DONALD BEASLEY INSTITUTE

Disabled Person-Led Monitoring of the UNCRPD

My Experiences, My Rights: Disability Supports and Services

Report 3 - Disability Support Services (DSS)

Whakarakatira te tākata,
ahakoa ko wai, ahakoa nō hea.

Respect and treat all with dignity,
irrespective of who they are and where they come from.

Author: Donald Beasley Institute (DBI). The DBI is an independent charitable trust that conducts disability research and education. The DBI is committed to ethical, inclusive, and transformative research and projects that promote the rights of disabled people.

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Kōrero Whakamārama: We apply the Kāi Tahu dialect when writing in te reo Māori, that includes Kāi Tahu specific words and replacing the 'ng' with a 'k'.

Tohu description: The DBI's tohu depicts the round shape of a wharerau, a temporary shelter once built at mahika kai sites (food gathering areas). The top of the wharerau sits above the earth with a rau (lined pit) below. As a place of shelter and story sharing, the wharerau reflects the DBI's commitment to working respectfully alongside whānau whaikaha to share and grow knowledge and understanding.

Project Artwork: Eve McCoy.

Kupu Rāpoto / Acronyms

ACC: Accident Compensation Corporation

ADHD: Attention Deficit Hyperactivity Disorder

ASD: Autism Spectrum Disorder

ASH: Acceptable Standard of Health criteria

DBI: Donald Beasley Institute

DPO: Disabled People's Organisations

DSS: Disability Support Services

EGL: Enabling Good Lives

FASD: Fetal Alcohol Spectrum Disorder

GP: General Practitioner

IF: Individualised Funding

LGBTQIA+: Lesbian, Gay, Bisexual, Queer, Intersex, Asexual community, sometimes shortened to the 'Queer community'

MoE: Ministry of Education / Te Tāhuhu o te Mātuaranga

MoH: Ministry of Health / Manatū Hauora

MSD: Ministry of Social Development / Te Manatū Whakahiato Ora

NASC: Needs Assessment Service Coordination

NZSL: New Zealand Sign Language

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

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1 Whakarāpopototaka Mātua / Executive Summary

Project Brief

In 2021, the Disabled People's Organisations (DPO) Coalition asked the DBI to do disabled person-led monitoring on how well the New Zealand government is making the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) a reality in Aotearoa New Zealand. Disability supports and services were the chosen monitoring topic. When DBI started the project, significant changes happened in the disability sector. For example, Whaikaha - Ministry of Disabled People was created in July 2022. In March 2024, limitations were placed on some disability support services and funding. And, the government made further changes to the new Ministry after an independent review in August 2024.

The disabled person-led monitoring team collected data through interviews, focus groups and a nationwide questionnaire. The findings presented in this report focus on disabled people's perspectives and experiences of disability supports and services, in the context of the ongoing review and governmental response. Participants also shared recommendations on how to improve disability supports and services based on disability rights.

Key Research Findings

Information about disability supports and services

Participants highlighted that they need accurate information to be able to access the disability supports and services they are entitled to. However, information about disability supports and services is hard to find. Many participants found information inaccessible, mainly because it was not always available in alternative formats such as plain language and New Zealand Sign Language.

Funding

Some participants could not access disability supports and services or benefits because: the Government does not recognise their condition as a disability; they are in a relationship; they have natural supports; they are older than 65 years of age; and/or diagnoses from overseas are not recognised.

The primary way to access funding for supports and services is through needs assessments. Participants often felt that NASC assessments are based on the medical model and a deficit understanding of disability, and have long wait times. Regardless of the source, participants felt that funding is inadequate, resulting in them receiving either insufficient or no support for essential disability supports and services. Participants felt the Government's underinvestment in disability supports and services is reflective of how it values disabled people.

Participants emphasised the disparity between disabled people's access to supports and services provided through ACC and DSS based on how they became disabled. For people who are born with a disability, have a genetic condition, or have a health-related disability, supports and services are provided by DSS (within MSD). For people who acquire a disability through injuries and accidents, their supports and services are provided by ACC. The disparities between these two funding systems and pathways, each offering differing levels of choice, control and resourcing, have been well-recognised and consistently critiqued.

Choice and control

Participants said having choice and control was essential for them and their whānau. It gave them confidence in disability supports and services and access to them in a way that suited them. Maintaining choice and control often requires strong self-advocacy. However, sometimes participants did not have real choice and control over their funding, hours of support and who their support workers are. Participants in residential care experience a severe lack of choice and control, including inadequate or inappropriate support staff, not being supported to engage in activities that matter to them, as well as a general lack of freedom, respect, and

dignity. These experiences led to participants feeling disrespected, uncomfortable, and frustrated. Family, whānau and aiga of disabled people in residential care settings also struggled with the system's inadequacies and the lack of choice and control. They expressed concerns about their loved ones not being cared for, staff being unsupportive of independent living and proactive, meaningful interactions with others, a lack of staff training, and a general distrust of residential care facilities.

Disability support workforce

Participants expressed anxiety, mistrust, and fear that they would not have access to support due to unreliable agencies, a lack of staff training, and staff shortages. This can lead to unsafe situations where disabled people are unable to access care for a period of time, or have to accept inappropriate care. Participants highlighted insufficient job security, low wages and poor treatment of staff by agencies as reasons for high staff turnover. Privacy and confidentiality were also concerns raised by participants. According to participants, privacy breaches occur both within and outside of the disability support workforce.

Intersectional experiences of disability supports and services

Some participants experienced difficulties with disability supports and services due to the lack of culturally, gender, and age-appropriate care. Participants highlighted experiences where their cultural needs were unmet and disrespected by government agencies and disability supports and services. Cultural assumptions and stereotyping negatively affected some participants' access to support. Participants in the LGBTQIA+ community highlighted difficulties accessing healthcare services due to health professionals' lack of understanding around disability and intersectionality. Participants also shared concerns around inappropriate support placements (for example, placements of younger disabled people in aged residential care), as well as disparities in support provision based on age (particularly disabled people who age out of pediatric services and disabled people over 65 years of age).

Recommendations

Outlined below are participants' vision for a strengthened, improved, te Tiriti- and rights-based disability supports and services system in Aotearoa New Zealand.

1. The DSS system is led and driven by disabled people and their whānau and family, including assessments, funding allocation, training and service provision.
2. Information about DSS can be accessed early and easily, uses plain language, and is available in alternative formats.
3. Healthcare professionals are informed and able to support people in accessing the supports and services they need, as they are an important gateway to disability supports and services.
4. Supports and services are based on need, not the cause of disability. Eligibility for DSS includes people with psychosocial disability, chronic health conditions, FASD, people whose diagnoses have been made overseas, and people over 65 years of age.
5. Needs assessments are timely, strengths- and human rights-based, and include flexible eligibility criteria.
6. The Government invests in DSS so that disabled people can participate meaningfully in their communities and achieve their full potential. This includes matching the level of DSS funding to ACC funding.
7. DSS recognises the interrelated nature of disability and health. There is greater collaboration between agencies and service providers to ensure holistic care for disabled people.
8. All people who are involved in DSS receive disabled person-led disability rights training, including government officials, service providers, connectors, assessors and support workers.
9. Disabled people (including those in residential care and other living situations) have greater choice and control over their supports and services. This is achieved through the use of supported decision-making to decide which support provider they use, who their support people are, and how they want their support provided, and how they use their funding, including respite funding.

10. Support work is a career with secure hours, good wages and proper training that comes with a career progression pathway.
11. Disability supports and services provide cultural, gender, and age-appropriate care.

2 Whakatakika / Introduction

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is an international agreement that sets out the fundamental human rights of disabled people. While no specific article directly relates to supports and services, Article 19 articulates disabled people's right to live independently and be included in the community, and the role of supports and services in upholding these rights. According to Article 19, State Signatories, or governments, must ensure that:

> a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
>
> b) Persons with disabilities 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;
>
> c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs. (United Nations, 2006)

In Aotearoa New Zealand, supports and services for disabled people are provided by multiple government agencies[1] based on the genesis of the disability or condition and the purpose of the funding. For example, disability funding related to day-to-day support is provided by Disability Support Services (DSS) within the Ministry of Social Development (MSD),[2] and includes people with congenital or medical-related disabilities. According to the Disability Support Services website, types of DSS include:

- Autism Spectrum Disorder Support
- Behaviour Support
- Child Development Services

[1] Supports and services for disabled people can be provided by both governmental and non-governmental organisations. However, this monitoring report focuses on the government's role in providing disability supports and services in Aotearoa New Zealand.

[2] From 2022 to 2024 DSS was located within Whaikaha Ministry of Disabled People. Prior to 2022 it was located within the Ministry of Health.

