all the operations and all the complications and all the different diagnoses and pain and issues I have, the two times that I’ve been denied service has been mental health services which are you know? So underfunded and not yeah. Yeah. But I think, like, in my own personal situation, like, people like me need to be believed.” (Interview #17)

And finally, one Interviewee recalled an experience where important dietary requirements had been denied by a mental health respite centre:

“I think it’s run by the DHB as well and they had a problem with me being gluten-free as well. Because, in fact, the lady that was in charge said to me, “Oh, we only have a limited budget for our food and there’s no way we’re spending \$10 on a loaf of bread just because you’re gluten-free.” And I was the only one in respite at the time and, anyway, she was really difficult about the fact I was gluten-free and what she did was she went out and she got a packet of couscous. Nothing else with it, just couscous, which I’d never actually even used before and like you can just put water in it or something and then, you know, say you eat it but it’d be like eating a bowl of noodles with nothing. You know, you use couscous to make a meal but there wasn’t anything else to make a meal with.” (Interview #10)

### 8.6.2 Denial of Choice and Control

Another factor relating to the denial of health care was the lack of choice and control disabled people had over the type and timing of medication and treatment they received. This was largely based on the economic disadvantage experienced by the disability community.

For example, when the Government’s national referendum on cannabis legalisation was rejected in 2020, many people within the disability community felt a deep sense of disappointment. Even though medical cannabis products have been available by prescription since April 2020 (Ministry of Health, 2021d), the cost of both the appointment and the product remains prohibitive for many people. Five Interviewees explicitly shared their preference for cannabidiol (CBD) over other, more harmful, medications. However, they also noted the financial cost of CBD oil, given that it is not currently subsidised by PHARMAC. While this might not be considered a direct denial of health care, it can be argued that because disabled people are more likely to experience financial hardship, it is an indirect denial of medicine on the basis of disability:

“[...] So, it’s just that my choice is to not take something that I know is dangerous to me but is funded, and my other choice is to try and purchase things I cannot afford [...].” (Interview #69)

A further example of denial of health care was reported by an Interviewee with a psychosocial disability. As outlined in the He Ara Oranga Report of the Government Inquiry into Mental Health and Addiction (2018), the Mental Health (Compulsory Assessment and

Treatment) Act 1992 (Mental Health Act), which legally allows for compulsory treatment, restraint and seclusion, does not constitute a human rights approach to health care. Furthermore, during Aotearoa's examination by the United Nations Committee on the Rights of Persons with Disabilities Committee in 2014 it was deemed that the Mental Health Act was inconsistent with the principles of the UNCRPD (Ministry of Health, 2017). The practices, however, continue to occur, with one Interviewee highlighting how they had been denied choice and control under the Act:

“I'm under a compulsory treatment order. So, I have a depo injection every four weeks and I've just had a meeting with my psychiatrist last week and he's keeping me under the treatment order. It could last as long as I live. [...]. There's no outs through the Act either for us.” (Interview #1)

### 8.6.3 Denial of Health Care and Services During the COVID-19 Pandemic

The COVID-19 pandemic and lockdowns resulted in major disruptions to health care and disability support services for disabled people in Aotearoa. As discussed in Section 8.1.3, the generic and inflexible public health response to the COVID-19 outbreak meant that many disabled people were denied health and disability support services. The four most common examples of where Article 25.f of the UNCRPD was not met are summarised below:

- A lack of accessible information during the COVID-19 pandemic and lockdowns:

“Information is the other thing I've come across... Autistic people need the information in Easy Read form. And sometimes it isn't available. So, for Covid there was no information about Covid for Autistic people for our community.” (Interview #13)

- Disruption to health care and support services:

“[...] All of my brain injury, all my brain rehabilitation was all put on hold during the first and second lockdowns because I couldn't have someone visit home, I couldn't have an OT [Occupational Therapist], or neurophysio, I couldn't go see any of them and also I couldn't go out to see any of the extra things I do like osteo or acupuncture for the pain. I couldn't go to the gym, I could go for a walk around the neighbourhood, but I couldn't go for a swim or do anything that needed other people. Yeah, so basically my 2020 rehab is just on hold [...].” (Interview #51)

- Interviewees experienced technological barriers when accessing health and support services. For example, when health services moved to online platforms:

“Needing to see a counsellor during Covid and there's Skype, telehealth. And then I have to beg for money from MSD because the internet isn't considered a necessity.” (Interview #3)

- Deaf Interviewees also reported communication challenges, such as mandatory mask use:

“The masks definitely get in the way of communication, you can’t lip read so you get a bit stuck with that and then the people get stuck you know so it gets a bit frustrating, it’s not easy.” (Interview #55)

### 8.6.4 Denial of Health Care in Prisons

Further to the issues identified above, one ACC-funded Interviewee who was recently imprisoned reported they were denied much-needed health care, leaving them in extreme pain for an extended period of time, with a deteriorating condition:

“M: So, with what you’re saying, about how your surgeries were put on hold when you were in prison, so were you saying that all through your prison experience, they didn’t do anything about your disability basically?”

“I: No. [...] Nothing at all. Not at all, because they didn’t want to pay for guards to come to the hospital and stay with me while I had the operation and so, and they don’t provide pain relief either, they just give you Panadol. Panadol is the only, Panadol and Ibuprofen and Losecs to counteract the Ibuprofen effects, you know. So, yeah, it was pretty uncool.”

“M: Yeah, and were you in quite a bit of pain?”

“I: Yeah! Yep. Actually, I was working on the grounds and they stopped me working on the grounds because you could actually see my leg was collapsing the more I walked on it, and the metal was coming out the side of my leg. So, they stopped me working and then I just became more isolated. Yeah.”  
(Interview #77)

### 8.6.5 Article 25.f Summary

Article 25.f holds that disabled people must not be denied health care, health services, food, and fluids on the basis of their disability. The purpose of this Article is to specifically address and prevent discriminatory policies and practices that are not covered by the other sections of Article 25. While the monitoring research did not find evidence of the denial of food and fluids, many Interviewees spoke of circumstances where they had been directly or indirectly denied health care due to their disability.

