



**DONALD
BEASLEY**
INSTITUTE



Disabled Person-Led Monitoring of the UNCRPD

My Experiences, My Rights: Disability Supports and Services

**Report 1 - Whaikaha - Ministry of
Disabled People**

**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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Disclaimer: The Disabled People's Organisations Coalition has made every effort to ensure the information in this report is reliable but does not guarantee its accuracy and does not accept liability for any errors.

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.

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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 United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) come true in Aotearoa New Zealand. The DPO Coalition chose *supports and services* as the topic to be monitored. When DBI started this project, many big changes were happening in the disability sector. For example, Whaikaha - Ministry of Disabled People was established in 2022. However, some disability support services were restricted since March 2024 and the function of Whaikaha changed after an independent review in August 2024.

The following findings mostly come from interviews with leaders from the disability sector. These interviews happened between late 2022 (after the launch of the new Ministry) and mid-2023 (one-year after the launch of the new Ministry and after the general election). The findings highlight how participants felt about the structure of Whaikaha - Ministry of Disabled People and how it works / was working. Findings from focus groups and questionnaires completed by disabled people and their family, whānau, aiga and close supporters are also presented. They shared their frustrations, fears, hopes, and recommendations for the Ministry. These findings can be used to monitor the New Zealand Government's decisions about Whaikaha - Ministry of Disabled People and to show the New Zealand Government what the disability community would like to see happen with Whaikaha - Ministry of Disabled People.

Key Research Findings

Structure: Te Tiriti o Waitangi, the UNCRPD and Enabling Good Lives (EGL) principles are the foundation of Whaikaha - Ministry of Disabled People. However, participants felt that these foundations were not always respected. Participants said the partnership between tākata whaikaha Māori, disabled people and the Crown

were important. They recognised that tākata whaikaha Māori and disabled people must be resourced to be good partners - especially to make decisions and share power. They also said promoting and celebrating disability culture was important for the new Ministry's aim to "[l]ead a true partnership between the disability community, Māori and Government" (Whaikaha - Ministry of Disabled People, no date).

Operations and functions: Participants highlighted that the responsibilities of Whaikaha - Ministry of Disabled People must be in line with the vision and needs of the disability community. Participants were hopeful about Disability Supports and Services (DSS) being under the new Ministry. They also wanted DSS to be well-resourced and focused on achieving equity for disabled people. The differences in funding between ACC and DSS was seen as a challenge for the Ministry. The Ministry's role to coordinate disability response across government was seen as a way of improving attitudes towards disability. However, there were concerns that other Government agencies might not fulfill their responsibilities regarding disability issues by directing them to Whaikaha - Ministry of Disabled People. Participants were also excited about what is possible with EGL under the Ministry. They were confident it would overcome the challenge they face now with the changes and improve well-being and outcomes for disabled people and their whānau.

Whaikaha - Ministry of Disabled People: Frustration, worry and cautious optimism: The most common frustration was the lack of accessible information about what Whaikaha - Ministry of Disabled People does and what support it could offer disabled people and their whānau. Participants worried that a change in government would affect what the new Ministry does and how they do it, and that it might not follow through on its aims. Participants were also concerned that people with psychosocial disability and chronic health conditions were left out of the new Ministry's operations. Some participants said the Ministry did a good job for providing emergency response information and for responding to complaints. Participants also wanted the Ministry to be a strong advocate and voice for the disability community.

Recommendations

Disability sector leaders, disabled people and their family, whānau, aiga and close supporters shared their worries and frustrations about Whaikaha - Ministry of Disabled People. At the same time, many of them also supported the Ministry, with one questionnaire participant saying, “*Keep it going.*” Below are some of the hopes, dreams, and recommendations the participants had for the Ministry. Although the recommendations were made before all the changes to the Disability Support System and the Ministry took place, they provide clear guidance on what disabled people would like to see from any government ministry focused on representing disabled people’s interests, needs, and human rights.

According to monitoring participants, Whaikaha - Ministry of Disabled People:

- must be underpinned by the social and human rights models of disability, Te Tiriti o Waitangi, Enabling Good Lives principles, and advances the UNCRPD and concluding observations of the UNCRPD Committee.
- Makes sure there is commitment and accountability across government to the EGL approach, equity and disability rights.
- works in partnership with disability communities.
- has strong voice and leadership of tākata whaikaha and whānau hauā.
- helps build and bring together the disability community.
- changes society’s attitudes towards disability.
- strengthens policy and legislation to make sure equitable outcomes for disabled people, including between ACC and disability supports and services funded by other Ministries.
- includes people with psychosocial disability, chronic health conditions, and disabled people over 65-years of age.
- is properly funded and resourced.
- is staffed by people with diverse lived experiences of disability.
- is a “one-stop-shop” for disability information and support.
- Provides accessible and easy-to-find information about what it does and can offer disabled people and their family, whānau, aiga and close supporters.

2 Whakatakika / Introduction

Me he aka rātā ka tipu-tahi, ka puāwai-tahi kia tū kaha I ngā hihi ō Tamanuiterā.

Like the rātā vines constantly growing and flourishing together to stand strong in the warmth of the sun. - Whakataukī of Whaikaha - Ministry of Disabled People

In 2021, the New Zealand Government announced that a new ministry, Whaikaha - Ministry of Disabled People, would be established within the Ministry of Social Development (Ministry of Social Development, 2021). This news was welcomed and celebrated by many disabled people and their families, whānau, aiga, and close supporters.

The idea to establish a ministry solely dedicated to disability matters was not a new one - disability advocates had long campaigned for a stand-alone ministry separate from the Ministry of Health and the Ministry for Social Development. After three decades of advocacy, in 2018 the idea was considered by the Machinery of Government Group, which envisioned a dedicated disability ministry with three core functions:

- Hosting the funds and contracts for Disability Support Services (DSS);
- Overseeing policies related to disability across the government; and
- Community engagement (Ministry of Social Development, 2021).

The government then set an ambitious goal of launching the new Ministry in 2022, less than a year after announcing its intentions. As promised, Whaikaha - Ministry of Disabled People launched on 1 July 2022, tasked with:

- Leading partnership between the disability community, Māori and the Government; and
- Helping to transform the disability system to be in line with the Enabling Good Lives (EGL) approach (Whaikaha - Ministry of Disabled People, no date a¹).

Importantly, the new Ministry was established with a strong commitment to tākata whaikaha Māori and whānau hauā and disabled people, including meeting the

¹ Instead of using APA 7 style referencing (for example, “n.d.a”), for accessibility reasons “no date a” has been used here and throughout the rest of the report.

Government's obligations under Te Tiriti o Waitangi and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD); following the principles of EGL and Whānau Ora; supporting other government agencies to respond more effectively to the needs of disabled people; and delivering better services for disabled people (Whaikaha - Ministry of Disabled People, no date a). Touted as the world's first ministry of its kind, disabled people and their families, whānau, aiga and close supporters looked forward to ushering in a new era of disability support, services and advocacy.