- Community Day Services
- Community Residential Support Services
- Equipment and modifications for disabled people
- Hearing and Vision Services
- Home and Community Support Services
- Individualised Funding
- Respite
- Supported Living (Disability Support Services, 2024).

The Accident Compensation Corporation (ACC) provides supports and services for people who acquire disability through accident or injury (ACC, 2025). Other government agencies that provide disability funding for supports and services include the Ministry of Education, Oranga Tamariki, the Ministry of Health and the Ministry of Justice.

The New Zealand Government has been a signatory to the UNCRPD since 2008, meaning it is obligated to progressively realise all of the rights contained within the Convention, including Article 19. This Disabled Person-Led Monitoring report was commissioned by the Disabled People's Organisations Coalition (DPO Coalition) as part of the Independent Monitoring Mechanism (IMM) under Article 33 of the UNCRPD. This monitoring research aims to understand how well the government is implementing the rights of disabled people, and their family, whānau, aiga, and close supporters when accessing the supports and services they need to live in, and be part of, the community. This report is the third of five reports focused on disability supports and services in Aotearoa New Zealand, and recent changes in the disability sector.

In the first report, we collated participant reflections on the Government's consultation processes concerning DSS, while the second report detailed disabled people's perspectives on Whaikaha Ministry of Disabled People as the new (albeit temporary) home for DSS. The current report presents disabled people's perspectives on DSS in the context of the ongoing review and the government's response. The fourth report in the series explores disability sector leaders' perspectives on, and disabled people and their family, whānau and close supporters'

experiences of Enabling Good Lives (EGL).[3] A fifth and final report outlines participants' recommendations for a disability rights-based DSS system.

[3] Therefore, there is limited mention of EGL in this report.

3 Te Aramahi / Method

This monitoring research utilised the Disability Rights Promotion International (DRPI) methodology. Data were collected from 219 participants across three key phases:

- Phase one: Interviews with disability sector leaders
- Phase two: Focus groups
- Phase three: Nationwide questionnaire

Phase One: Individual interviews with disability sector leaders

The first phase of this research involved qualitative DRPI interviews with disabled leaders who were, or had been, actively engaged in the establishment of Whaikaha - Ministry of Disabled People and/or the development of the Enabling Good Lives approach (EGL). In total, 16 disability sector leaders were each interviewed twice between August 2022 and October 2023. Leaders identified with a wide range of genders, ethnicities, ages and disability backgrounds. Some leaders were family members of people with multiple and complex disabilities.[4]

Phase Two: Focus groups

The second phase of this research consisted of DRPI monitoring focus groups and individual interviews with specific cohorts of disabled people and their family, whānau, aiga and close supporters. The focus groups and interviews were primarily determined by the system(s) of support (or funding) a participant had access to, either under the Ministry of Health's outgoing Disability Support System (DSS) or another government agency. The monitoring team also conducted a series of targeted focus groups and interviews with harder-to-reach and intersectional populations to ensure the research included people known to experience challenges in accessing supports and services. Each focus group included between two and six participants and was organised according to the support they received, disability type, or intersecting identity, including:

- ACC (Māori 3, Pākehā 2; disabled people 4, whānau 1)
- Individualised Funding (IF) (Pākehā 14; disabled people 4)

[4] To maintain confidentiality, leader demographics have not been included in this report.

- Personal budgets based on Enabling Good Lives principles (EGL pilots) (Pākehā 5; disabled people 5)
- Home and Community Support Services (Pākehā 6, Māori 2; disabled people 8)
- Te Whatu Ora (formerly DHBs) (Pākehā 4, Asian 1; disabled people 4)
- Māori (Tākata whaikaha and whānau hauā Māori 1)
- Pasefika (Pasefika disabled people and tagata sa'ilimalo 6)
- Migrants and refugees (Asian 1; disabled people 1)
- LGBTQIA+ (Pākehā 3; disabled people 3)
- Women (Pākehā 1, Pasefika 1; disabled people 2)
- People living in group homes and/or people with learning disabilities (Pākehā 15, Asian 3; disabled people 14, whānau and close supporters 2)
- People with psychosocial disabilities (mental health) (Pākehā 3; disabled people 3)
- Ministry of Education supports and parents of disabled children (Pākehā 3, Māori 1; Parents of a disabled child 2, disabled people 2)
- Family, whānau, aiga and close supporters of people with multiple and complex disabilities (Māori 2, Pasefika 1, Asian 1, Pākehā 1; family, whānau and aiga 5)
- D/deaf people (Pākehā 4, Māori 1, Pasefika 1; Deaf 6)
- People with no access to supports or services (Pākehā 6, Māori 2, other 1; disabled people 7, whānau and close supporters 2)

In total, 29 interviews/focus groups[5] involving 82 participants took place between April 2023 and March 2024. Sixty-three participants identified as female, 17 as male, and two as non-binary. The participants were between the ages of mid-20s and early 90s. Fifty-seven participants identified as Pākeha, 13 as Māori, nine as Pasefika, including Cook Island Māori, six as Asian and one person identified with other.[6] Seventy participants identified as being disabled, including whaikaha Māori, whānau hauā and tagata sa'ilimalo, and twelve participants were family, whānau, aiga and close supporters of people with multiple and complex disabilities.[7] The purpose of

[5] If a person indicated they preferred individual interviews for accessibility reasons, this was arranged.
[6] The total equates to more than 82 as some participants registered multiple ethnicities.
[7] For the purpose of anonymity, participant details are not specified in the findings of this report.

this phase of data collection was to explore disabled people's access to supports and services under Articles 9, 19, and 21[8] of the UNCRPD, and following their experiences of DSS, the establishment of Whaikaha - Ministry of Disabled People, and EGL.

Phase Three: Nationwide questionnaire

A DRPI monitoring questionnaire formed the basis of the third phase of the research. The questionnaire enabled a greater range and number of disabled people and family, whānau, aiga and close supporters to share their experiences of supports and services, and to reflect on the establishment of Whaikaha - Ministry of Disabled People and national roll out of the EGL approach. The questionnaire was translated into accessible formats and languages and made available online. In total, 121 participants completed the questionnaire. Seventy-one participants identified as male, 38 as female, seven as non-binary, three as gender diverse, and two chose not to disclose their gender. Nineteen participants were aged between 18 and 30, 77 participants between 31 and 64, 22 participants were older than 65 years, and three chose not to disclose. One hundred and three participants identified as Pākehā, 20 participants as Māori, four as Chinese, two as Cook Island Māori, one as Fijian, one as Indian, and five as 'other' ethnicities, and one chose not to disclose their ethnicity. Eighty-seven participants identified as disabled (including tākata whaikaha Māori and whānau hauā), 13 as tākata turi/Deaf, and 28 as family members, whānau, aiga or close supporters of people with multiple and complex disability.[9]

Findings shared in this report are drawn mainly from data collected during Phase Two and Phase Three (disabled people and their family, whānau, aiga and close supporters).

[8] Articles relevant to this monitoring cycle are not limited to these three articles. A full list of UNCRPD Articles related to disability supports and services will be discussed in subsequent reports.
[9] The total equates to more than 121 as participants often registered multiple identities.

4 Kiteka / Findings

Disabled people and their family, whānau, aiga and close supporters who participated in this monitoring research shared a wide range of experiences, including the challenges of accessing and maintaining disability supports and services, both under the DSS system, as well as under health, education and social protection systems, and ACC. The following themes —information, funding, choice and control, workforce, and intersectional experiences of disability supports and services — articulate the key findings of the research.

4.1 Information about disability supports and services

Under Article 9 of UNCRPD - Accessibility of Information, the New Zealand Government must ensure that disabled people have access to information, while eliminating obstacles and barriers to accessibility (United Nations, 2006). Despite this obligation, many participants reported challenges when accessing information about disability supports and services. These challenges included difficulties in finding accurate information, including information presented in plain language and other alternative formats.

4.1.1 Access to accurate information

Participants identified access to accurate information as being the first step in obtaining disability supports and services. Without access to information, many participants said they did not know what supports and services they were entitled to, or that were available to them:

> *I am a recipient of [Individualised Funding scheme] but only got that recently [and] only found out through a friend that I may be entitled to it. (Questionnaire Participant)*

> *I still don't know what kind of supports would make it better, because I'm still not sure what kind of support is out there. (Refugee and Migrants Focus Group)*

As a result, the process of accessing supports and services was very drawn out and came too late for some participants, who were forced to use their own funds due to the slow responses from agencies.