### 8.6.6 Duty Bearers Who Should be Concerned

- Disability Support Services (DSS)
- District Health Boards (DHBs) and their successor organisations
- Health NZ
- Māori Health Authority
- Mental Health and Wellbeing Commission
- Mental health service providers

- Ministry of Health (MoH)
- Ministry of Justice (MoJ)
- Primary, Secondary and Tertiary health care providers
- Relevant ministers

## 9 Discussion

The findings outlined in this monitoring report represent a vast array of human rights issues, challenges and barriers experienced by disabled New Zealanders and our right to the highest attainable standard of health.

It is important to note that the issues discussed in this report are not all unique to disabled people. As was acknowledged in the recent Health and Disability System Review and current reform processes, many of these issues also affect the wider population. However, as frequent and often life-long users of the health and disability system, together with the well-documented socio-economic disadvantages experienced by our community, health and wellbeing issues impacting the wider population are compounded for disabled people. As the findings demonstrate, this has resulted in poor health outcomes, which fall short of the highest attainable standard of health.

A further point to consider is that while the purpose of this monitoring research was to identify the barriers experienced by disabled people regarding their health, some Interviewees reported positive experiences where their rights were being met in effective and meaningful ways. For example, many Interviewees reported feeling both fortune and a sense of gratitude when they found a GP who would listen to them, investigate health issues, speak to them with respect, take their concerns seriously, and communicate effectively and accessibility. In a sense, GPs were perceived as being the gatekeepers of health. However, for the sake of succinctness, such findings have not been included in this report.

In addition to the findings presented by Interviewees, outlined below are a collection of overarching themes identified by the disabled person-led monitoring team, which even though are not directly addressed by Article 25 of the UNCRPD, remain relevant to the wider discussion on disabled people's health and wellbeing in Aotearoa. These include wellbeing, the health and disability system reforms, models of disability, and four key systems that have been identified as underpinning many of the barriers and issues reported by Interviewees.

### 9.1 Wellbeing

Wellbeing has been defined as a “state of complete physical, mental, and social well-being” (Hassall & Karacaoglu, 2021, p. 52). Many factors influence health and wellbeing. For instance, socioeconomic factors (such as education, employment, family support, income, community support, and so on), health behaviours (such as tobacco and alcohol use, diet and exercise), physical environment, and healthcare (Health and Disability System Review, 2020).

Over the past five years, Aotearoa has seen several inquiries, reviews and investigations into the wellbeing of New Zealanders. For example, the 2018 inquiry into Mental Health and Addiction revealed that disabled people have some of the highest unmet mental health needs (Government Inquiry into Mental and Addiction, 2018). The 2020 Household Labour Force Survey (HLFS) reported twice as many disabled people feel lonely as non-disabled people do (Statistics New Zealand, 2020), and the 2020 Health and Disability System Review



again highlighted a range of concerning health and wellbeing outcomes experienced by the disability community (discussed further in Section 9.2).

In line with these findings, the current monitoring research has brought to light serious and prevalent mental health and wellbeing challenges experienced by people throughout Aotearoa. This includes people living with psychosocial disabilities, as well as people living with coexisting disabilities (for example, sensory disability and psychosocial disability). When asked to think about their wellbeing, Interviewees reported a range of factors that impacted their mental health and general wellbeing. For example, some of the more frequently mentioned factors included:

- **Engagement with health and disability systems:** The stress and anxiety that was felt when engaging with the health and disability system. Several interviewees reported that the system has “destroyed our lives” (Interview #2, Family Member) and found dealing with the health system as “emotionally draining” (Interview #16). According to one Interviewee with a physical disability, “To fight the system was the hardest thing that I’ve ever done in my life. It was quite difficult in terms of mental health, emotional and everything. [...] You have a system that is just pretty much saying you are rubbish.” (Interview #12)
- **Financial hardship:** A lack of financial security had a negative impact on Interviewee health and wellbeing. “I should mention at this point that I’m having to taxi because I can’t get public transport because I’m in so much pain. It’s such a strain on my relationship because my husband works his arse off. [...] Because I’m married, [I’m] not eligible for one cent of support! At all!” (Interview #17)
- **Loneliness and isolation:** Reflecting existing research, the monitoring findings showed that many Interviewees experienced loneliness and isolation, “The isolation and loneliness of disabled people who are not able to get out in the community and the high cost of transport to enable them to do this [is an issue for mental health].” (Interview #43)
- **Inaccessibility:** Being a part of and contributing to the community are important factors of mental health and wellbeing. Despite clear legislation and guidelines, many environments, products, and services remain inaccessible for disabled people. As highlighted by one Interviewee with a physical disability, many disabled people “[...] haven’t gone to a movie for years [...] [because] it’s not easy, getting in and out of a theatre; that’s not a lot of fun. It’s not necessarily accessible.” (Interview #5)
- **COVID-19:** The experience of COVID in Aotearoa also had implications for the emotional and cognitive wellbeing of the disability community. The harmful impact of quarantine and physical isolation resulted in frustration, loneliness, and boredom, and appeared to disproportionately impact people with pre-existing medical conditions, mental illness, older populations, people with learning disabilities and people living in unsafe circumstances (Brooks et al., 2020; Chatterjee et al., 2020). In line with the literature, and as previously discussed in Sections 8.1.3 and 8.6.3, the wellbeing of Interviewees was significantly impacted by COVID-19. “I felt quite uncomfortable... I wasn’t able to go out and see my



friends and family. I felt quite depressed actually. I could feel my mood just really lowering.”  
(Interview #29)

Finally, when asked about how to maintain and improve mental health and wellbeing, almost all Interviewees expressed a desire to have a balanced life, social connections, a good diet, and physical activity. However, these factors were also perceived as aspirational, as Interviewees were often inhibited by the disadvantage they experienced due to factors related to their disability, which prevented them from being able to achieve the highest attainable standard of mental and physical health.

## 9.2 Health and Disability System Reforms (2021)

Another key factor influencing this cycle of monitoring research was the review of the national health and disability system, and subsequent reforms. On Wednesday 21st of April 2021, the New Zealand Minister of Health Hon. Andrew Little and Associate Minister of Health (Māori) Hon. Peeni Henare announced major reforms to the health and disability system. In his announcement, Minister Little acknowledged that “if you’re disabled, we don’t even know what is happening with you because we don’t gather enough information” (New Zealand Government, 2021a).