This cycle of Disabled Person-Led monitoring of the UNCRPD in Aotearoa New Zealand took place amongst these historical developments. In 2021, the Donald Beasley Institute (DBI) was contracted by the Disabled People's Organisations Coalition (DPO Coalition) to conduct a cycle of monitoring on the progressive realisation of disabled people's human rights with respect to supports and services. The DPO Coalition intentionally selected this topic in response to the concerns and priorities of participants who contributed to previous monitoring cycles. For example, in 2019, disabled people's right to adequate housing was monitored (Article 28 of the UNCRPD) (Donald Beasley Institute, 2020). During this monitoring cycle, disabled people linked housing to health and wellbeing, which was then selected as the next cycle of monitoring (Article 25 of the UNCRPD) (Donald Beasley Institute, 2022). From health and wellbeing, disabled people talked about the importance of supports and services. However, when supports and services were selected for monitoring, the DPO Coalition and DBI monitors did not expect the changes in the disability sector - the establishment of Whaikaha - Ministry of Disabled People in 2022 nor its subsequent reduction in functions following an independent review in 2024. The monitoring team adapted the design of the project so that these changes were captured.

This report details the perspectives of disability sector leaders, disabled people and their family, whānau, aiga and close supporters in relation to Whaikaha - Ministry of Disabled People. It is important to note that all data and evidence were collected *before* the independent review process took place in 2024. While compiling this final report, the New Zealand Government announced changes to Purchasing Guidelines (Whaikaha, no date b) and that it was no longer financially sustainable for Whaikaha

- Ministry of Disabled People to deliver Disability Supports and Services; therefore, these functions would transition to the Ministry of Social Development from October 2024. Whaikaha - Ministry of Disabled People would also no longer operate from within the Ministry of Social Development but as an independent Ministry with reduced capacity and functions (Minister for Disability Issues, 2024).

With this context in mind, this report draws on participant responses to both monitor the New Zealand Government's decision-making processes regarding Whaikaha - Ministry of Disabled People and to inform the government about what disabled people and their families, whānau, aiga and close supporters envisioned for a ministry dedicated to disability matters. The data and evidence included in this report are important and timely due to the absence of government consultation with disabled people and their families, whānau, aiga and close supporters, regarding the changes to: Purchasing Guidelines; Whaikaha - Ministry of Disabled People; application of the Enabling Good Lives approach; and Disability Supports and Services. This report begins with a summary of the methodology used in this monitoring cycle, followed by findings and recommendations.²

² This report is the first of four detailing the monitoring findings on: Whaikaha - Ministry of Disabled People; consultation; disability supports and services; and Enabling Good Lives. A full report, inclusive of all four reports, as well as further details regarding the methodology and summary of recommendations will be made available in 2025.

3 Te Aramahi / Methodology³

This monitoring research utilised the Disability Rights Promotion International (DRPI) methodology, whereby data was collected from 219 participants across three key phases:

- Phase one: Interviews with disability sector leaders
- Phase two: Focus groups
- Phase three: Nation-wide 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 involved 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 interviewed twice between August 2022 and October 2023. Leaders identified as having a wide range of genders, ethnicities, ages and disability backgrounds. Some of the 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 with specific cohorts of disabled people and their family, whānau, aiga and close supporters. Focus groups 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. To ensure that people known to experience challenges in accessing supports and services were included in this research, the monitoring team also conducted a series of targeted focus groups with harder to reach and intersectional populations. Each focus group consisted of two to six participants and were organised according to the support they received, disability type, or intersecting identity, including:

- ACC (Māori 75%, Pākehā 25%; disabled people 75%, whānau 25%)
- Individualised Funding (IF) (Pākehā 100%; disabled people 100%)

³ For full details of the methodology and methods used in this monitoring cycle, please refer to the full report (available 2025).

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

- Personal budgets based on Enabling Good Lives principles (EGL pilots) (Pākehā 100%; disabled people 100%)
- Home and Community Support Services (Pākehā 75%, Māori 25%; disabled people 100%)
- Te Whatu Ora (formerly DHBs) (Pākehā 75%, Asian 25%; disabled people 100%)
- Māori (Tākata whaikaha and whānau hauā Māori 100%)
- Pacifica (Pacific 100%; tagata sa'ilimalo 100%)
- Migrants and refugees (Asian 100%; disabled people 100%)
- LGBTQIA+ (Pākehā 100%; disabled people 100%)
- Women (Pākehā 50%, Pacific 50; disabled people 100%)
- People living in group homes and people with learning disabilities (Pākehā 80%, Asian 20%; disabled people 100%)
- People with psychosocial disabilities (mental health) (Pākehā 100%; disabled people 100%)
- Ministry of Education supports and parents of disabled children (Parents of a disabled child 50%, disabled people 50; Pākehā 75%, Māori 25%)
- Family, whānau, aiga and close supporters of people with multiple and complex disabilities (Māori 40%, Pacific 20%, Asian 20%, Pākehā 20%; family, whānau and aiga 100%)
- D/deaf people (Pākehā 66.6%, Māori 16.6%, Pacific 16.6%; Deaf 100%)
- People with no access to supports or services (Pākehā 70%, Māori 20%, other 10%; disabled people 80%, wānau and close supporters 20%)

In total, 29 interviews/focus groups⁵ involving 82 participants were conducted between April 2023 and March 2024. This phase of data collection had the purpose of exploring disabled people's access to supports and services under Article 9, 19, and 21⁶ of the UNCRPD, and following their experiences of DSS, the establishment of Whaikaha - Ministry of Disabled People, and EGL.

⁵ If a person indicated they preferred individual interviews for accessibility reasons, this was arranged.

⁶ 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.

Phase Three: Nation-wide questionnaire

The third phase of this monitoring research consisted of a DRPI monitoring questionnaire. The questionnaire enabled greater range and number of disabled people and family, whānau, aiga and close supporters to share their experiences of supports and services, and their reflections 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 participants chose not to disclose their gender. Nineteen participants were aged between 18 - 30, 77 participants between 31 - 64, and 22 participants were older than 65 years. 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 '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 disability⁷.

⁷ The total equates to more than 121 as participants often registered multiple identities.

4 Kiteka / Findings

Throughout the different phases of data collection, disabled people and their families, whānau, aiga and close supporters shared their perspectives on the establishment of Whaikaha - Ministry of Disabled People and wider implementation of Enabling Good Lives (EGL). They also reflected on how a fit-for-purpose disability supports and services system (DSS) could and should be delivered. The findings have been drawn from two sets of data:

- Interviews with disabled people in leadership positions, conducted between late 2022 (following the launch of the new Ministry) and mid-2023 (one-year post-launch and post-general election) concerning the structure and operations of Whaikaha - Ministry of Disabled People.
- Participant responses from the focus groups and questionnaire are also presented to provide insight into the frustrations and fears disabled people, family, whānau, aiga and close supporters held about the new Ministry, as well as their hopes, aspirations and recommendations for its future.