> *The response I got from [organisation name removed] was very, very poor. [...] It took me a while, constantly having to follow up for what I need. Like, when I started a job I needed to get transport, I needed technology that I need, and by the time they responded I was already two months into my job. I had to personally fork out all those costs in the beginning. (Pasefika Focus Group)*

Participants expected healthcare providers to know more about disability supports and services, but noted that this was often not the case. They expressed frustration at having to do their own research using online resources or community networks, noting that these did not always provide accurate and current information.

> *Because it wasn't a GP [General Practitioner] or a doctor who told me about funding or support, or even sending you to somewhere like the [disabled people's organisation], you know? It wasn't a healthcare specialist, or nurses that sent me there when it really should have been. It had to be me sitting sick, spending too much time in the internet, stumbling over it to find it; and that just shouldn't be how it is. (Individualised Funding Interview)*

> *And that's another part of having a disability is that you don't always know what's out there until you meet people who are like, "Hey, do you know this service exists?" And that can be really frustrating when you know, you have health professionals who you see like your GP who you kind of expect to know these things! But they don't! (Pasefika Focus Group)*

As was highlighted by one participant, the inability to share information between the health and disability sectors led to confusion over what supports and services were available to them:

> *[I]t's just kind of stuff that even the hospital I don't think understand around ACC systems, and processes and all that they're telling me to*

file like new claims and all this. And I'm like, "But I have a claim with ACC." And you know, they just don't understand a lot of the bureaucracy stuff, they don't understand, how are we meant to understand? And how is our whānau meant to understand it? (ACC Focus Group)

Participants also raised concerns with communications related to supports and services. Specifically, participants felt important updates and developments about supports and services were not communicated effectively, resulting in those who are reliant on supports and services feeling uninformed and excluded from decision-making processes:

[Y]ou have to be hooked into the right emails or the right organisations to get any information as to what's going on. And even then it's so limited because they're not sharing what's happening. So even though I still get information from, you know, emails from this, that and the next, I wouldn't have a clue what's going on to be frank. (ACC Interview)

4.1.2 Accessibility of information

While accurate information was a crucial component of disability supports and services, the accessibility of available information also posed significant challenges for participants. For example, one participant reflected on the importance of plain language:

Sometimes they worded [things] differently and people with disabilities sometimes have the confusion around the language used. We need clear outline of what they can and cannot do because when they, you know, agree something, they need to follow how it is [...] rather than sitting in front of the screen half of the day just wondering, just confused at the end of the day. (Pasefika Focus Group)

One Deaf participant expressed that information is rarely available in New Zealand Sign Language, causing frustration and isolation:

There's some of the information that's in Sign Language but not all of it. But I think it would be worthwhile for the Deaf Community to know

more about human rights. Yeah they need access to that information. (Deaf Focus Group)

The inaccessibility of information was also raised by disabled refugee and migrant participants, who shared that there is no clear pathway or assistance to identify relevant information about the disability supports and services that are available to them:

[I]t took me a really long time to seek medical attention. So like, to begin with, I didn't know what a GP was. I didn't know how the health system works at all. (Refugee and Migrants Focus Group)

4.2 Funding

The second theme related to disability supports and services was funding. Article 19.b of the UNCRPD states that the New Zealand Government must ensure that "[p]ersons with disabilities 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" (United Nations, 2006). For Article 19 to be realised, disability supports and services must be adequately funded. Participants shared significant challenges with funding eligibility criteria and needs assessments, the impact of under-investment in disability supports and services, and the inequities between different funding systems.

4.2.1 Eligibility criteria

Some participants reported a lack of access to disability supports and services caused by them not meeting eligibility criteria. These participants included people with diagnoses or conditions not recognised by the Government and DSS as a disability, those in relationships with their natural supports, individuals over 65 years of age, and those with internationally obtained diagnoses not recognised by the New Zealand Government.

Notably, Deaf participants reported being unable to access funding packages available to other disabled people, such as Individualised Funding under DSS.

Currently, under the NZSL Act 2006[10] Deaf people can access some funding for NZSL interpreters in public settings such as courts, employment, and education environments. A small number of community funds are also available for interpreters at personal events such as weddings. However, these funds are limited and location-based. According to Deaf participants, being ineligible for DSS funding packages such as IF results in restricted access to funding for NZSL interpreters in non-justice, employment and educational settings, leaving them excluded from social and community engagements.

> *I don't have any access to funding for interpreters. I'm not aware of funds to be able to do that. (Deaf Focus Group)*

Other cohorts within the disability community also failed to meet the eligibility criteria for disability supports and services funding, including people with chronic illness and pain, and people with Fetal Alcohol Spectrum Disorder (FASD). While these are conditions that align with the UNCRPD definition of disability, they are not recognised by the New Zealand Government as meeting the criteria for disability supports and services.

> *I'm a part of the rare community, we're already lost in the system because we don't have that data to support us. So usually what happens is we get told that we've got a rare diagnosis and then people don't know how to deal with us. So, like, we don't get NASC funding because most of our conditions are pain-based and pain isn't classed as a disability. (LGBTQIA+ Focus Group)*

> *I wanted to laugh when you talked about New Zealand Government have to support people with disabilities. I think it's a joke and they're in denial because FASD's not recognised as a disability for any funding by [the] Government. (No Support Focus Group)*

One participant who did not have access to disability supports and services felt that the determination of disability eligibility was often reduced to a checklist approach, leading to the denial of vital supports for some people:

[10] New Zealand Sign Language Act 2006 - https://www.legislation.govt.nz/act/public/2006/0018/latest/whole.html#DLM372783

The other one is very tick box. So if you don't tick a couple of boxes, you don't make the criteria for support. Or if you tick a couple of boxes you're actually excluded because you're i.e. at risk to the service. Or you know, the debate between ASD and ADHD and that sort of thing. (No Support Focus Group)

For disabled participants in relationships or who have access to natural supports[11] the income of a partner or proximity of natural supports affected their eligibility for means-tested benefits[12] and disability funding packages.[13] This led to apprehension about the risk of disclosing their relationship status and natural support relationship. In the case of means-tested benefits, while restrictions apply to all beneficiaries regardless of disability status, the additional costs associated with disability compounded the challenges disabled people experience in the welfare system. For example, one participant talked about the difficulties of accessing a means-tested disability benefit given the systemic assumption that their spouse would financially support their disability-related needs:

[T]hey said, "Yeah, you'd qualify" [for WINZ support], and they said, "Oh, by the way, are you married?"; and I said, "No, but I'm in a relationship, you know, a permanent relationship." And they say, "Oh, do you have a wage of his?" And suddenly that was like, that was the end of the whole situation. And I said, "But what has his job got to do with my disability? His job isn't ever gonna cover two people's wages." Um, you know, like; and he's not signing up to take on financial responsibility of me. (Individualised Funding Focus Group)

Similarly, needs assessments for DSS funding ask whether a disabled person has natural supports - the disclosure of which could result in the reduction of funding an individual is eligible for:

[11] Natural support refers to informal support disabled people have from people in their lives such as family, partners or friends (Field, 2012).
[12] For example, the Disability Allowance and Supported Living Payment.
[13] For example, to access Household Management support under IF, people need to have a community services card (Ministry of Social Development, n.d.). However, if they are in a relationship, and a partner earns above a certain wage, they do not qualify for a community services card (Work and Income, n.d.). Other types of IF such as Personal Care do not require a community services card (Ministry of Social Development, n.d.).

> *[NASC] is still asking, "Do you have any natural supports? [...] can your neighbour help you?" I'm not asking my neighbour, it's not my neighbour's responsibility. It's not even my partner's responsibility; you're here to do an assessment to work out what part of it is the Government's responsibility. (Individual Funding Focus Group).*

Another participant described their frustration when they discovered they are ineligible for disability equipment because of their age:

> *I turned 65 a number of years ago and since the age of 65 I'm no longer considered a disabled person. I am an older person and so consequently [...] I was not eligible for any more [wheelchair] cushions. (No Support Focus Group)*

Other participants shared that the New Zealand government does not recognise diagnoses obtained overseas, leading to refugees and migrants encountering significant barriers when trying to access disability supports and services. Relatedly, the discriminatory immigration policy known as ASH, or the Acceptable Standard of Health[14] criteria, means that migrants often go without any support or services to avoid negative repercussions on their future visa status:

> *So, when I approached them; the first thing they asked me was, "Oh, you need to get diagnosed again in New Zealand. And, you have to pay it yourself." And it's like a super long waiting list even if you go private [...] I wasn't able to do that, so yeah. They just say, "Well, there's no support, you're not covered by the funding, and you don't, your diagnosis is not recognised here, so we can't do anything to support you." So I didn't get anything. (Refugee and Migrants Focus Group)*

4.2.2 Assessment

The next aspect of funding discussed by participants related to needs assessments. According to Te Whatu Ora website (2024), "Every person who wishes to receive

[14] See the UN Committee on the Rights of Persons with Disabilities (2022) 'Concluding observations on the combined second and third periodic reports of New Zealand'.

disability support services funded by a Health District must be needs assessed by the NASC. The information from the assessment is then used to determine the level of need the person has – very low, low, medium, high or very high." Participants shared several challenges related to the needs assessments process, including feeling like it is an arbitrary process underpinned by the medical model of disability, has unreasonable wait times, and is part of a disjointed supports and service system.