The Government’s announcements were made as the data analysis for this report began. The purpose of this monitoring research is for disabled people to identify examples of where the New Zealand Government is not meeting its obligations under the UNCRPD, with a specific focus on disabled people’s right to the highest attainable standard of health. However, April 2021’s announcement envisioned a health and disability system that has the potential to address some of the concerns raised by disabled people throughout the interviews. For example:

- Improving the health and wellbeing outcomes for tāngata whaikaha/ whānau hauā (reform focus #1)
- Financial, physical, mental, communication and sensory access of the health system (reform focus #2)
- Wait times (reform focus #2)
- Post-code health care for disabled people (reform focus #3)
- Digital access for disabled people (reform focus #4)
- Health professional training and awareness (reform focus #5)
- Collaboration and coordination of health care and disability support services (reform focus #5)
- Health and care of people with multiple and complex disabilities (reform focus #5)

However, according to the findings of this report, there are also challenges and concerns raised by the Interviewees that do not appear to have been directly addressed by the vision articulated in the health and disability system reforms. These are, however, important aspects of ensuring disabled people have the highest attainable standard of physical and mental health and the progressive realisation of the UNCRPD. These include:

- Inconsistent and inadequate funding systems
- Needs Assessment and Service Coordination services (NASCs)
- Access to diagnosis
- Medication subsidies
- Disabled people in prisons
- Inaccessible complaints procedures

In signing and ratifying the UNCRPD in 2008, the New Zealand Government committed to progressively realising all rights contained within the Convention. However, when it comes to health and wellbeing, many participants felt that 13 years on, the Government was not upholding their responsibilities: “They sign the Convention, but they are not applying the principles.” (Interview #12)

It has been acknowledged that as frequent and prolonged users of the health and disability system, disabled people were not intentionally consulted with or involved in the health and disability system review, nor the proposed reforms. Instead, it appears that the experiences and expertise of disabled people continues to be treated as a separate issue that will be addressed at a later date.

While in an email following the Government’s announcements, Disability Issues Minister Hon. Carmel Sepuloni reassured the disability community that a “stronger consumer voice in the design of locality services and planning will give disabled people opportunities to shape services that better suit their needs and help them stay well in the community,” and that “there will be opportunities to influence the details of how our future health system will work.” There remains a sense of scepticism and ‘wait and see’ amongst our community.

### 9.3 The Rights Model of Disability

The way in which disability and impairment is understood and responded to by the health and disability sector has a significant impact on the way we navigate our health and wellbeing. For example, the medical model of disability understands impairment as an individual pathological problem that can be managed or fixed through medical intervention (Goodley, 2017). The social model, on the other hand, presents disability as a form of socially created oppression (Lawson & Beckett, 2021). Importantly, it differentiates between impairment and the disabling barriers that exist in society by embracing the idea that impairment is a natural variation of human life (Oliver, 2013). As a result, addressing and responding to the health and wellbeing inequities experienced by disabled people is the responsibility of society, and not that of the individual.

However, the rights model is considered to be more comprehensive than the social model, in that it encompasses both sets of human rights, civil and political as well as economic, social and cultural rights (Degener, 2016). It sees equity and rights as inclusive of all people, and that human rights are universal, inherent and inalienable (Al Ju’beh, 2017). While some theorists have framed the rights model as an extension of the social model (for example, see Degener, 2016), more recent commentaries have reflected on the rights approach as its own

distinct model. As discussed by Lawson and Beckett (2021) the social model is a descriptive, heuristic device that operates to identify where policy reform is needed. The rights model, on the other hand, is a prescriptive model of disability policy, and more suited to disabled person-led monitoring of the UNCRPD.

Reflecting on this monitoring report, two key disability model themes have emerged. At a systems level, the health and disability system review and reforms appear to have made a positive move away from the medical model of disability and embraced the ethos of the social model by recognising existing barriers within the current health and disability system. However, at the time of writing this report there was little evidence of a rights-based approach being utilised to guide policy responses to disability rights violations (Lawson & Beckett, 2021).

At an individual level, however, findings from the monitoring interviews indicate that there is still a long way to go until health and wellbeing professionals fully understand the difference between the medical, social and rights models of disability, and actively move towards the unapologetic promotion of the rights model of disability within their respective professions.

## 9.4 Systems that are Failing Us

Finally, as part of the analysis process four systems at the centre of Interviewee' health and wellbeing experiences were examined on a deeper level. This process was initiated by the DPO Coalition following the former cycles of monitoring. Having considered the findings of the two monitoring reports on housing, the question remained - what systems have led or contributed to the reported rights issues and violations?

Systems are the foundation of the delivery of health and disability services in Aotearoa. Therefore, it is important to explore where Interviewees experienced challenges in order to activate discussions on how to progress and improve systems so that they consistently deliver on the obligations contained within the UNCRPD.

### 9.4.1 Honouring Te Tiriti o Waitangi

Te Tiriti o Waitangi (Te Tiriti) is the founding document of Aotearoa. It guarantees the partnership, protection and participation of Māori and the Crown in the way the country is governed (New Zealand History, 2017). Te Tiriti is a major instrument in asserting indigenous rights in Aotearoa, with negotiations between Māori and the Crown establishing important principles that are relevant to disability rights (Convention Coalition, 2010). Although the English and Māori documents have different meanings and promises, there are some undisputed similarities - one being the right for Māori as the indigenous people of Aotearoa to live as Māori (Human Rights Commission, 2010a). However, as highlighted by Hickey and Wilson (2017), differing perspectives held by Māori and Pākehā concerning Te Tiriti have often made it difficult for tāngata whaikaha/ whānau hauā (Māori disabled people) to have their rights realised.

It is important to begin by acknowledging that much work has already been done in this area, particularly by Māori health organisations (for example, Whānau Ora). At a systems level,

the New Zealand Public Health and Disability Act 2000 openly acknowledges the principles of Te Tiriti in health and disability support. The Health and Disability System Review (2020) recommended amending the New Zealand Public Health and Disability Act 2000 to reflect more recent interpretations of Te Tiriti in the health and disability system (Health and Disability System Review, 2020), and the proposed health and disability system reforms of 2021 envision a stronger emphasis on Te Tiriti principles through a designated Māori health authority (Ministry of Health, 2021e).