4.1 Structure

The first collection of findings relates to the perspectives of disability sector leaders on the overall structure of Whaikaha - Ministry of Disabled People. Disability sector leaders held strong views about what they wanted and expected when it came to developing a ministry dedicated to disability matters that, as a duty bearer,⁸ would ultimately be responsible for upholding and implementing disabled people's human rights across all government agencies. When discussing the establishment of the structure of Whaikaha - Ministry of Disabled People, disability sector leaders typically focused on the role of Te Tiriti o Waitangi, the UNCPRD, governance and leadership, and disability culture.

⁸ Individuals and/or parties that have a responsibility to respect, uphold, and promote relevant human rights (Inter-agency Network for Education in Emergencies, no date).

4.1.1 Te Tiriti o Waitangi

As articulated on its website, one of the primary aims of Whaikaha - Ministry of Disabled People is to partner with disabled people and Māori, by meeting obligations under Te Tiriti o Waitangi (Whaikaha - Ministry of Disabled People, no date a). During interviews with leaders from the disability sector, there was some acknowledgement of the efforts that had been made by the new Ministry to embed Te Tiriti o Waitangi in the fabric of the organisation:

[M]y understanding is that there has been quite a lot of work done around the concept of partnership in the context of Te Tiriti and kind of what that means and kind of informing how Whaikaha works with particularly tāngata whaikaha Māori and there has been a very, like, intentional and specific focus on that. (Disability Sector Leader 05-02)

However, there were concerns that this commitment had not been characterised by authentic partnership with tākata whaikaha and whānau hauā Māori:

I'm not aware that Whaikaha has carried anything forward, other than the bare minimum you would expect from a ministry. I'm not aware they've actually considered Te Tiriti-based partnership with tāngata whaikaha Māori. My opinion is, it doesn't exist. (Disability Sector Leader 09-02)

Reflecting on the implementation of Te Tiriti o Waitangi within the structure of Whaikaha - Ministry of Disabled People, another leader shared:

I'm quite disappointed and a bit surprised with the whole lack of knowledge and it also seems like, lack of appetite too, to have that kind of Te Tiriti leadership and really underpinning everything that they do. (Disability Sector Leader 04-01)

Concerns specifically relating to kaimahi Māori (Māori staff) working for the new Ministry were also expressed:

There are a few Māori staff working in Whaikaha, but they get frustrated because they are the minority and they get told how things should be. So a lot of Pākehā people are telling Māori people how they

should operate. And Māori people are frustrated by that and push back on that really, they say we don't want to be told what to do. And so it's trying to change the system so that it can work for Māori people, but the Māori staff are a minority, so they do what they can, but they are overridden by the majority in these organisations. (Disability Sector Leader 14-02)

By the second engagement⁹ with disability sector leaders there was growing concern about the negative impact the new Coalition Government's approach to Te Tiriti o Waitangi and Māori-Crown relations could have on the new Ministry's relationship with tākata whaikaha Māori and whānau hauā:

I think probably the most concerning changes is the change of government and the implications of that, particularly for Māori. The notion of doing away with mentions of the Treaty in legislation is a giant leap backwards and is causing a great deal of harm to people in the sector, who have been fighting for a long time and were really starting to see the light. [...] You know, that approach to dealing with the Treaty issues by essentially not dealing with them is, in my view, racist. And that, therefore, makes me wonder; if they're prepared to be overtly racist, what are they going to be like when it comes to ableism and disablism? So it's a very disheartening turn of events, and the way that the Coalition is functioning is disturbing in a democratic sense. (Disability Sector Leader 06-02)

As summarised by another disability sector leader:

I think, if we're rating it out of ten, the Treaty of Waitangi in Whaikaha takes about a four out of [ten]... Because if they're really committed to the Treaty of Waitangi, there'll be a partnership of disabled Māori. But that's not there. (Disability Sector Leader 02-02)

⁹ Approximately one year post-launch of the new Ministry and following the 2023 general elections.

4.1.2 United Nations Convention on the Rights of Persons with Disabilities

Obligations held as a signatory to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) are also asserted as a key focus of Whaikaha - Ministry of Disabled People on their website (Whaikaha, no date a). Therefore, disability sector leaders were also asked to reflect on the extent to which the New Zealand Government upheld Article 4.1.c of the UNCRPD during the establishment of Whaikaha - Ministry of Disabled People, which obligates the Government to: “take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes,” as well as Article 4.3, which states:

[I]n the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations (United Nations, 2006).

A small number of disability sector leaders thought the Government upheld aspects of these Articles, but only when it was beneficial and convenient to them. However, more than half of the disability sector leaders said they believed the Government was not yet fulfilling their obligations under these Articles, particularly in relation to the establishment of Whaikaha - Ministry of Disabled People. One reason for this was the exclusion of the wider community from opportunities to engage in Government processes - an exclusion felt most strongly by people from intersectional communities and harder to reach populations. This was despite the efforts made by disability advocacy groups such as the ‘Mana, Self-determination and Voice group’, which was developed as part of the new Ministry’s establishment process (Machinery of Government Review, 2018):

So everyone, depending on your impairment, brings a different strength to the collective view, you know, people with a learning disability have a different view than D/deaf or to say, like, we all have different cultural backgrounds too. So, and tāngata whaikaha Māori, or and Pacific disabled people, they bring other flavours to the conversations and the

way we work and all that sort of not woven together, but sort of foundational to the way we work together. (Disability Sector Leader 11-02)

Another disability sector leader also highlighted the value of disabled people's voices and expertise but felt that this was not recognised or prioritised by Government:

So without that implementation of Article 4.3, being done to a high level, where people can get upskilled to be able to participate really effectively and get the cut through that's needed. And when you combine that with the watering down of their voice in those other groups that have to arrive at decision by consensus, a lot of the time, and even then, they're often advisory groups rather than decision-making groups. So, from that perspective, I'd have to say that Article 4.1 isn't being greatly upheld, because of those limitations that exist there. So I go back to what I said first 'better than ever' - that's still better than it ever has been, but there's plenty of room for improvement. (Disability Sector Leader 06-02)

For example, the disability sector leader quoted above shared a commonly held view that when interacting with government officials, it was clear that officials were often surprised by the level of knowledge held by disabled people. Even so, disabled people were regularly relegated to 'advisory groups' that had no decision-making power. This led to a general agreement amongst disability sector leaders that Articles 4.1.c and 4.3 were not being effectively implemented by the Government on a consistent basis. This disability sector leader recognised the need for Government to build the capacity and capability of disabled people, as part of its commitment to the UNCRPD, asserting:

The big missing piece really here is in Article 4.3, the lack of implementation of General Comment No.7,¹⁰ where there's a lot more scope for disabled people's organisations to be supported, and for disabled people, generally, to have access to capacity building and

¹⁰ General comment No.7 refers to the gap between a Government's commitment to, and enacting of, Article 4.3 and 33.3 of the UNCRPD (United Nations Human Rights Office of the High Commissioner, 2018).