According to participants, needs assessments are based on the medical model and a deficit understanding of disability. They felt that assessments were overly focused on what disabled people cannot do or what medical condition a disabled person has, resulting in some participants feeling misunderstood or considered 'too hard' to assess.

> *The NASC agency must still follow the medical models of disability that disadvantages many who experience disadvantages due to disabilities - yet stroke, cerebral palsy, spinal bifocals and disk extrusions are treated differently even though the disablement impacts are very similar. (Questionnaire Participant)*

This prescriptive approach to needs assessment was also criticised by the Health Services and Outcomes Kaupapa Inquiry (Wai 2575) as not working for Māori communities (Waitangi Tribunal, 2019). For example, a monitoring participant expressed their experience of assessments being diagnosis-based rather than needs-based:

> *I feel like it's so diagnosis-focused. And people can have the same diagnosis, but such different quality of life. Well, I don't understand why it's so diagnosis-focused, because to me, it should be needs-focused. (No Support Focus Group)*

A further challenge reported by participants was the long wait times for needs assessments:

> *And so I went to Whaikaha eight months ago and they said, "We'll do a desktop assessment that doesn't involve your [child]." And it's taken them eight months, nearly nine months, and it's just been done now when my [child] exits out of care in three weeks' time. (No Support Focus Group)*

> *[I'm] treated like I'm faking it and ripping off the system. Whenever my assessment says I need help it's ignored or delays are created. (Questionnaire Participant)*

The disjointed and siloed nature of assessments is an additional barrier to adequate support. Participants noted that some parts of the system did not recognise supports and services provided by other parts of the system, nor were disabled people's support needs considered holistically. For example, one participant described how accessing a review for a specific need led to them being referred from agency to agency:

> *I've been trying to push for a medication review with the psychiatrist; and I can't get one at all. I've been trying to push for psychological support; I can't get any at all. They tell me to go privately and because I'm disabled, and access funding from the NASC, they're like, "Oh, you've gotta go through Explore Behaviour Support, again; because you're disabled." (Psychosocial Disability Focus Group)*

Another participant highlighted that the siloed nature of disability supports and services provision meant they had to repeat their story to multiple people and organisations. They pointed to the significant administrative cost of regulating the system, while the direct support provided to disabled people is inadequate:

> *It's frustrating that we have to justify our needs to the NASC. And then we have to do it again to our host. It's like why do we have to justify so many times. Again what [Participant 2] said, where they could save all that money just giving us the money. (Ministry of Education/Parents of Disabled Children Focus Group)*

4.2.3 Underinvestment

There was consensus amongst the participants that, regardless of the funding pathway, funding allocations were woefully inadequate. This left participants living with less support than necessary, or without any funding for essential disability supports and services. Many participants also shared that

underfunding led to high personal costs, long wait times, and a lack of access to essential care.

For example, one disabled participant talked about the financial burden of self-funding mental health support:

> *I couldn't even get a referral for mental health, because I didn't have a mental health condition. I said, "You find me someone who's disabled, who doesn't need some therapy." And they said, "No, that's not the criteria." [...] In the end, like, I had to pay privately to go to a therapist, and I had to pay privately to get a taxi there and back, cause I don't have a car that will take me. And it was $300 per session, by the time I'd paid for the appointment. And the appointment was reduced because I didn't earn a high income. And I'm like, who has $300, literally, to put aside to talk to someone about their disability? (Individualised Funding Focus Group)*

Another participant suggested that the Government's underinvestment in the disability sector reflects how the Government perceives and values disabled people:

> *[I]n my experience, conservative governments tend to think of numbers before they think of people. And that of course has an effect on us; because I've always thought that tacitly society thinks of us as not entire people. And that's partly why we're treated the way we are. If we were thought of as entire human beings the way they are within the same aspirations; things would be quite different. So, I think that's part of it, we tend to be thought of as a burden, or a cost, rather than an asset; in terms of societies. That's in terms of both numbers and social costs. (Enabling Good Lives Focus Group)*

However, this same participant emphasised that there is enough money, but that how the money is spent is determined by what is considered important.

> *[D]isabled people are more than a number, and statistics are arbitrary; to some extent, they aren't gonna tell you everything. And I think there's like, it's how we're valued as people. Like, being able to, as far*

as money goes, it's what you prioritise, isn't it? As a society. (Enabling Good Lives Focus Group)

Echoing the insight that funding reflects a Government's priorities, a parent of a child with FASD highlighted they are unable to access disability supports for their family. However, they also noted that there is ample funding to uplift a disabled child from their whānau:

MoE [is] useless and our [child] never received any funding for support and was managed out of school, age 14. If your disabled child's needs are too high and complex to manage in the home we lose our parenting rights as the child has to go into care under the same orders as if we had abused her. (No Support Focus Group)

Another participant highlighted how families and other natural supports are expected to provide assistance without equitable recognition for their care work. Moreover, this participant's experience revealed the system of 'carer-support' recognises parent-to-child support, but not 'carer-support' provided by a partner:

[W]e're getting told that "He's your official carer," and he gets sent a letter saying, "Hey, here's your carer-support," which is just pathetic. Because you're told that, "Hey, this isn't actually gonna fund someone per hour, it's this token amount to go towards things." But they can't tell you what those things are, and say, "Oh, it's going for things like having someone look after your child." And I was like, "But I'm not a child." But they're like, "This is carer support for parents." And I was like, "Well that's not my situation, so why do you even write a letter to my partner, talking about his child, when I'm an adult?" Like, you haven't even looked into it. (Individualised Funding Focus Group)

Participants also highlighted underinvestment in mental health related supports and services. Some participants felt this reflects the Government's attitude towards disabled people, particularly those with psychosocial disabilities, as being insignificant and not a priority:

I don't trust mental health [services]. I don't think that people with disabilities are a priority, and I don't think people care. And I think that

we are just left to survive on our own, a lot. I think things have deteriorated over the years; cause I've been around for a long, long time, I've seen a lot of things. And I also think that they don't think we're worth an investment. (Psychosocial Disability Focus Group)

4.2.4 Disparities between DSS and ACC

Participants emphasised the disparity between disabled people's access to supports and services based on the genesis of their disability. For people who have congenital disability, a genetic condition, or health-related disability, their supports and services are provided by DSS within MSD (formerly Whaikaha Ministry of Disabled People and the Ministry of Health). For people who acquire disability through injuries and accidents, their supports and services are provided by ACC, a two-tiered system that has long been criticised (Donald Beasley Institute, 2022; Foster, 2022).

For example, one participant shared that they can receive temporary support for their injury through ACC, but they remained ineligible for permanent support from DSS because their condition is not considered a disability.

I got a concussion [...]. Yes, ACC sprang into action so which is equally frustrating and great because, yeah. They confirmed I could have a cleaner for three, 12 visits over three months. So yay, I've got some help. But I had to hit my head really, really hard and suffer the consequences of concussion to do it when I could have had this you know, the whole time. Do you know what I mean? So yeah, it's yeah. It's equally frustrating as well as unofficial because of course it's brilliant that I'm getting some help finally, but really? This is what it took? (No Support Focus Group)

Another participant asserted that the inequity in funding, supports and services means that under DSS, disabled people are at greater risk of injury and death than those who are ACC-funded:

I only get one access way out of my house. If I was ACC I would get two accesses out of my house. So if I actually have a fire that blocks my front door off, I'll be fried to a cinder because I cannot get out my

back door or my sunroom. That's just one difference between ACC [and DSS]. (Home and Community Support Focus Group)

Another well-known inequity between ACC and DSS is the differing levels of funding for equipment. One ACC participant said they appreciated the flexibility to choose their preferred equipment, which enables them to make their own decisions about what works for them:

I'm an ACC client; I kind of feel like I've got a lot of choice in what supports I use. I've got a lot of choice in, for instance, what type of wheelchair I could go for. (ACC Focus Group)

Conversely, a participant who is funded by DSS articulated the lack of choice and control they have over what equipment they can access:

They told me that I had to have a bigger wheelchair. I said, "Well, why?" I said I've had the other one, I'm still the same size. Why do I need a bigger wheelchair? [...] since [they]'ve given me this wheelchair, all [they]'ve done is set me backwards (Home and Community Support Focus Group)

Participants with chronic illnesses also expressed frustration over the lack of support available to them, contrasting their experiences with those who are funded by ACC or DSS. For example, one participant described a hierarchy when accessing supports and services, highlighting a critical gap in the supports and services system for people with chronic illness.