Even so, according to Ngā Mana Hauora Tūtohu (Health Status Indicators) Māori continue to have significantly lower health outcomes when compared to non-Māori populations (Ministry of Health, 2018b). For people who identify as Māori and disabled, these already concerning health indicators are negatively impacted by intersectionality.

Take, for example, the 2019 report commissioned by the Waitangi Tribunal for the Health Services and Outcomes Inquiry (Wai 2575) to investigate the experiences of tāngata whaikaha/ whānau hauā. Findings revealed that when it came to disability and health, Māori populations experience significant barriers and challenges in their everyday lives. These include inequalities within the health and disability system itself; a lack of participation and inclusion; gaps in services and support; differential treatment; discrimination and racism; limited options in the kinds and types of services they receive; a lack of culturally responsive and Kaupapa Māori services and support; inadequate and insufficient Crown funding; restrictive contracting; misunderstanding of kaupapa Māori services by Crown agencies; obtuse funding mechanisms; an under-developed and under-paid workforce; a lack of support for family carers; and a lack of understanding and implementation of Te Tiriti principles (Kaiwai & Allport, 2019). As highlighted by one Interviewee of this monitoring research, “So basically I think that if you’re disabled and if you’re Māori it’s sort of like not really good.” (Interview #3)

When reflecting on the reasons as to why tāngata whaikaha/ whānau hauā continue to experience such significant health disadvantages, the findings of this monitoring research point towards two systemic issues discussed below.

#### **9.4.1.1 Cultural Responsiveness within Population-Based Health Programmes**

The first systemic issue identified was the lack of cultural responsiveness within population-based health programmes. As highlighted above, Māori experiences of disability show there are wide disparities between how tāngata whaikaha/ whānau hauā experience disability when compared with non-Māori experiences of disability (Hickey & Wilson, 2017; Ratima & Ratima, 2007). This finding suggests that population-based health programmes are not meeting the specific needs of this population. Furthermore, the inequitable outcomes indicate a failure to uphold both Te Tiriti, the UNCRPD, and the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) in a meaningful way: “I’ve tried to see what they do for Māori and somehow they put us in a diversity category when we actually have Te Tiriti o Waitangi that cements our place here.” (Interview #45)

For example, within te ao Māori health and wellbeing is not confined to the individual. Rather, as demonstrated by Māori models of health such as Te Whare Tapa Wha (Ministry of Health, 2015a), wellbeing extends to taha whānau (family and social wellbeing), taha tinana (physical wellbeing), taha hinegaro (mental wellbeing), and taha wairua (spiritual wellbeing) (Durie, 1999). To ensure better health outcomes for tāngata whaikaha/ whānau hauā, te ao Māori approaches to health must be valued and upheld:

“Yeah, they [tāngata whaikaha/ whānau hauā] have been marginalised. So, they don’t have what they need, they’re not surrounded by their culture, they’re discriminated against, they’re put down. Whereas the system is focused for the Pākehā way, what the Pākehā need. That’s right, so they feel like they’re not important, they feel like they’re left by the wayside. You know, that Pākehā have all of the power, all of the control in those situations. So there needs to be a change in attitude and a change in the system that suits their values and beliefs.” (Interview #33)

#### 9.4.1.2 Differing Cultural Concepts of Disability

The second systemic issue concerns the different cultural concepts of disability. During a phase one focus group, tāngata whaikaha/ whānau hauā facilitators shared that in te ao Māori ‘disability’ is understood differently from the Western perspective, which impacts the way tāngata whaikaha/ whānau hauā engage with the health and disability system as well as disability rights monitoring.<sup>10</sup> These different views can create barriers for Māori, who are unsure whether their experiences will be accepted and acknowledged:

“I understand where my little sister is coming from, I understand where you are coming from too, that people do need to identify [as ‘disabled’], especially for things like this, it’s helpful to find people that acknowledge that, and they all acknowledge that they’ve got disability, but they don’t want to make an issue out of it. For them, we just want to get on with our lives. [...] I know that it was a little bit difficult, well they were happy to talk with me about it one-on-one, but the idea of them coming into a focus group, then again felt like they were getting labelled. So, I thought, oh well, I can always feed that back. I wasn’t sure how you were going to take it but yeah. So, I know that with a few of them that I spoke with, that was an issue for them, was that... I think it’s, there’s that thing of whakamā, that shame of being labelled as disabled but everybody understands, like in te reo Māori we’re told, you don’t have a disability, you’ve got super powers doing something else. [...] These conversations for me, because we are asking about their personal situation, their whānau, their life, if we want to talk to them, talk from a place of aroha, then it’s not something that I can do by Zoom. It is something that I have to go in and have one-on-one conversations. And the other thing that I have learnt, is it’s not an hour and a half. It’s never an hour and a half when you’re talking

<sup>10</sup> For further research and commentary on Māori concepts of disability, see Hickey (2015); Higgins et al. (2010).

to Māori. You've got to have the cup of tea and look at all the whānau photos, you've got to have a look at the new grandchild and possibly the things they've put in their garden bed and whatever else. So, that takes about four to five hours before you actually get to the interview. But it is having that ability to have that personal discussion with them before they start sharing any of their personal information." (Māori hui facilitator)

In summary, for the New Zealand Government to honour Te Tiriti, the UNCRPD, and the UNDRIP, the health and disability system must not only adopt more recent interpretations of Te Tiriti that facilitate its realisation, but it must also consider te ao Māori perspectives of disability and mātauranga Māori (Māori knowledge), while adapting procedures, processes and policies accordingly.

### 9.4.2 Inequitable Funding Systems

As highlighted in Section 8.1.1, different systems of funding affected Interviewee health and wellbeing in different ways. Whether it was inadequate funds, or the inconsistency between funding systems, the consensus was clear - funding pathways in Aotearoa are unequal, which impacts negatively on disabled people's health and wellbeing.

The funding systems under examination are ACC and the MoH - two Crown agencies that provide support and services to disabled people depending on whether the disability or condition was acquired through an injury, or another non-injury related cause (for example, a congenital condition, or through illness). ACC services are funded by compulsory levies paid by anyone who works or owns a business in Aotearoa, while MoH funding is derived from the Government's tax-funded national budget.