capability building to participate effectively. (Disability Sector Leader 06-02)

A different disability sector leader also felt that the UNCRPD was not being upheld (particularly Articles 4.1.c and 4.3) because New Zealand legislation and policies had not been updated to align with the UNCRPD. They said the underlying factor for this was a lack of motivation to review and harmonise domestic laws with international human rights laws obligations,¹¹ which would require wide consultation with diverse disability communities:

[W]hen it first incorporated the UNCRPD we had about 187 pieces of law out of sync with it, not a lot of them have actually been brought into compliance [...] In fact, they are reluctant to even bring that into line with the human rights laws so the Government does what it wants to do.
(Disability Sector Leader 10-01)

4.1.3 Governance and leadership

The second sub-theme discussed in relation to the structure of Whaikaha - Ministry of Disabled People concerned governance and leadership. As stated on its website, Whaikaha - Ministry of Disabled People's aims to "[l]ead a true partnership between the disability community, Māori and Government" (Whaikaha - Ministry of Disabled People, no date a). Disability sector leaders highlighted that in order for this aim to be realised, the Government needed to further consider how it shares power and decision-making control with disabled people. This desire for a shift in power and control was an important point made by all of the disability sector leaders who were interviewed, and represented a move away from traditional approaches to power sharing and decision-making, to an approach more closely aligned with Te Tiriti o Waitangi and the UNCRPD. In order for this shift to occur, disability sector leaders talked about the importance of robust induction processes to ensure officials recruited to work for the new Ministry were appropriately educated about power sharing and decision-making. Regular monitoring by disabled people themselves was considered as being necessary to ensure that officials were held accountable to disabled people's vision for Whaikaha - Ministry of Disabled People:

¹¹ Such as the Protection of Personal and Property Rights Act 1988 and Immigration Act 2009.

[S]ome of the staff come across from the Ministry of Health and of course, [they had to] change mindsets and attitudes, that's been ingrained. And working in public service doesn't just switch over like that when you get a new title, under a new ministry, under a new CEO. So we put in a lot of work in the establishment phase to lay the foundation in terms of Te Tiriti, we wanted that partnership to be adopted, you know, taken on board in a positive way [...] that hasn't happened as quickly as we wanted. And it's been a lot of advocacy, reminding what our role is as kaitiaki. (Disability Sector Leader 13-02)

[M]onitoring is a massive part of this mahi, I mean how do we keep on track to make sure that what we are doing is right and it needs to evolve in ways that still keeps the foundational EGL approach and principle while upholding Te Tiriti and the human rights United Nations all of that stuff? So they are our foundational building blocks, so I guess we need to monitor against that. (Disability Sector Leader 16-01)

While there was a sense of excitement about the potential shift of power and control, disability sector leaders also recognised it would be one of the new Ministry's greatest challenges. For example, disability sector leaders regularly referred to the Establishment Unit, which was tasked with transitioning DSS from the Ministry of Health to Whaikaha - Ministry of Disabled People. However, they considered this transition to only be material and logistical. There were already concerns that the Unit did not have the mandate, capability or capacity to change the structure and culture of the former system and approach to supports and services that existed under the Ministry of Health. As a result, disability sector leaders felt that the new Ministry had simply inherited a structure and culture that disabled people did not want or need, and had hoped to leave behind:

[A]t the moment we have got a lot of surface-level change, disabled people being more welcome into different spaces at Government, disabled people having a voice, a limited voice, but the structure is the same and I think until we change the structure, which includes the procurement processes, includes the time-frames, includes the way

that we engage, until we change all of those things I think we will still be sort of in the same place or still sort of fighting the same fight.
(Disability Sector Leader 01-01)

Disability sector leaders acknowledged that the work to develop a structure and culture within the new Ministry was still in its infancy. For example, they commented that due to existing employment contracts, many officials from the Ministry of Health had been transferred to the new Ministry. While this provided the necessary capacity, many disability sector leaders expressed concern that transplanting public servants without sufficient disability training and knowledge would ultimately hinder the power shift that needed to occur. While some officials were supportive of the shift, others actively resisted it:

[I]t's been quite challenging for Whaikaha to stand an agency up and get the staff they needed. So we had people moving across from Ministry of Health, MSD, you know, from the agencies, because they were entitled to retain their employment. And then there's been the process, I guess, of establishing a culture and a way of working within Whaikaha. (Disability Sector Leader 11-02)

[Y]ou want officials who are willing to change their mindset and see they had to be part of the transformation, not be part of the business as usual operating in the old paradigm and they have to go in and be open for co-designing with disabled people who are, you know, who are motivated and wanting to be part of the solution. So they had to be open to learning and not being, say, they don't have all the answers clearly, that's why things have to change so they had to have a different way of sharing power. (Disability Sector Leader 13-01)

Disability equity was another significant theme within the interviews. Disability sector leaders noted that an equitable approach to power sharing would result in greater support for disabled people and their family, whānau, aiga and close supporters to be included in decision-making processes. Even during the establishment of Whaikaha - Ministry of Disabled People, disability sector leaders felt they had to fight for disabled people to be at, and remain at, the decision-making table:

[I]t's quite funny because the old ministry people [officials from MoH] tried very hard to stop us actually being the governance team, they kept trying to cut the Terms of Reference from us so we've had to really push and fight to have deemed to be valuable enough to be heard and that's been hard, they have tried to undermine us all the way but we have stood our ground. (Disability Sector Leader 10-01)

The need for collective perspectives to inform policy and practice was also identified by disability sector leaders. At the same time, this was not always possible because of the way traditional engagement with the government is structured. One disability leader raised this as a challenge relating to power and control, and governance and leadership:

We're very strict about the fact that no one person carries a single view forward. We operate very strictly as a collective. What happened in that meeting is I was essentially unable to provide advice because they did not allow my colleagues to view the paper. So I felt very marginalised in that process. Like, I read the paper line for line, word for word, I knew everything that was in it - couldn't tell anybody about it - those were the terms that Minister [name removed] set. So I felt devastated. (Disability Sector Leader 09-02)

Disability sector leaders reported an additional tension created by an awareness that their attempts to bring their communities on the journey of the establishment of the new Ministry was occurring while the Government was simultaneously making decisions that were not aligned with the direction disabled people wanted to be moving in:

I feel like that puts our leadership in a really difficult, a rock in a hard place, because on one hand you are building positive relationship with the decision-makers at the government level, and on the other you are representing your grassroots community and you are actually part of that community. So you know how do you balance that? (Disability Sector Leader 16-01)

Some disability sector leaders said they had already felt compelled to push back against officials working in the new Ministry. This included advocating for fairer

reimbursement for their work; regularly reminding officials of their obligations under Te Tiriti o Waitangi; and reminding the Ministry of their responsibility to provide accurate, timely and accessible information:

I've always thought that if we were brought in as consultants, we would be getting a lot more rather than just being remunerated for our time. They are kind of quite different and that hasn't really changed. And also, you know, the process kind of hasn't been, you know, very easy to use.
(Disability Sector Leader 04-02)

Further analysis of the experiences reported by disability sector leaders suggests the continued subjugation of disabled people's knowledge, expertise and needs, with the Government's systems, processes, and attitudes taking precedence. This can be evidenced as ableism whereby systems and processes favour people with certain characteristics and who work in certain ways - in this case, people with bureaucratic experience and expertise was prioritised over disability expertise and lived experience; non-Māori expertise over Māori expertise; and people who do not need disability accommodations over people who need accommodations. Despite these challenges, disability sector leaders continued to hold fast to the ideology of 'nothing about us, without us' as being key to the new Ministry's success:

We need to get away from a place where officials and providers are making decisions about us. We need [disabled] people driving that and being in control of that. I see a world where in the future there are disabled people-led support organisations. Why not? That would be super cool and a lot more empathy around and I look forward to that.
(Disability Sector Leader 09-01)

4.1.3.1 Tripartite partnership

When discussing power and control within governance and leadership, leaders frequently referred to a model they believed had great potential within the context of Whaikaha - Ministry of Disabled People - the tripartite partnership. Having been many years in the making ("too many years" according to one leader), the tripartite partnership was conceptualised as a framework that could facilitate an authentic relationship between tākata whaikaha Māori and whānau hauā, disabled people, and

the Government. The model embodies both Te Tiriti o Waitangi and the UNCRPD by ensuring the Government is in active partnership with tākata whaikaha Māori and whānau hauā and disabled people.

Tripartite is a great mechanism for ensuring the voices of disabled people, Māori and the crown are in one place. (Disability Sector Leader 09-01)

Despite feeling positive about the potential of the tripartite partnership, disability sector leaders expressed frustration and concern about officials' lack of understanding of, and respect for, Te Tiriti o Waitangi, and tākata whaikaha Māori and whānau hauā. Leaders were especially mindful that Te Tiriti o Waitangi needed to be intentionally embedded within the structure of the new Ministry from the outset, rather than progressively implemented over time:

[T]here were lots of gaps but I have to say also, disappointingly, there was just lack of knowledge and competence around Te Tiriti and it really showed as time went on. In fact, I was still a bit concerned about that and also within the disability context. (Disability Sector Leader 04-01)

Authentic implementation of Te Tiriti o Waitangi is essential for any Government agency working with disabled people. Throughout the monitoring research tākata whaikaha Māori and whānau hauā participants repeatedly indicated they identified as Māori first, and as a disabled person second. While this perspective was not always reflected in how Te Tiriti o Waitangi was understood and implemented by officials, the tripartite partnership was consistently reported as being critical to honouring the experiences and expertise of tākata whaikaha Māori and whānau hauā. While the tripartite model is still in its infancy, it was celebrated as a significant step towards realising true partnership between tākata whaikaha Māori and whānau hauā, disabled people, and the Government:

We have a really robust insights alliance that's a true tripartite partnership so all the data and the monitoring that's done is a tripartite view, sense making of it and that really influences the direction of the

Ministry and also drives cross agency change. (Disability Sector Leader 11-01)

In summary, disability sector leaders highlighted the importance of the new Ministry's leadership structure, the potential of the tripartite model, and its commitment to a new way of doing things under the guidance of Te Tiriti o Waitangi and the UNCRPD. However, as the establishment process progressed, entrenched power dynamics within the existing machinery of government were observed and experienced, highlighting how true partnership is not possible while one party (the Government) holds power over the other (tākata whaikaha Māori and whānau hauā, and disabled people).

4.1.4 Disability culture

The next key theme regarding the structure of Whaikaha - Ministry of Disabled People was 'disability culture', a term used by disability sector leaders to refer to ways of working, ways of relating to each other, and ways of understanding disability. Research shows that globally, governments struggle to work effectively and respectfully with disabled people and their family, whānau, aiga and close supporters (Löve et al., 2017; Priestley, et al., 2016; Prince, 2009). While efforts to include disabled people in decision-making processes during the establishment of the new Ministry were acknowledged, disability sector leaders also said more work was needed to realise true partnership between disabled people and the Government. They pointed to the culture of the Government as being a main barrier:

I think for me, having the new Ministry also meant that, for things to change, there really needed to be a cultural shift, not just the shift in systems. (Disability Sector Leader 04 - 01)

Regarding this "cultural shift," disability sector leaders referred to the importance of acknowledging the existence of ableism¹² and disablism¹³ within Government (attitudes, systems, policies, and processes), and the impact this had on their

¹² Ableism: The system of assigning value to people's bodies and minds based on societally constructed ideas of normality, productivity, desirability, intelligence, excellence, and fitness (Lewis, 2022).

¹³ Disablism: "Discriminatory, oppressive or abusive behaviour arising from the belief that disabled people are inferior to others" (Miller et al., 2004, p. 9).

relationships with disabled people. For example, disability sector leaders recalled instances where officials who had negative perceptions of disability felt they were justified in asserting power over disabled people. The leaders also talked about needing to be “stropky” at times, in order to be heard.

Conversely, understanding and celebrating disability as a culture was suggested as being central to “do[ing] things differently than other ministries” (Whaikaha - Ministry of Disabled People, no date a). According to Brown (2002), disability culture is about taking pride in being disabled, and it includes recognition of disability history (Brown, 2002), crip-time (Kuppers, 2014), and the shared experience of having bodies and minds that function differently from non-disabled people (Barnes & Mercer, 2001). For example, crip-time refers to the extra time disabled people sometimes need to do things (Kuppers, 2014), which is an important consideration for equity and disabled people’s participation:

We operate on disabled time and disabled time is quite different to able-bodied time. (Disability Sector Leader 07-01)

[T]hen they have this question and this desire and intention to be disability inclusive at a Government level, but the timeframes they put around the projects are never long enough to actually be disability inclusive because what they are not realising is that reaching, communicating and ensuring the participation of disabled people takes way longer, so I think the Government has this idea of things being done and done now, but that’s never really going to foster the participation of our community. (Disability Sector Leader 01-01)

Disability sector leaders also referred to the importance of moving from disability being conceptualised as a deficit, to a strength-based approach. This was identified as a key factor in cultivating a collective disability culture:

[O]vertime developed into a community where disabled people across the board, like pan-disability, were connecting through, you know, strengths and abilities and also you know through having things in

*common including disability and really building their disability identity.
(Disability Sector Leader 04-01)*

In order to reframe disability as a culture, disability sector leaders consistently highlighted the need for building community and connection between disabled people. They also highlighted that if disability is intentionally valued, then disabled people can be their full and unapologetic selves:

[W]e see disability as something of value and so when we create things that are accessible, not only does it mean that disabled people can enter them or be present in them, it also means that they can be themselves in those spaces. (Disability Sector Leader 01-01)

4.2 Operations and functions

The second group of key findings relate to the operations and functions of Whaikaha - Ministry of Disabled People. Not only was it important for the structure of the new Ministry to be aligned with the vision of the disability community, but it also needed to fulfil its operational responsibilities. These findings have been grouped according to the three core functions of Whaikaha - Ministry of Disabled People as identified in the independent review (Weavers et al., 2024). While findings related to Disability Supports and Services (DSS) and EGL will be explored in greater detail in forthcoming reports, outlined below are summaries of findings related to the core functions of Whaikaha - Ministry of Disabled People.