Feels like we're on a hierarchy if you've got ACC you're okay. If you've got Ministry of Health [now DSS under MSD] you're doing a bit better. But if you've got a chronic illness, sorry, you're screwed. There is just no support available. (No Support Focus Group)

However, not all participants reflected positively on their experiences with ACC. One participant stated that disclosing their personal trauma to access funding for psychological support under ACC was unfair because they are only allowed to see a psychologist for trauma related to a past assault, rather than their psychosocial disability. This story, along with others, highlights the additional trauma disabled

people endure when attempting to access necessary disability and mental health supports and services through either ACC or DSS.

> *I do have an ACC-funded psychologist. But I feel like that's absolutely disgusting that I can only access funded mental health support because I was assaulted. Not because I have a disability. It's ridiculous in this world that we can have a disability, and we can be really sick and really ill; and we have to use other, unfortunate things that have happened in our life to get us the support that we need, and we have to justify that. [O]ur lives are worth so much more than that. (Psychosocial Disability Focus Group)*

4.3 Choice and control

The third theme was that of choice and control within the context of disability supports and services. Choice and control, a significant aspect of upholding Article 3.a of the UNCRPD, states that a key principle of the Convention is to respect the "inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons [with disabilities]" (United Nations, 2006). Within this theme, the following sub-themes were also identified: The importance of choice and control, lack of choice and power, and choice and control within residential care settings.

4.3.1 Importance of choice and control

Participants emphasised the importance of having choice and control over the supports and services they access and receive. Importantly, participants related choice and control over supports and services to the choice and control they have in their daily lives. For example, one whānau member highlighted the independence that Enabling Good Lives (EGL) had enabled for their disabled child:

> *[M]oving from IF to Enabling Good Lives has meant you choose what you want and how you want it so that you don't have to use support staff. You can use mainstream services like Driving Miss Daisy or do your dance or do other things that make a good life. (Questionnaire Participant)*

Similarly, another participant shared that having choice and control gives them confidence to access support in the way they know suits them best. This made them feel a sense of equality with non-disabled people who can access mainstream services:

> *With Enabling Good Lives there are no restrictions so you can actually look at what's really needed. Instead of having to pay for support staff you can find other ways of doing things. Instead of the support person taking you to the gym you can pay for an instructor at the gym to actually be training people. So you're getting support but it's in a very different way, just like everyone else in society may go and see a personal trainer. So you're having someone with a person but in a more socially acceptable way. (Questionnaire Participant)*

However, authentic choice and control often did not occur easily or without persistent self-advocacy. One participant shared the lengths it took to have control over their supports while in hospital:

> *I needed ACC to intervene to ensure that my caregivers were paid to come to hospital, and provide my care for me. It was a battle because they sent through some DHB-ACC agreement snippet that they had taken out of their policies and their procedures. So they took out the snippet that supported their decision to not provide my support carers at that particular time. Now I went into that same document, and down a little bit there was the area that supported them to send the carers in for me, because of my level of my injury and the complexities involved with that. So that's where I took that snippet, sent it back to them, but I'm really sick at this time. (ACC Focus Group)*

4.3.2 Lack of choice and control

While participants highlighted the importance of choice and control, they also described the impact of having no choice and control when accessing supports and services. Many of the challenges participants experienced related to a lack of choice and control over their funding, hours of support, and who their support workers are. Participants also experienced a lack of choice and control when accessing support

worker agencies. One participant shared an experience where they had no choice or control over their supports and the negative impact this had on their dignity:

> *At one point I couldn't get anybody [support workers] for four days. So, I was in [the same] clothes for four days and four nights. (LGBTQIA+ Focus Group)*

Participants also reported a lack of choice and control regarding the adequacy, quality and safety of the support they received. A participant expressed frustration with a support worker agency that frequently failed to communicate changes regarding their support workers. As discussed further in section 4.4, many of these workers lacked proper training and often exhibited condescending attitudes:

> *The services that provide home support who come in to assist. [...] they find it quite acceptable to send in people without telling me they've changed them. Without telling me anything about them. Sending in people who actually have no training to do what they're required to do. And one of my personal hates is when they ask me yet again, "So how do you feel about having a male support worker?" So it should be on record that I don't accept that. (Home and Community Support Focus Group)*

Participants expressed feeling controlled by agencies and organisations, and not having autonomy over their own supports and services. Participants also wanted more choice and control when making decisions that affect them.

> *I don't get to choose who I have. I get given someone. Don't always like them and some are bad. Some are good too. [...] [Some of them] don't do job properly, like don't shower me and talk down to me [...] some not comfortable with doing stuff [...] I want to go out walking on tracks, have a coffee. That kind of stuff. (Home and Community Support Focus Group)*

One participant expressed strong dissatisfaction with people in positions of power who had frequently imposed restrictions on the allocation of funding, thereby dictating which resources they were able to access. The participant described the continuous struggle as exhausting and burdensome:

[F]or years I've had to fight for that, you know? And I managed to push through using my respite care, for cleaning and household management. Because I said to them, "I'll go, you know; I'll go as high as I have to prove to someone." Because it's not like some little, tiny loophole, it's something that's not right. And you're not even asking the people who need the help; you know, I'm not asking you to give me more money, I'm asking you to let me use it in a way that works for me. (Individualised Funding Focus Group)

Participants also recalled instances where staff members, including support services and health professionals, disregarded their needs, were dismissive and refused to listen to their will and preference when it came to support:

[W]e had things like [support workers] on their phones, people going to private work, people don't ask you what [you] want. They ignore your choices. Some people were doing their other jobs [...] while they were supposed to be working with you and there's not much you can do about it. (Questionnaire Participant)

Several participants also shared experiences of unprofessionalism and neglect by support staff, such as staff using alcohol while delivering support:

I'll tell you why. I knew one of them was drinking on the job. (People with Learning Disabilities Focus Group)

Finally, participants spoke about the lack of choice and control as being a systemic issue. Some participants identified that this was because of limited collaboration between organisations and government entities.

And just everything being so siloed and nothing connects. [...] we wanted that person to work quite closely with our physio who knows [disabled family member] really, really well and knows what her needs are and also understands the equipment. That didn't go well. The person from the Ministry basically told her to go away and not butt in. So that's been a real challenge and quite disappointing too. (Ministry of Education/Parents of Disabled Children Focus Group)

4.3.3 Choice and control in residential settings

Given that the voices of tākata whaikaha, D/deaf and disabled people living in residential care and other controlled settings are often unnoticed or ignored (Royal Commission of Inquiry into Abuse in Care, 2024), it is essential to highlight participants' experiences within residential care settings. Participants in residential care shared many of the same challenges and frustrations as other participants; however, they also shared experiences that demonstrate a severe lack of choice and control. These experiences included having inadequate or inappropriate support staff, not being supported to engage in activities that mattered to them, as well as a general lack of freedom, respect, and dignity.

> *My mental health housing provider treats us like children, makes all rulings on a group basis and does not allow for individual differences or [personal] preferences. (Questionnaire participant)*

Another participant described how the rigid policies within a residential service had led to them not being given privacy while bathing due to their medical history:

> *It was years ago but when I lived at [service name removed] and I had seizures and I didn't have them for over ten years. Their policy was you cannot have a bath without someone staring at you [...] to me that was not okay. (People with Learning Disabilities Focus Group)*

Participants in residential care also reported being unable to shop for food, not having enough assistance with personal care tasks, and not being supported to engage in their preferred activities:

> *[I would like] more support round our needs and stuff like doing food shopping and all that sort of stuff. Being able to choose our food on the cell phone or the iPad. But we don't get that chance to and I'd like to learn. (People with Learning Disability Focus Group)*

These experiences are in contradiction to Article 12 of the UNCRPD and the principles and approaches of Supported Decision Making (SDM). SDM is about supporting disabled people's will and preference rather than making decisions for them based on notions of best interest (Watson & Joseph, 2015). Not being able to

make decisions for themselves left participants feeling disrespected, uncomfortable, and frustrated. Their lack of autonomy, choice and control calls into question the delivery of Article 3.a of the UNCRPD in these settings.