In 2021, the New Zealand Government announced that they were "[i]nvesting \$4.7 billion in Health, which includes more funding for PHARMAC, plus the transition to a new health system and establishment of a Māori Health Authority" (New Zealand Government, 2021b). Despite the Government's considerable commitment to health, the findings of this monitoring research and other recent studies have all indicated that disabled people continue to face disproportionate challenges when accessing adequate and accessible health and wellbeing care and services.

When comparing the responses of MoH-funded Interviewees and ACC-funded Interviewees, the stark inequalities between the two systems were quickly illuminated. Until recently, official statistics confirming these inequalities were difficult to find. However, in a recent briefing paper to the Minister of Disability Issues on how ACC treats priority populations, ACC confirmed:

There are also inequities between the level of support provided via ACC to people who become disabled as a result of injury, and the level of support provided through other parts of the system to other disabled people. Rehabilitation provided by ACC (which comprises treatment, social rehabilitation and vocational rehabilitation) is available to ACC claimants on



an entitlement basis, unlike Ministry of Health-funded services for disabled people, which are rationed. This can result in differences in the level and type of support – for example, the amount of treatment, or standard of assistive device – provided to ACC claimants compared to those whose disabilities arise from non-injury causes. Similarly, compensatory entitlements available to some ACC claimants are non-means-tested and often more generous than benefits and entitlements provided by the Ministry of Social Development (Accident Compensation Corporation, 2021a, p. 3).<sup>11</sup>

Statistics on how much more ACC-funded disabled people are compensated when compared to MoH-funded disabled people are hard to find. However, in 2017 a briefing paper prepared by the New Zealand Artificial Limb Service Board stated that amputees who are funded by ACC receive, on average, 214% more funding than amputees who are funded by the MoH (New Zealand Artificial Limb Service, 2017). Other research has shown that people who receive support from ACC are less likely to be negatively affected by their disability (as cited in Broughton, 2017).

When these experiences are considered alongside the Government’s obligation to recognise disabled people’s “right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability” (Article 25, United Nations, 2006), the existence of a system that discriminates based on the cause of disability is also unacceptable and a violation of Article 25.

While the health and disability system reforms have the potential to alleviate some of the issues articulated by Interviewees, it has also been noted by the disability community that they do not go far enough to address systemic issues related to funding: “We’ve still got the issue of a two-tiered disability system, we’ve got ACC and DHBs ... we’ve got a multiple system that discriminates in multiple ways and none of that is covered in the [Simpson] report” (Huhana Hickey, as cited in Palmer, 2020).

However, experts working in this area have cautioned against reforming ACC but suggest that systemic failures might instead be addressed through the development of a more equitable system that is not determined by the cause of disability, but that is instead needs-based (W. Forster, personal communication, July 7, 2021).

In summary, for Article 25 and other Articles of the UNCRPD to be effectively realised, sector reforms must extend beyond the current health and disability system reform, to consider the inequities between MoH and ACC funding and services.

### 9.4.3 Inaccessible Health Literacy

Analysis of the monitoring findings suggests that disabled people must acquire certain knowledge and skills in order to effectively navigate the health and disability system. Many Interviewees believed that the outcome of their interactions with the system were directly correlated with the information and knowledge they had of the system itself. The more knowledge they had, the better the treatments, services, and support they received.

<sup>11</sup> Further inequalities were reported for women, Māori and Pacifica (Accident Compensation Corporation, 2021b).

This concept refers to 'health literacy'. That is, the interaction between the skills and knowledge of individuals and the demands of the health system (Institute of Medicine, 2004). In Aotearoa, health literacy has been defined as "the capacity to obtain, process and understand information and health services in order to make informed and appropriate health and wellbeing decisions" (Ministry of Health, 2015b). This definition highlights the critical role of the health system, health care providers, and health practitioners in communicating information and ensuring consumers understand and carefully consider the information when making health-related decisions.

One of the underpinning themes of the Convention is that the enjoyment of human rights is based on self-determination and supported decision making. This requires targeted approaches that improve the health literacy of disabled people, health practitioners, service providers, and support people. Health literacy can result in more informed choices and lead to the empowerment of individuals who interact with the system.

The MoH has developed a framework for health literacy that outlines expectations for the health system, health organisations, and health workforce in order to facilitate a culture shift to incorporate health literacy into the system and reduce health literacy demands from consumers (Ministry of Health, 2015c). However, this monitoring research indicates that the framework has not been made accessible to disabled people. Interviewees required high levels of health literacy for interactions at every level of engagement with the system; from arranging appointments (understanding appointment letters, making contact, arranging transportation) to attending appointments, interacting with professionals, understanding instructions, tests, and medications, and future follow ups.

Regardless of the type of disability, Interviewees felt that the demand for health literacy was high. For instance, many Deaf and NZSL users felt disadvantaged when navigating the health and disability support system - the result of a lack of accessible health knowledge and education. For many disabled people, acquiring this knowledge is challenging as population-based health education often excludes the disability community, leaving them feeling like they "missed out on a lot of that [health education]" (Interview #27).

Furthermore, this monitoring research highlighted the shortcomings of the health and disability support system in maintaining and promoting health literacy for disabled people. This is a critical challenge for the system, as studies have shown a strong link between consumers' level of health literacy and their health status (Neter & Brainin, 2019).

In summary, greater rights-based mechanisms must be built into the health and disability system to reduce the health literacy demand on consumers, especially disabled people who experience additional financial, physical, communication, and mental access barriers.

#### **9.4.4 Problematic Complaints Procedures**

A fourth system that was frequently referenced by Interviewees concerned the procedures and processes that are required to make a formal complaint. There is growing recognition that complaints from health consumers have the potential to improve systemic issues within



the healthcare systems, as health consumers have the ability to recognise issues that health professionals may not recognise (Liu et al., 2019; Reader et al., 2014; Ward & Armitage, 2012). Health consumers have the ability to detect problems and risks within the delivery of health care in Aotearoa, and, if taken seriously, can help to prevent medical error in the future (Ward & Armitage, 2012). However, Interviewee' experiences captured in Section 8.1.5 of this report show that there is a long way to go before disabled people's complaints are used to drive systemic change.