4.2.1 Disability Supports and Services (DSS)

Prior to the launch of Whaikaha - Ministry of Disabled People, the Disability Support Services system (DSS) was administered by a directorate within the Ministry of Health. Following many years of campaigning and advocacy by disabled people, in 2022 DSS transitioned to Whaikaha - Ministry of Disabled People, with the intention of implementing the Enabling Good Lives approach across all disability matters - including DSS. Leaders from the disability sector celebrated this transition, with one stating:

If you go back to 1993, the National government at the time was trying to do something where disability support funding was going to be

transferred to the Ministry of Health or it was going to stay in what was called the Government Department of Social Welfare. [...] [O]ver the last two decades some of us have been pushing against the idea of keeping DSS at the Ministry of Health and [advocated for] taking it somewhere else. I'm happy that we've got a new Ministry, I don't think we've got a new system though. I think that it's going to take a little while for what we could perceive to be truly transformative. (Disability Sector Leader 03-01)

Again, equity was a key feature of the interviews with disability sector leaders who highlighted the inequities experienced by many disabled people in Aotearoa New Zealand. They hoped that with DSS being delivered by Whaikaha - Ministry of Disabled People, together with greater investment in the DSS system, the gap between resourcing and disabled people's needs would improve. While disability supports and services will be discussed in greater depth in a forthcoming report, it is clear that disability sector leaders, as well as other participants, felt a great sense of hope and optimism about DSS finding its home in Whaikaha - Ministry of Disabled People:

I would like to hope that yeah, it's [DSS] kind of resourced enough, to actually be able to progress some really substantive work programs, and, there's enough kind of funding given to those work programs to actually start shifting outcomes for disabled people. And a recognition that because most disabled people are starting from a really low base that there is a level of investment that matches that. So it's not just comparative to other government departments, but it takes into account all the compounding and like, long-standing barriers that disability communities face, and matches that with the level of investment. (Disability Sector Leader 05-01)

Another aspiration shared by leaders was that the inequity of disability support provision between ACC and Whaikaha - Ministry of Disabled People would be addressed, and that the new Ministry would provide a level of support that matched the support provided by ACC:

I would say bridging that gap between ACC and Ministry, that would be the ultimate dream if we were able to get the support that ACC clients get, that would be a dream come true. And then, once they sort out housing issues, be sweet. But that would be the dream for me is just closing that gap between ACC and the Ministry. (Disability Sector Leader 15-01)

When thinking about the potential of DSS under Whaikaha - Ministry of Disabled People, and the new and improved ways of support being provided to disabled people, one disability sector leader reflected:

[T]he chance of having a good life, the potential was there [...] You know, so, the system is set up in which we can flourish rather than exist. (Disability Sector Leader 07-01)

4.2.2 Cross-Government coordination

On establishment, a second key function of Whaikaha - Ministry of Disabled People was to support other Government agencies to respond more effectively to the needs of disabled people in areas such as employment, education, health and wellbeing:

“Over time, Whaikaha will facilitate more cross-government work in partnership with disabled people to remove barriers for disabled people” (Whaikaha - Ministry of Disabled People, no date a). This mandate recognises that disability exists within every government jurisdiction. For example, the aim was for the Enabling Good Lives approach to be progressively applied across all of the Government’s work, guided by Whaikaha - Ministry of Disabled People. Recognising the challenges and inequitable realities experienced by disabled people, one leader shared that they hoped the new Ministry would contribute to the shift in negative attitudes about disability:

[T]he ambition would change the paradigm about disabled people and what we knew as a society. And I thought that Whaikaha could contribute to the thinking. (Disability Sector Leader 03-01)

However, disability sector leaders shared the concern that other Government agencies might avoid their responsibilities by directing all disability issues and

matters to the new Ministry, rather than working to improve their own capacity and capabilities to respond to disability in an way that was aligned with EGL:

And it will take a while for Whaikaha to get completely across Government buy-in and for different ministries and departments to develop their own response to the EGL principles, to the eight principles. And they won't come running to Whaikaha and say, "Oh we don't understand this about disability, help us, help us, do it for us." You know, they'll start to take responsibility to develop their disability response and in the process you start to chip away at that disabling society, that kind of thinking which is in that department at the moment. (Disability Sector Leader 07-02)

I hope that it [Whaikaha - Ministry of Disabled People] lives up to the rhetoric and the expectation that it would be an influencer of other government agencies to be fully inclusive and uphold the Convention rather than becoming the default go to solution that other organisations point to and say, "Well, not our problem, go over there." (Disability Sector Leader 06-01)

4.2.3 National implementation of the Enabling Good Lives approach

Though still early in its implementation, on establishment Whaikaha - Ministry of Disabled People was tasked with the national implementation of the Enabling Good Lives approach:

The EGL approach is a foundation and framework to guide positive change for disabled people, tāngata whaikaha Māori, whānau, families, communities and governance structures. The aim is to shift authority from 'the system' to regarding disabled people and their families as experts in their own lives, and leaders in their lives and communities (Whaikaha - Ministry of Disabled People, no date c).

As such, Enabling Good Lives envisions a disability support system whereby disabled people have greater choice and control over their supports and lives:

Expanding the EGL approach involves transforming the way disability support is provided by Whaikaha and across the wider government systems. Whaikaha has a mandate to work with other government agencies to transform the services and supports they provide in order to align with the principles of EGL. Transformation of the system alone does not result in the EGL vision and principles being realised, but it will make it easier for disabled people, tāngata whaikaha Māori and whānau to build good lives of their own (Whaikaha - Ministry of Disabled People, no date c).