Family, whānau and aiga of disabled people in residential care settings also struggled with the system's inadequacies and the lack of choice and control. Family participants expressed concerns about their loved ones not receiving adequate care and about staff being unsupportive of independent living and not proactive about the person being able to have meaningful interactions with others. One participant was horrified when a residential care provider made a unilateral decision to make their son wear nappies, even though he was able to use the bathroom independently:

> *They want to put him in nappies now. So from a pretty average kid that can toilet himself they basically [made him] bedridden. (Family, Whānau and Close Supporters Focus Group)*

Participants with family and whānau in care also expressed concerns about the lack of training among staff in secure care and protection units, leading to the abuse of residents who were required, or had no other choice but to receive support in those specific settings.

> *But from there she went [...] into a care and protection secure unit. And she was there for ten months. While she was in there, she was abused because none of the staff had any training in FASD, and they used behaviour modification. And for my daughter, because she could never make the behaviour modification, cause she's got a brain injury, you're punished. (No Support Focus Group)*

One participant believed that a residential care facility was breaking the law and allowing alcohol and drugs onto the property, causing the participant to feel distrustful of residential care homes and questioning whether their loved one was receiving safe and adequate support:

> *I knew they weren't delivering those care plans. I knew that they were allowing him to drink. I knew that there were methamphetamine dealers on properties. There are sexual abuse cases. Staff were told to keep quiet. (ACC Focus Group)*

4.4 Disability support workforce

The third category of findings concerns the disability support workforce and relates to the skilled labour shortage, difficulties in recruiting support workers, and the quality of support provided.

4.4.1 Skilled labour shortage

Participants expressed anxiety, mistrust, and a sense of fear due to the unpredictability of the supports and services provided by agencies in the disability sector. According to participants, high staff turnover disrupts the continuity of care and creates anxiety among those who rely on the services:

> *I'm terrified they're not going to turn up. I'm terrified they're not gonna be vetted. I'm terrified they're just gonna say no to me. And I just, I can't risk that. (Individualised Funding Focus Group)*

Participants noted that many support workers juggle multiple jobs due to unreliable hours and a shortage of full-time positions. This, coupled with insufficient job security and training, resulted in fragmented support:

> *I get individualised funding. I get it year to year. At no time can I guarantee you [support worker] a job past a year. (Individualised Funding Focus Group)*

When asked about the shortage of support workers, participants identified several factors, including low wages and poor treatment of staff by agencies.

> *[I]t really scares me that so many people are being forced [...] to take on carers who don't want to do the job, just know that it's above minimum wage, and have no experience. (Individualised Funding Focus Group)*

> *[I]t has to do with how they treat their staff. They leave them in situations where they don't train them properly. (Te Whatu Ora Focus Group)*

Participants also said that the inability to recruit dedicated and competent support workers stems from such roles being perceived as temporary positions rather than a valued career pathway. Participants perceived that the challenges were shared

across the different funding systems, including ACC, Individualised Funding and other Disability Support Services (DSS).

> *We don't make it a career. We don't make it a worthwhile job in this country. It's a paycheque. Or it's for people who are perceived not to be any good at doing anything better than. It's not promoted or treated as a worthy job. Yet, what they do is critical to the lives of those of us who need them. (ACC Focus Group)*

4.4.2 Training

According to participants, support workers often do not have access to training or qualifications on how to provide high-quality care and assistance, which can lead to unsafe situations.[15] There was a perception that this started at the recruitment level, as many organisations do not require applicants to have basic training or qualifications to apply for support worker roles:

> *They quite frequently have been sending in new people who have no experience. No training in hoist. So they will send them without asking me. I had two people for hoist without asking the person cause then there's a while to train them. So they're effectively not asking for consent to do training. They're not even doing the courtesy to their own staff to say, are you happy to do this? (Home and Community Support Focus Group)*

One participant shared how a support worker's limited training led to a lack of autonomy over their care preferences and needs:

> *I had another person come in and she was, this person was so used to showering someone quadriplegic or paraplegic, or it might not be paraplegic. But they did my private[s] first time, and then I told them no, the next day they came and did it again. And I said, "No, aren't you*

[15] This is despite The Care and Support Workers (Pay Equity) Settlement Act 2017, which articulates the employers' responsibilities to offer the support workers the opportunities to attain relevant qualifications (S.17).

listening?" And I put a complaint in to [disability support organisation] about it. (LGBTQIA+ Focus Group)

Advocating for adequate support was tiring, with providers reported as lacking transparency over the services they offer, leading to participants feeling responsible for negotiating with providers, and battling against the system there to support them:

So overall support I've found that you do a lot of, if you're just getting on with your life for support you spend a lot of time having to negotiate, having to argue. Making very many, many complaints. (Home and Community Support Focus Group)

Some participants said that disabled people and their family members are often required to train support staff themselves, as agencies do not provide sufficient training about working with disabled people with specific needs such as Down Syndrome, multiple disabilities, learning disability, physical disabilities, sensory disabilities and neurodivergence.

[E]very support worker needs to have training to be around people with Down's Syndrome. They need to have training and need to be vetted. They also need to be medically trained for those who have epilepsy for instance. (People with Learning Disabilities Focus Group)

Resource allocation for training and professional development was also a key issue, with one participant noting that training hours were sometimes used to cover travel costs for support staff, resulting in a reduction of actual training time:

Then I had a random email from my coordinator telling me that her manager has said that they're not approving the training hours because I've already had so many training hours this year. Those were those three ladies that I had trained. And she said and we've already given this lady ten hours. I was like huh? She hasn't done ten hours. And then I remembered her telling me about the travel and I was like ah! The hours have been included with travel to pay for her, these training hours have been included. Extra training hours were included to pay for her travel. (ACC Focus Group)

4.4.3 Privacy and confidentiality

A third challenge participants shared regarding their interactions with support workers and service providers was privacy and confidentiality. According to participants, privacy breaches occur both within and outside of the disability support workforce. This finding calls into question Article 22 of UNCRPD - Respect for Privacy, which recognises the Government's responsibility to protect the personal information of disabled people (United Nations, 2006). However, participants highlighted that disabled people and their families are not always afforded these protections. For example, one participant recalled being pressured to disclose personal information to administrative staff and felt that if they did not do this, they would not be able to access disability supports and services:

> *[T]hey ask you personal things in front of people waiting at the desk. I've had that happen. I've had that happen in my doctor. "Why do you want to see the doctor?" I said, "I'm sorry that's my business." And that's not the first time that's happened to me. It's almost like, "Oh you are vision impaired you must ask why she is coming in." I do find that there are a lot of gate keeping. There's huge amount of gatekeeping in all sorts of support services and medical situation. (Women's Focus Group)*

Another participant shared an experience where a NZSL interpreter disclosed their story to someone else without consent and not within a supervision setting. This breach of privacy meant the participant did not feel safe to express themselves freely during their own counselling sessions:

> *Then I saw this interpreter offloading to this person about what had happened in my counselling session and there I was looking at them and they were divulging what had happened in my counselling session. (Interview with Deaf Participant)*

4.5 Intersectional experiences of supports and services

The following collection of findings relates to participant experiences of intersectionality, which is a framework used to describe how people with different

identities can experience different and compounding forms of disadvantage or discrimination (Crenshaw, 1989). Intersectionality highlights whether and how disabled participants had differing disability supports and services experiences because of their ethnicity, gender, sexuality, age, or other intersecting factors. Participants had a range of support experiences, with some experiencing difficulties due to the lack of culturally appropriate care, gender appropriate care, and age-appropriate care.

4.5.1 Culturally appropriate care

Culture is the values, beliefs, and behaviours that are shared by a group of people that influence members' behaviour and understanding (Spencer-Oatey, 2008). Culturally appropriate care describes supports and services that understand and uphold the cultural context of service users. The right to culturally appropriate care is enshrined in Aotearoa New Zealand's Code of Health and Disability Services Consumers' Rights, which states that "Every consumer has the right to be provided with services that take into account the needs, values, and beliefs of different cultural, religious, social, and ethnic groups, including the needs, values, and beliefs of Māori" (Right 1(3), Health and Disability Commissioner, 2023). This monitoring project engaged with a wide range of disabled people, families, whānau and close supporters from different cultures and ethnicities, including migrants, and disabled members of the LGBTQIA+ community, who all shared challenges when accessing disability supports and services in Aotearoa.