In Aotearoa, there are various formal complaints procedures to ensure the quality of health and disability services. For example, the right to complain is part of the Code of Health and Disability Services Consumers' Rights. When there is a concern and/or problem, there are many courses of action that can be taken. Disabled people can make a complaint directly to the health practitioner and/or service provider. In this report, these direct actions were mainly referenced under the theme of 'self-advocacy' (Section 8.1.4). Similar to health literacy, Interviewees shared that they were required to actively self-advocate in order to access the health care services they needed. When the issues were not resolved through direct complaints or advocacy, independent advocacy services, such as the Health and Disability Commission or the Ombudsman's Office could become involved. However, all but one Interviewee who shared their complaint experiences stated that the outcome of third-party intervention was unsatisfactory. For example, wait times were long, and they were referred to different agencies without reaching a satisfactory resolution. Interviewees indicated that under the current structure, escalating a complaint had not always resulted in a favourable outcome, and therefore was not worth pursuing.

Moreover, the multilayered system of complaints procedures was reported to be inaccessible for many in the disability community. Interviewees felt that both self-advocacy and engagement with the complaints procedures to be taxing, and at times re-/traumatising. As a result, Interviewees preferred to change health practitioner or service rather than engage in a complaints process. However, not all Interviewees had the privilege of choice and control. For example, two Interviewees said they were blacklisted after making complaints, but had nowhere else they could access the medical services they needed.

In summary, formal complaints procedures should be reviewed to address the lack of accountability and accessibility experienced by disabled people. In order for disabled people to attain the highest attainable standard of health guaranteed by Article 25 of the UNCRPD, it is crucial for the Government to provide complaints procedures whereby disabled people's adverse experiences can be effectively resolved. Such procedures must be timely, while providing protection for the complainant so that they are not disadvantaged by the process. Additionally, while it is important for complaints procedures to respond to individual concerns, the procedures themselves must also drive systemic change so that other health consumers do not experience similar challenges in the future.

## 10 Recommendations

In the same way that disabled people are in the best position to inform and guide health and wellbeing support and services, they are also in the best position to recommend how best to ensure the UNCRPD is being progressively realised in Aotearoa. Outlined below are examples of recommendations that were raised repeatedly throughout the Monitoring interviews, as well as less-frequently mentioned recommendations that also provide clear and practical solutions for advancing disabled people's right to the highest attainable standard of health.

- Free Primary Health Care for disabled people (including dental care):
  - “I think it [primary health care] should be free.” (Interview #48)
  - “So, I would love there to be, even if it was every five years you could get a dental check-up or a health check-up. That’s gotta be better than what it is now. If people haven’t been to the dentist for forty years. People haven’t had a cervical smear or mammogram, or they’ve got this huge lump on their arm which is a melanoma and they don’t know.” (Interview #38, Family Member)
- Removal of the two-tiered funding system (ACC and MoH), and the implementation of an equitable funding and support system for all people regardless of the cause of disability:
  - “I think one of the big things would be combining the ACC model and the DHB model so that everyone is entitled to the same services regardless of how they acquired the disability.” (Interview #101)
- Prioritising tāngata whaikaha/ whānau hauā in all aspects of health care and programmes:
  - “[...] I think Māori have not had equitable access to what they need. Like and you know, we have to be very aware of the Treaty of Waitangi that was signed in 1840, and what that means in terms of their treatment [...].” (Interview #33)
  - “Yeah, I would love in five years’ time to have a co-constructed [...] some kind of close relationship just to make sure that the community out there have the rights, ya know, have the right to kind of speak up and the right to be heard really, to work together with one another. I would love to have a Māori person kind of leading this within the community, a Māori, Māori person at the top, where they can kind of oversee everything, yeah that Māori kind of protocol side of things I suppose, adherence to that [...] So, in five years’ time I think it’s really important that the community out there grows, that we grow mana, that we grow strength, that we work together.” (Interview #68)
- Formalised consultations with a diverse range of disabled people on all policy design and reforms:

“Nothing for us, without us’ and I believe that consultation with disabled people about what is needed is vital to being able to honour that Convention and being able to enable people with disabilities and impairments to lead those fulfilling and healthy lives.” (Interview #82)

- Employment of skilled and experienced disabled people in key decision-making roles throughout the health and disability system:

“There should be [a] percentage [employed] in all the government as well. And in Cabinet. There should be. They need to give us a chance. We are not invisible, we can’t be left invisible.” (Interview #53)

- Increased Deaf representation in health care professions (including mental health services):

“I think hospitals, maybe mental health departments, A&E - they should have Deaf people working there. Deaf social workers. I think that’s important.” (Interview #23)

- Recognition of the ‘right to the highest attainable standard of health’ in legislation<sup>12</sup>:

“I’ve got this as a challenge. I would like to see that [right to the highest attainable standard of health] embedded in our Health Act. I would like to see that embedded in our code of rights at hospitals.” (Interview #13)

- Introduction of the Accessibility Act into legislation:

“That’s why you need a Disability Act because then you’re going to have standards and they will give the guidelines.” (Interview #12)

- Update the Building Act to ensure health care services are accessible:

“[...] The Building Act and Building Code needs to be revised ASAP. I don’t know how any commercial building - whether it be a corner dairy or a GP’s office - cannot be accessible to everybody in this day and age. I think if a business is getting set up it should be accessible. I’ve really struggled to find a GP that has an accessible office. There are just so many out there that are in these converted houses or even new built commercial buildings that don’t have elevators or ramps or anything like that. It’s bizarre. Even hospitals in my experience don’t really cater very well to mobility-related disability.” (Interview #6)

- Introduction of legislation that protects disabled people from discrimination and abuse:

“I want to see lots of things, but I want to see the disabled community that when they’re in vulnerable positions, I want to see them protected and I want legislation that is specifically to safeguard them. I wanna see some safeguarding adults from abuse legislation and protection because I think it’s a right” (Interview #24, Support Person)

<sup>12</sup> In Aotearoa there is currently no law that expressly articulates the right to health. However, by ratifying the various international human rights conventions the New Zealand Government has accepted an undertaking to comply with global health standards (Human Rights Commission, 2010b).

- Increased awareness of the UNCRPD and disability rights amongst the disability community:

“I do think the Government would be funding more to teach us, anybody about what our rights are as disabled people and I think you hear the term ‘right’, [and] this is how you’re expected to be treated.” (Interview #79)

- Increased health literacy for disabled people:

“Everybody would be able to get the medical treatment and information they need, and the disability support they need. There would be more control given to patients, so they could make better informed decisions.” (Interview #21)

- Increased awareness of Deaf culture and NZSL by health practitioners (including mental health services):

“I think that nurses and doctors should learn some signs, you know like and if they’ve worked with Deaf before they could communicate with each other about how that went and how they used signs and gestures, you know that kind of thing.” (Interview #46)

“I hope that nurses and doctors and medical professionals out there will have a greater understanding of Deaf plus and ya know Deafness and also an understanding of the cultural perspectives as well, Māori culture, Pacifica culture, Indian culture, a variety of cultures out there. [...] imagine having that attitude [Deaf awareness] within the mental health service [...]. We could have a hui, ya know, Māori getting together and talking about mental health.” (Interview #68)

- Improved disability rights training and professional development for medical students and health practitioners:

“I would like to see University of Otago and University of Auckland [medical schools] have some disability training.” (Interview #13)

- Increased awareness of learning disability by health practitioners:

“The knowledge about learning disabilities, I would want to be educating doctors and health care professionals. Especially about learning disabilities. About how to work with people with learning disabilities with their patients.” (Interview #40)

- Improved accessible communication for disabled people engaging with the health and disability system:

“To me it would look like [an] email address would be provided alongside phone numbers. It would look like information being provided in readily accessible formats in terms of me not having to advocate or ask. For example, captioned video or video in NZSL. It would mean that I feel competent in being able to contact services like [the] GP or mental health, or Healthline... and then I could be seen by someone who has an awareness and good attitude or [who] is willing to adapt.” (Interview #98)

- Increased health and disability support in rural areas:
  - “[...] If we want New Zealand to thrive, we need to put money into the regions. We put more money into the cities. We need money in the cities when, if we don’t put money into the regions our regional hospitals will get dire and yeah.” (Interview #7)
- Greater equality for disabled people navigating fertility treatment, maternal health, and parenting:
  - “My ideal experience of going through the maternity system would be one without prejudice and one where myself and my child would be looked after, and my disability would be taken into account in terms of making sure that my child and myself had the best possible needs met.” (Interview #81)
- Recognition of FASD as a disability, with greater access to early diagnosis, funding, and services:
  - “What do I want? I want FASD to be recognised as a disability by the government and funded. There’s no clear funding pathway. All the professionals need to upskill and train in FASD because it’s two and a half times more prevalent than Autism. We need to have professionals that understand it.” (Interview #2, Family Member)
- Dedicated health professionals to oversee disabled people’s health needs in their entirety, rather than fragmented and siloed services:
  - “This is why I keep saying we need something like what they do in paediatrics. They have somebody who oversees everything; so you have all these specialists who bring it together.” (Interview #84)
- Abolish medically unnecessary surgical interventions on intersex bodies:
  - “Abolish surgical interventions on intersex bodies and I think like the pathology and medicalisation of disabled people in general. And look at a, like, flip the kind of story around like disability being like less than and actually like a lot more like empowerment and joy and creativity.” (Interview #99)
- A clearer distinction between the health system and DSS through the removal of disability services from the MoH, and replaced with its own dedicated ministry or agency:
  - “And we need our own Ministry of Disability. And our own Minister for disability, we need to come out of health because we’re not sick.” (Interview #83, Family Member)
- Greater support for older disabled people (65+):
  - “As oldies, disabled people, or people with disabilities or whatever you like, it’s got to be acknowledged that we’re getting older... and we are living longer. I mean I’m one of the oldest long-term wheelchair users that I know. Especially someone with Cerebral Palsy. And so it has to be acknowledged, everybody

talks about you know, people over sixty-five people over seventy-five blah blah blah. But there has to be a real acknowledgement that there is support of old people with disability. I mean... and I mean maybe not just financial, but the everyday sort of supports we talked about. And I think... I hope we don't sort of get lost." (Interview #71)

- Increased funding for more highly qualified carers and support people:

"The training of care-givers to an acceptable standard and paying caregivers better wages so that there is not such a high turnover." (Interview #43)

- Commitment to an urgent national roll out of Enabling Good Lives (EGL):

"It would be good if Enabling Good Lives would get rolled out to the rest of the country. It's been very frustrating that it's been a pilot in some areas for so long." (Interview #83, Family Member)

In addition to Interviewee recommendations, outlined below are systems-level recommendations, as proposed by the DBI disabled person-led monitoring team, evidenced by relevant Interviewee quotes:

- In order to uphold legal obligations under the UNCRPD, it is essential that the New Zealand Government adopts a rights-based framework when working through the details of the upcoming reforms, and all other policy/programme developments. In particular, the application of a disability rights-based framework will ensure that disabled people are involved and contributing to these processes as experts from the outset, rather than retrofitting policies and programs to align with International Human Rights Laws obligations. All future decisions must be made with the Convention in mind, with a particular focus on Article 25 (Health) and other relevant articles.

"I think that if there was a real shift towards um shift towards social models of because you know about medical model and social model of disabilities for barriers for example, if there was a real understanding of that in terms of the health sector understanding the bias that are just intrinsic to the health sector at the moment does create some barriers." (Interview #98)

- The monitoring research team also recommends ensuring a dedicated response to the areas of improvement recognised in this monitoring report. This monitoring research has collected and analysed the experiences of over 250 disabled people, and therefore provides an unparalleled body of evidence which can and should be used to inform the review, and ongoing health and disability system reforms.

"I mean I'm just absolutely dumbfounded that the health and disability review report doesn't even talk, like, doesn't even consult with disabled people. Barely mentioned. Like it's in the title, it's tokenism. It's just beggar's belief." (Interview #17)

- Finally, the monitoring team recommends measuring all health care programmes, policies and reforms against the Government’s commitments under the UNCRPD, together with robust, ongoing, disability-led data, evaluation and monitoring processes (as obligated in Articles 31, 33 and 35 of the Convention).