One Māori participant spoke about their experience with a government agency and how, throughout the process, their cultural needs were unmet and disrespected:

> *The four organisations that, services that my son went into, contracted to ACC continually dishonoured us as Māori and our connection and whānau work together. They completely pulled us apart. They completely segregated us. (ACC Focus Group)*

Another participant shared an experience where whānau were excluded from their disabled family member's care plan:

For as, as Māori, like I don't think there is any understanding of like, being a whānau kind of environment. You know like, you're there as whānau not as your individual self. (ACC Focus Group)

Participants also highlighted the lack of representation and meaningful involvement of Māori people in the workforce of agencies such as ACC. The absence of authentic Māori representation reflects a broader issue, amplifying power imbalances, ongoing impacts of colonisation, marginalisation, and discrimination in health and disability service delivery for tākata whaikaha and whānau hauā (Ingham et al., 2022). For example, one participant spoke about the lack of authentic representation and cultural tokenism within ACC and the impact it had on them:

There is no Māori reps in ACC. They're meant to have them but they don't. If they are, they're token gestures with old aunties who haven't really got anything to do. I said it to one of the aunties. I said, "You know you're a token gesture in here. When we have meetings you're brought into the room as a token Māori." She was horrified. She said, "Actually you're right." I said, "I'm totally right. You're just being used [name]. It's an insult to have you sit here and not really have any knowledge but just be the brown face in the room." I mean I've been called upon to be the brown face at times. This is absolute racism and colonisation at its highest. (ACC Focus Group)

While examples raised by the participants related to ACC, lack of representation and culturally appropriate disability supports and services are widely recognised by the Health Services and Outcomes Kaupapa Inquiry (Wai 2575) (Waitangi Tribunal, 2019).

Pasefika participants also highlighted a lack of culturally appropriate care and training within disability supports and services. One Pasefika participant reflected on how cultural assumptions about who should provide support and care impacted their access to supports and services:

Participant: Is it something that we're not seeing? Is it, is it our language? Or is it our stories? Is it something, like, we're complaining,

instead? But if we don't have our parents in the room, no one's going to listen to us […] And I'm nearly [age removed], you know what I mean? I shouldn't have to have my mum in the room.
Monitor: So do you think there's a cultural element to that assumption for support services to say, "Oh, well you've got your mum, you don't need that support"?
Participant: Yup. (Pasefika Focus Group)

Similarly, another participant recognised that being of European descent meant they received better treatment than others when accessing supports and services:

I'm always embarrassed to go to these places being European because I know that that cultural bias is there and I will get better treatment. (Family, Whānau and Close Supporters Focus Group)

Refugee and migrant participants also shared their challenges. Some participants felt that healthcare professionals dismissed their disability-related needs based on racial stereotyping and presumptions about poor English proficiency:

I'm a migrant and a person of colour because people assume that it's either my English problem, or I'm too shy because I'm Asian. [...] and even after I told them I'm Autistic, they kind of just put that aside. Like, "Oh, you're just shy." Like, "Oh, it's not a big deal; you can talk, you're just a bit shy." (Refugee and Migrants Focus Group)

With regards to the Deaf community, a participant reflected on the lack of awareness around the importance of having interpreters and Deaf culture in State services, including public hospitals:

I've had to have my baby at hospital, for surgery; and I wasn't provided with an interpreter. I asked for one, and for access to information; they didn't give it to me. You know, and I was in labour for over 24 hours, with no support. It's like you know, they're telling us like we're not good enough. (Deaf Focus Group)

4.5.2 Gender appropriate care

Gender appropriate care, which upholds and affirms people's gender (including LGBTQIA+ identities), is an essential component of disability supports and services, and a requirement under Article 25 of the UNCRPD - Health (United Nations, 2006). However, the intersection between disability and gender, especially within the LGBTQIA+ community, often leads to further marginalisation (O'Shea et al., 2020; Wickenden, 2023). As highlighted by one participant:

> *So, as a queer woman with disabilities, I don't think anything in my thirty years of being out has changed for people with disabilities in the queer community. I still think the alienation and segregation for some, for people with significant disabilities in particular is there. It concerns me that the acceptance within that community is probably not there to the same degree (ACC Focus Group)*

Research also shows that people from Queer communities may hesitate to engage with supports and services, particularly the health system, because of medical model framing and a history of pathologising LGBTQIA+ identities (Quint et al., 2025). For example, a LGBTQIA+ focus group participant described the challenges disabled transgender people specifically experience when accessing health care, and the fear of being denied treatment due to healthcare professionals' lack of knowledge around the interaction between disability and gender affirming care:

> *I know for myself and a lot of other transgender people there is a hesitancy to seek medical transition services like accessing hormones or surgeries because you know that if you have a complicated medical situation that it might be a barrier to you accessing those. Cause the doctors will be like oh we're not sure how hormones for example will react with whatever your medication is or whatever health condition you have. (LGBTQIA+ Focus Group)*

Participants also expressed frustration with being categorised by only one aspect of their identity, rather than being viewed within the full context of their intersecting identities. This ongoing failure of supports and services to meet their cultural needs led to unresolved medical issues:

> *I mean I'm a woman, I'm overweight, queer and you know, with a disability. And I feel like any time I'm in a doctor's space, even if it's a new specialist or something like that and you start saying all these different things that you've got, it doesn't matter. They're gonna put me in that mental health box or that everything is related to my weight. Whereas they don't actually stop to consider that maybe my weight is because of the disability. Or the fact that my cultural and spiritual needs as far as my queer identity goes isn't being taken into account that my mental health is having an impact. (LGBTQIA+ Focus Group)*

Another participant described difficulties in accessing long-term counselling, and the challenges of finding a mental health professional who understands the complexities of being disabled and transgender:

> *[A]t the moment they got a counsellor for me, or more of [a] psychologist, seeing her at the moment, which I've been needing for years. And [it's] very difficult to find someone, especially, I think it's harder to find someone who understands not the disability only, with being a trans woman it is harder to find someone who's suitable to work with you. (LGBTQIA+ Focus Group)*

In addition to the experiences of LGBTQIA+ participants, contributions by disabled women also highlighted the importance of gender affirming care within disability supports and services. This intersection between disability and gender is particularly significant because of the entrenched attitudes within healthcare towards women (Merone et al., 2021). For example, research shows that women's pain is less likely to be believed, taken seriously, and treated appropriately (Merone et al., 2021). Participants emphasised the lack of respect and support for disabled women by supports and services, meaning their needs often went unnoticed or neglected. One participant highlighted how internalised ableism and sexism contributed to a lack of support options for people living with chronic conditions that commonly affect women:

> *It is often women around my age; young kids who are suffering from things like ME [myalgic encephalomyelitis] or fibromyalgia or POTS [postural orthostatic tachycardia] syndrome. And, geez we get no*

> *respect. It's like, it's like these diseases don't exist in peoples' minds, it's like, actually, I know people who have ME who don't get out of bed all day, every day, and they just can't. And like, they get no services whatsoever. (No Support Focus Group)*

Neurodivergent participants also discussed gender and disability barriers they face when seeking supports and services. For example, one participant spoke about their experience with health professionals not believing them and failing to understand how neurodivergence can present differently in women:

> *[Y]ou've still got to overcome the barrier that some doctors don't think that women can have autism or ADHD, or they don't understand how it varies. It's so limiting. (People with Psychosocial Disability Focus Group)*

While these experiences primarily relate to health care services, the earlier identification of health care services as a pathway to disability supports and services (see section 4.1.1) draws attention to the compounding forms of marginalisation experienced by some cohorts within the disability community. Without access to gender appropriate healthcare, access to disability supports and services can be further limited.

4.5.3 Age-appropriate care

The third type of care participants spoke about was age-appropriate care. Participants identified the need for a cohesive disability supports and services system that provides age-appropriate care and considers and accommodates the changing needs of both younger and older disabled people.

For example, a younger participant spoke about being placed in an aged care facility to rehabilitate after an injury, even though they were significantly younger than the other residents. The participant found the arrangement inappropriate for their needs, as well as contributing to their sense of isolation and separation from their peers:

> *And having to spend two years in a rest home before I could get out to a placement because they only place you in a rest home no matter what your age was or abilities. (Home and Community Support Focus Group)*

Family and whānau of younger disabled people also noted the difference between paediatric and adult services, particularly with regards to funding and equipment:

> *One of our biggest issues is when she transferred from paediatric to adult services all of the support just disappeared medically and even down to her supplies. You know, suddenly, "Does she need that many catheters? Does she need nappies?" (Family, Whānau and Close Supporters Focus Group)*

For older disabled participants, age-related criteria for supports and services were a cause for concern. Under the current disability support system, disabled people over the age of 65 cannot access disability support services unless they were already in place before they turned 65. While the support needs of disabled people often increase with age, under the current system, the level of support does not, which participants felt increased the risk of misdiagnosis, diagnostic overshadowing and neglect. As was highlighted by an older participant:

> *When I was in hospital they diagnosed it. I had undiagnosed [condition]. But I think they just looked and thought, "Fat old lady, heart condition or stroke is gonna get her any day now. Why should we give her an expensive medical treatment, when other people who are still in the workforce are falling, you know, have to stand behind her in the queue?" Now I can see the reasoning, but it's not very pleasant to be on the end of being told you're only worth dying. (Te Whatu Ora Focus Group)*

While the experiences of older people and disabled people are often conflated (Lamb, 2015; Reynolds, 2017), older disabled people have specific disability related needs as well as age-related needs. For many older participants, accessing and navigating age-appropriate supports and services was a challenge. As was summarised by one disabled participant:

> *I'm quite concerned that we're doing a lot for our youth, which is great but we're not looking at people in my age group. (Individualised Funding Focus Group)*

5 Tūtohi / Recommendations

Throughout the interviews, focus groups, and questionnaire, participants highlighted many challenges when accessing disability supports and services in Aotearoa New Zealand. However, participants were clear about how they could be improved, and the actions government and service providers need to take to achieve this. Participants recognised that for these changes to be implemented meaningfully, the changes must be led by people with lived experience of disability and an in-depth understanding of disability supports and services. This finding was also central to Report 2 - Consultation and Engagement. From high-quality and accessible information and services, to assessments, training and leadership, outlined below is the participants' vision for a strengthened, improved, te Tiriti- and rights-based disability supports and services system in Aotearoa New Zealand.

1) **The DSS system is led and driven by disabled people and their whānau, family and aiga, including assessments, funding allocations, training and service provision.**

   That it would be disability led. That in fact we would be assessing the providers, not the providers assessing us but those who are disabled who have been for a long time whether they're new to a disability or not, with the experience of living with that disability and their families. My greatest dream is that we would bring that funding back into communities. That in fact the disability community would be a part of assessing who would hold that money for the disabled. That would be totally disabled focussed, totally driven. (ACC Focus Group)

2) **Information about DSS is accessible early, easily, uses plain language, and is available in alternative formats.**

   A good life for me is a life where support services are easy to access and information about support service is available when you need it, where you need it, and in any format, accessible format. (Pasefika Focus Group)

English isn't a Deaf person's first language; Sign Language is the first language. So we need access visually; so they need to be aware of that. You can't just put out information in English text, and have it ah, kind of government language, and expect Deaf people to be able to access that. The information needs to be translated into NZSL, to be clear when it's being put out. (Deaf Focus Group)

3) **Primary, secondary and tertiary healthcare professionals are key distributors of information and a gateway to DSS. They must be informed and able to support people to access the supports and services they need.**

[A]nybody who is going to a GP that gets told that they have a disability, or meets the criteria through disability should be handed a booklet that says, "Hey! Welcome to Disability New Zealand. Here's all the different things. Here's where support is, here is equipment. Here's who's responsible." (Individualised Funding Focus Group)

4) **The provision of supports and services is based on need, not the cause of disability. Eligibility for DSS includes people with psychosocial disability, chronic health conditions, FASD, people whose diagnoses have been made overseas, and people over 65 years of age.**

I do think that there needs to be clearer communication about where people fit in terms of funding. But there also should be some grace for people; so if, maybe if people fit in, and they have a disability; then their mental health funding goes under that entity, so that it's clearer, [...] it's more appropriate care for them. (People with Psychosocial Disability Focus Group)

That FASD is recognised as a disability. (No Support Focus Group)

That's my experience of support and having a chronic illness, rather than technically having a disability, limits my access to support services. (No Support Focus Group)

[W]hat does happen is that people at 65 can be shuffled into the health system, which is a lot less amenable to supporting [disabled] people. (No Support Focus Group).

5) **Needs assessments are timely, strengths- and human rights-based, and include flexible eligibility criteria.**

[I]t would look like them believing us when we told them what it was like for us. And then putting the support in place that we need. (Ministry of Education Focus Group)

6) **There is a greater investment in DSS so that disabled people can participate meaningfully in their communities and achieve their full potential. This includes matching the level of DSS funding to ACC funding.**

Disabled people could achieve so much more if our government didn't look on disabled people as a liability to try and spend the least they possibly can on. (Questionnaire Participant).

I'm sure that you know there's a huge discrepancy between ACC and Ministry of Health, and that in itself needs to be changed. (Individualised Funding Focus Group).

7) **DSS recognises the interrelated nature of disability and health. There is greater collaboration between agencies and service providers to ensure holistic care for disabled people.**

I said this funding should cross over because we would be saving money by helping people be able to do what they need to do. So I just get quite frustrated at the whole system - doesn't seem to be cohesive or work together. (Home and Community Support Focus Group)

8) **All people who are involved in DSS receive disabled person-led disability rights training, including government officials, service providers, connectors, assessors and support workers.**

[H]aving competent and very thoroughly trained people who are working in these spaces. And I think, like it would be great if the government can take a lead on educating themselves so that they can implement cultural change around especially medical providers, it's really important for the government to set that tone. (Women's Focus Group)

[S]ome sort of relational connection between those of us who have a disability, and staff. So that we can actually go back, and know that we're being cared for, to know that there's someone who's thinking about us. That we're not just another name on a page, or a number in their system. (People with Psychosocial Disability Focus Group)

9) **Disabled people (including those in residential care and other living situations) have greater choice and control over their supports and services. Supported decision-making is used to achieve greater choice and control over which provider they use, who their support people are, how they are supported, and how they use their funding, including respite funding.**

[W]hat happens when we give people the supports they need to thrive; we can be a participating member of society, we can achieve our goals, we can be contributing equal members to society, and support one another. (EGL Focus Group)

We don't need able-bodied people, or anyone else to tell us what we need; we know our own minds. And then, if there are people who don't know what they need, or don't know what they want, then they need supported decision making; not substituted decision making. (EGL Focus Group)

10) Disability support work is a career with secure hours, good wages and proper training that comes with a career progression pathway.

Those caring professions are so essential and so undervalued. It's often women that work in those professions. It's often not white women that work in those professions. [...] It would be really nice if those were appropriately valued and since we live in a capitalist society, valuing them would mean paying people properly. (LGBTQIA+ Focus Group)

11) DSS providers deliver culturally appropriate care, gender-appropriate care, and age-appropriate care.

[O]bviously most older people are disabled and most trans people have experiences of disability and neurodivergence and lots and lots of overlap but we keep coming up empty. There is just not enough going on in that space. There's not enough either training or resourcing or education or what have you. (LGBTQIA+ Focus Group)

[W]e need the services to be agile and adaptable to where they are at this time of their life. Understand the condition. Understand where you know, how their family dynamics are. Because having a 14 year old and a 21 year old is different to caring for a 57 year old you know. Different things. They just want to be normal, which is for their age group. So services need to allow that. Funding needs to understand that because you've got people that are sitting up there making all these decisions based on just them and not you know. So it's got to move with what suits the family. (Family, Whānau, and Carers Focus Group)

6 Kupu Whakamutaka / Concluding Remarks

> *But you know, I think that one of the big issues that's in New Zealand, is that we like to think that we're very good on human rights; and I think that the Royal Commission has shown very clearly that really, we've been in a lot of denial. And I think that people with disabilities are some, really the biggest group of people whose rights have been consistently denied; you know, as they said it was, has been a catastrophic failure for that group of people. (People with Psychosocial Disability Focus Group)*

This monitoring research has documented a wide range of concerns regarding Aotearoa New Zealand's disability supports and services system. Drawing on the experiences of those who the system exists to serve - disabled people and their families, whānau, aiga, and close supporters - over two years and more than 61 engagements with the disability community revealed a system that was (before March 2024), and continues to be (post March 2024), unfit for purpose.

Participants shared stories of a DSS system that is often inaccessible and difficult to navigate; that is reactive, inequitable, inflexible, inconsistent and insufficient; a system underpinned by the medical model and deficit approaches to disability; that has a significant skilled labour shortage; and a system that lacks cohesion and cross-agency collaboration. As a direct consequence of these inadequacies, disabled participants said they are unable to enjoy the fundamental freedoms and dignity afforded to them by the New Zealand Government's commitment to the UNCRPD.

While the disability community awaits the government's response to the independent inquiry into DSS, this monitoring research has provided insight into what happens when the voices, experiences and leadership of disabled people are absent from the design and delivery of DSS. As has been highlighted by participants, a genuine commitment to achieving the aspirations, vision and obligations contained within the New Zealand Disability Strategy, United Nations Convention on the Rights of Persons with Disabilities and Te Tiriti o Waitangi can only be achieved through

increased investment in DSS, greater choice and control over its design and delivery, and the leadership of disabled people. While this research has provided a comprehensive picture of the flaws of DSS, it has also provided a platform for solutions to grow and be nurtured. The knowledge, lived experience, and expertise held within the disability community are a taonga and should be treated as such. Only then will DSS be able to achieve its potential as a tool for promoting, upholding and celebrating the human rights of disabled people throughout Aotearoa New Zealand.

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