“I want to see some kind of accountability and some kind of monitoring. [...] There are now some great documents but there’s no expectation [...] that they’ll be followed.” (Interview #38, Family Member)



## 11 Conclusion

This monitoring report has provided a broad overview of disabled people's experiences of health and wellbeing in Aotearoa New Zealand. Under Article 25 of the UNCRPD, disabled people "have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability" (United Nations, 2006). Even so, while Aotearoa may have made progress towards promoting disabled people's rights (including the right to health) this research shows that we continue to fall short of ensuring disabled people can enjoy our right to the highest attainable standard of health.

Perhaps the greatest strength of disabled person-led monitoring is that it is, as the name suggests, led by disabled people who have first-hand experience of the injustices and disadvantages that have been reported by disabled people and their family, whānau and close supporters. In this way, disabled person-led monitoring brings life to Article 33.3 of the Convention, with every step of the research processes delivered by the disability community itself - from the researchers (Monitors), to the participants (Interviewees), transcribers, analysts, writers, editors, and translators. While this cycle of monitoring was limited by external factors (such as COVID-19), the absence of important cohorts of the disability community (such as disabled children), and with further work needed to amplify the experiences of specific populations (for example Māori and Pacifica disabled people), this report has successfully progressed important conversations about the health and wellbeing experiences of our community, and the realisation of Article 25 in Aotearoa.

Throughout the interviews, disabled people and their family, whānau and close supporters articulated challenges and barriers they experience when it comes to health and wellbeing. From financial, physical, communication, mental and sensory access to population-based health programmes and specialist care, to the negative attitudes of health and wellbeing practitioners - barriers were present at every level of engagement with the health and disability system. The findings, evidenced by direct quotes from Interviewees, were intentionally categorised into the six sub articles of Article 25 (Health) of the UNCRPD, in order to demonstrate key areas where the New Zealand Government has not fully realised its commitments under the Convention, some 13 years after its ratification.

A brief analysis of four key systems that underpin the adverse experiences of Interviewees was also included, which helped to identify where systemic change is needed. These included the failure of the health and disability system to uphold Te Tiriti o Waitangi for tāngata whaikaha/ whānau hauā; inequitable funding systems; a lack of accessible health literacy; and problematic complaints processes. It was also recognised that the current health and disability system reforms have the potential to address some of the barriers reported by Interviewees, as well as the four systemic issues identified above.

However, it is important to acknowledge that if Article 25 of the UNCRPD is to be implemented in its entirety, there remains much room for improvement. While the concept of



'progressive realisation' indicates that some aspects of the Convention can be implemented over time, it has taken more than 13 years to begin to address disabled people's right to the highest attainable standard of health. Much like the earlier housing monitoring reports, solutions to the identified challenges can be found in the wisdom of those who live through the challenges identified in this report. Throughout the Interviews a range of solutions and recommendations were provided as to how best to realise disabled people's right to the highest attainable standard of health. Despite only having only scratched the surface, this monitoring report demonstrates the potential for disability and family/whānau-led progressive realisation of the UNCRPD in Aotearoa and a future where all people can enjoy their rights, freedoms, and dignity in a full and meaningful way.

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## Annex A - Article 25 Health UNCRPD

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

- a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;
- b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;
- c) Provide these health services as close as possible to people's own communities, including in rural areas;
- d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;
- e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;
- f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

## Annex B - Interview Framework

### PREAMBLE

These questions have been informed by a wide and diverse range of documents, including:

- health and wellbeing surveys;
- human rights frameworks (specifically Article 25 of the UNCRPD, Article 25 of the UDHR, and Article 12 of the ICESCR);
- consultation with disability rights researchers;
- the 2016-2026 New Zealand Disability Strategy;
- and the initial consultation phase in which disabled people articulated what health and wellbeing violations, issues, and policies they would like monitored.

Not all questions will be relevant to all Interviewees, and some groups of disabled people will require targeted questions.

- To begin with, tell me a little bit about yourself...

Prompts...

- Job
- Hobbies
- Family / whānau

### Disability

Tell me about your experience of disability...

### Health and Wellbeing Experience #1

As you know, we want to learn more about disabled people's experience of health and wellbeing in Aotearoa New Zealand.

The United Nations tells us that disabled people have a right to the highest attainable standard of physical and mental health.

But sometimes disabled people receive inadequate health and wellbeing treatment, care, and services. Sometimes they miss out altogether.

One way we can learn more about why this is, is by asking disabled people to share with us their health and wellbeing experiences - the good and the bad.

Thinking about your health and wellbeing experiences over the past five years, what would you like to share with us today?

### Covid-19

Did Covid-19 have an impact on your experience? Why or why not?

## Attitudes

Thinking about the experience you have shared with me - why do you think [other party] did that / responded in that way / said that?

## Access

Thinking about the experience you have shared with me - what do you think were the main factors / barriers that contributed to that situation?

## Choice and control

- Do you feel like you had a choice in that situation? Why or why not?
- Do you feel like you had control in that situation? Why or why not?
- Do you feel like you had a good understanding of what was happening? Why or why not?
- Do you think the same thing would have happened to a non-disabled person? Why or why not?
- How did this experience impact your sense of dignity / How did this make you feel?
- (If relevant) Were you able to provide informed consent? Why or why not?

## Health and Wellbeing Experience #2

Is there another health and wellbeing experience you would like to share with me today?

## Wellbeing

An important aspect of health and wellbeing is how we keep ourselves well in our daily lives. Our body, mind, and environment are all connected. In order to have balanced wellbeing, it is useful to reflect how each of these things are working together throughout our lives. In these next questions, I will ask some questions about your overall health and wellbeing.

- What do you do to take care of your physical health?
- What do you do to take care of your mental health?
- How would you describe your social life?
- What things are important for your wellbeing?
- What stops you from feeling physically and mentally well?

## Awareness

Have you heard of the United Nations Convention on the Rights of Persons with Disabilities?

The United Nations tells us that all humans have the right to the “highest attainable standard of physical and mental health.” It also says that disabled people have a right to a high standard of health without discrimination on the basis of disability.

- What does this mean to you personally?
- Do you think the New Zealand Government is making sure disabled people have the highest attainable standard of physical and mental health? Why or why not?

Thinking ahead five years' time... the New Zealand Government is doing a really good job at making sure disabled people have the highest standard of physical and mental health.

- What does this mean for you?
- What needs to change for this to happen?

Thinking of disability, health and wellbeing, are there any issues we haven't covered today?

## Annex C - Monitoring Team

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