When asked about this vision, disability sector leaders reflected on the decades of Systems Transformation community consultations they had led and participated in, which preceded the development of the Enabling Good Lives approach:

[S]lowly start building up all the networks and then the whole thing can't go backwards anymore because the whole community is sort of linked, pushing forward to the next stage and that's my hope of what will happen. Because I think the worst thing that could happen is if there's entrenchment and not a generosity between us as a community to scaffold and lift others up. Because if we don't do that we are not going to get that change we need to see. (Disability Sector Leader 11-01)

Disability sector leaders also shared a sense of excitement about the new Ministry's aim of expanding EGL, even beyond DSS:

[T]he EGL approach is a hell of a lot more than the EGL principals. And EGL is a hell of a lot more than the Systems Transformation. EGL, the main part of EGL is about transforming all NZ into a non-disabling society and we start with the Systems Transformation because you've got to get people on the road in a really non-disabling way for them to become activists and making a non-disabled Aotearoa NZ. (Disability Sector Leader 07-01)

While concerns about the uptake of the EGL approach by supports and services and the wider government remained, and with the knowledge that transformational change would be slow, disability sector leaders were quietly confident that EGL would stand the test of time:

[W]e haven't been able to take everybody on a journey because EGL hasn't been socialised as much as it could be, and we talk about the roll out of EGL, I'm thinking that the longer you push, the longer the system responds to EGL. I've been fascinated by the bit, we're not even talking about what we do now to get EGL into our community, which doesn't include the allocation of resources. A simple example is what should organisations do to make their services mana-enhancing for disabled people, that kind of stuff. Because if we wait for the rollout there is going to be some people who might not know what this is for another 20 years. (Disability Sector Leader 03-01)

As summarised by one disability sector leader:

[I]f they lived EGL it would be a really different world with disabled people and their whānau, because disabled people and their whānau would decide what's important to them and the system could support them more. (Disability Sector Leader 03-02)

4.3 Whaikaha - Ministry of Disabled People: Frustration, fear and cautious optimism

The final set of findings draw on the interviews with disability sector leaders, focus group participants, and questionnaire responses, and detail the frustrations and fears of disabled people and their family, whānau, aiga and close supporters regarding the establishment of Whaikaha - Ministry of Disabled People, as well as their feelings of cautious optimism.

4.3.1 Frustrations

One of the most consistently shared frustrations throughout this monitoring cycle was the lack of available and accessible information about what Whaikaha - Ministry of Disabled People does, and what support the new Ministry could offer. For example, more than half of the questionnaire participants indicated they knew nothing about the new Ministry, knew a little bit (but not enough), or wanted more information:

I have visited their website & looked at info about IF Funding & found it accessible but still don't know what else is available to me for support. (Questionnaire)

While the establishment of the new Ministry had given many people hope, there was evidence that this hope was dissipating as time went on, with participants realising that change would be much slower than they had originally expected:

I was sort of, you know, quite happy to see it change to start with. But now a year in you sort of think, well you know, what is actually happening? (Ministry of Education Focus Group 01¹⁴)

What have they actually done other than stand themselves up, create a name, create all these hopes? Like, I feel let down. (Family, Whānau and Close Supporter Focus Group 01)

Other participants noted there was a lot of talk and expenditure, but very little tangible impact in disabled people's lives:

[I]t's a whole load of managers talking about what we can do, what we're thinking of doing, and discussing, discussing, discussing. When it's the people on the ground that really need the support and the help and the money needs to go there, as well. But I think, I wish it'd been sorted out a bit better before they, sort of, made the fan fair about it existing. It seems like nothing really was in place, besides the name. It's like, "Woohoo! Ministry for Disabled People, now what?" (No Access to Support Focus Group 01)

As one disability sector leader explained:

You can't just make things happen overnight because you've got to change various bits of legislation which allow you to make those changes happen and it's a slow iterative process. But you can understand why disabled people are impatient. (Disability Sector Leader 07-01)

¹⁴ Focus group for people whose funding/services/supports is provided by the Ministry of Education as well as parents of disabled children.

4.3.2 Fears

With these frustrations in mind, participants also shared the fears they had for Whaikaha - Ministry of Disabled People, which were created by the Ministry's failure to meet the expectations of both the disability community and the Government. For example, participants feared that a change in government would alter the direction, vision and function of Whaikaha - Ministry of Disabled People:

I fear also that with elections comes potential change of government and a potential change of government means a potential change of thinking and a potential change of priority and hence while we wait for just a few more years for more change and more, yeah. That's my real fear. (Pacific Focus Group 01)

My fear is that after the elections the new Government will not have a focus on disabled people and Whaikaha will be down-sized and their roles will reduce. This is certainly a danger when they haven't really got their act together after one year. (Questionnaire)

There was a common fear that if the new Ministry failed to meet its deliverables and that the Ministry of Social Development would become involved in disability matters and issues:

Yeah there are actual certain fears around, I feel that MSD shouldn't really even be involved... (Women Focus Group 01)

Participants also expressed concerns that Whaikaha - Ministry of Disabled People would become the same as other agencies, and have little or no impact across Government:

So we'll just have another paper pushing organisation. That's the fear that they'll just be moving the paperwork around and they won't get into the door of MSD or Ministry of Transport or anything like that. It'll just be moving bits of paper on the desk and hoping that they will be enough. (Women Focus Group 01)

[M]y concern is the 'ideal' will not be reflected in reality and it will be same old, same old under a different name. (Questionnaire)

Several participants shared the concern that the new Ministry was not set up to serve all disabled people (as defined by the UNCRPD), and that some disabled people (for example, people with psychosocial disability or mental health conditions, and people with chronic health conditions) would be left out of initiatives led by the Ministry:

[O]ne of the aims [of Whaikaha] hopefully is getting a more holistic social model [that] covers all disabilities. One thing that isn't covered is mental health. That has been kept under Ministry of Health and personally I am concerned about that. (Individualised Funding Focus Group)

4.3.3 Cautious optimism

While many participants shared their frustrations and fears about Whaikaha - Ministry of Disabled People, for most a cautious optimism and hope remained, as well as an appreciation for the positive aspects of the new Ministry. It was clear that many of the frustrations expressed by participants related to a lack of proactive, easy to find information in a range of accessible formats, focused on what the new Ministry could and could not do for them. By way of contrast, some participants held the view that Whaikaha - Ministry for Disabled People had shared accessible information, if one knew where to look:

Information that has been shared about Whaikaha and Enabling Good Lives has been very good as the information has come out in all formats so everyone is included. (Questionnaire)

The regular online hui were good but seem to have stopped without much explanation. (Questionnaire)

One focus group participant contributed that the new Ministry had provided much-needed information related to emergency response. This was first time this participant had encountered disability specific information from the Government about natural disaster, which for them affirmed the importance of Whaikaha - Ministry of Disabled People:

I do appreciate that Whaikaha is moving away from the health model and, you know, for example during the flooding like, that's probably the first time there was specific niche information for disabled people affected by that. And that wasn't you know, that didn't happen at prior natural disasters; and I think that is one of the perks of having Whaikaha. (Te Whatu Ora Focus Group)

Several participants specifically mentioned the new Ministry's role in navigating complaint processes:

The equity-led decision-making and advocacy I received from Whaikaha in my recent complaint against [organisation]'s inequitable decision making was invaluable. (Questionnaire)

Another participant shared a positive experience they had when making a complaint about one of the disability support services used:

[Whaikaha] are very helpful, they listen to my complaint through, it was of course it was emailed through to them. And they were, they did what they could at this point without going or threatening [organisation] with, and I think that gave [organisation] enough scare to deal with me. (LGBTQIA+ Focus Group)

Acknowledging inequities experienced by disabled people, several participants shared their hope that the new Ministry would be a strong advocate for the disability community:

Because a lot of people don't take people seriously with disabilities and that's what gets people down. So we gotta have a voice for them. Even if they don't have a voice, we've still gotta speak up for everybody with a disability. So that they can have a good life and they can be, have rights to go get a job. Have a right to have a bank account. Have a right to budgeting. Have a right to everything. [...] Disability is the way of life. People I've known, a lot of people over my time who needed help and I am glad that people are starting to step up and the Government's taking notice of us now. [...] I'd like to see the Ministry just putting

something good in place for people with disabilities to give them a better life. Because a lot of disability people need a job. They need somewhere to live. They need support and you know, without these things, people would be living in a let me say living in a corner in a cardboard box. (Home and Community Support Focus Group)

In summarising the frustrations, fears and hopes disabled people and their family, whānau, aiga and close supporters had for Whaikaha - Ministry of Disabled People, a disability sector leader reflected:

I am quite happy. I was skeptical at first because to me, oh god, are they going to make another ministry like all the ones that exist now? But getting involved in it means I know what's going on and we are definitely not going to be like the, that sit out there so I'm excited, I was surprised, I have been fighting it for over 20 years and then suddenly they fold and give it to you, I hadn't expected that. (Disability Sector Leader 10-01)

5 Tūtohi / Recommendations

While disability sector leaders, disabled people and their family, whānau, aiga and close supporters shared their frustrations and concerns, many articulated their support for Whaikaha - Ministry of Disabled People, with one questionnaire participant saying, “*Keep it going.*” Outlined below are some of the hopes and recommendations disabled people, and their family, whānau, aiga and close supporters had for Whaikaha - Ministry of Disabled People. While these recommendations were articulated before the findings of the independent review were made public, they provide clear guidance and expectations for any government ministry that is dedicated to disability matters and that represents disabled people’s interests, needs and human rights.

Participants’ hopes, dreams and recommendations for Whaikaha - Ministry of Disabled People	
Whaikaha - Ministry of Disabled People is underpinned by the social and human rights models of disability, Te Tiriti o Waitangi, Enabling Good Lives principles, and actively advances the UNCRPD and concluding observations of the UNCRPD Committee.	<i>Whaikaha has been launched, now we are sort of looking at all the operational layers and how a partnership lens can be brought to all that work in principle-based way, based on Enabling Good Lives principles and Te Tiriti of course being a foundational document. So the foundational documents for Whaikaha are Te Tiriti, UNCRPD, UNDRIP and UNCRC so you know there are some really fundamental obligations both nationally and internationally that we expect the Ministry to work to, and they’ll bring alive in their practice. (Disability Sector Leader)</i>
Whaikaha - Ministry of Disabled People works in partnership with disability communities.	<i>[T]he most important thing at the moment is working to the principles of Te Tiriti and EGL and and also the Whānau Ora pou approach and also embedding a partnership way of working, so the officials that moved across from the Health or</i>

	<i>MSD don't slip back into their business as usual way of working but always involve disabled community members from the formal groups you know, so that they are working in partnership and that decisions aren't made without disabled person's lens and whānau lens being put across them. (Disability Sector Leader)</i>
Whaikaha - Ministry of Disabled People has strong voice and leadership of tākata whaikaha Māori and whānau hauā.	<i>And I think then the independent, the Te Tiriti partner and the disabled people and family partners will need resourcing to go out and develop independent collective voice around from a tāngata whaikaha Māori and Māori iwi perspective, you know, those formal relationships and also disabled people so that together, they can also hold Whaikaha to account. (Disability Sector Leader)</i>
Whaikaha - Ministry of Disabled People strengthens policy and legislation to ensure equitable outcomes for disabled people, including between ACC and DSS funded by other Ministries.	<i>I want access legislation with teeth. Access Bill must be strengthened. (Questionnaire)</i> <i>To raise the profile of disabled people in NZ and increase their equity. (Questionnaire)</i> <i>When you compare TWO to ACC you see the gaps. (Questionnaire)</i>
The mandate of Whaikaha - Ministry of Disabled People is inclusive; including people with psychosocial disability, chronic health conditions, and disabled people over 65-years of age.	<i>It would have expanded Enabling Good Lives to all disabled people and to expand the definition of disability to include chronic illness and mental health so that all disabled people are actually receiving wrap-around services that allow them to participate more freely in the community. (No Access to Support Focus Group)</i>

	<i>My hope for Waikaha is that EGL will in the future serve people of over age of 65 years. (Questionnaire)¹⁵</i>
Whaikaha - Ministry of Disabled People is properly funded and resourced.	<i>So for Whaikaha to be successful it has to be properly funded and actually used. (No Access to Support Interview)</i>
Whaikaha - Ministry of Disabled People is staffed by people with diverse lived experiences of disability.	<i>[W]e need to have people with lived experience actually in the Ministry. So yeah and not just in, but actually in senior positions. (No Access to Support Interview)</i> <i>[Y]ou know breaking down those barriers where that a lot of people have viewed people with disabilities as not capable of doing certain jobs and not capable of doing certain things, and I think having a ministry that employ people with different disabilities prove that you know [...] we are active we are trying to contribute to the community and we are capable of doing much more. (Leader)</i>
Whaikaha - Ministry of Disabled People ensures cross-agency commitment and accountability to the EGL approach, equity and disability rights.	<i>I hope that they can have a big influence in how other governments deal with implementing certain things like accessibility, like educating providers and I think Ministry will be really good influence in that area. (Women Focus Group)</i>

¹⁵ According to Whaikaha, “[i]f a person’s impairment arises over 65, they are referred to Te Whatu Ora to receive support via the health of older people system. If a person turns 65 in the care of Whaikaha – Ministry of Disabled People, they will typically continue to receive that support until they are found eligible for supports via Te Whatu Ora. DSS and Te Whatu Ora NASCs will also be in contact to help ensure the person receives support that meets their needs.” (Whaikaha, 2023: p.20). However, it has been reported that some older disabled people are cut off from DSS when they turn 65 (Hunt, 2023).

	<i>[T]o hold other ministries, other Government departments to account when it comes to policies and legislation around disability and disability space. (Pacific Focus Group)</i>
Whaikaha - Ministry of Disabled People proactively provides accessible and easy to find information about what it does and can offer disabled people and their family, whānau, aiga and close supporters.	<i>I think the support needs to be advertised to the people. Otherwise we don't know what's out there, especially for us new to the country. What's available, and who is eligible needs to be advertised to the people. I think asylum seekers and refugees need to be specifically, like explicitly mentioned. (Migrant and Refugee Focus Group)</i> <i>We can go to website and occasionally see things on social media but don't feel there is a proactive approach to information sharing. (Questionnaire)</i>
Whaikaha - Ministry of Disabled People helps build and unify the disability community.	<i>But, that's another hope I guess, to help build the community. (Migrant and Refugee Focus Group)</i>
Whaikaha - Ministry of Disabled People changes society's attitudes towards disability.	<i>[A] lot of the issue when it comes to accessibility and supports and services comes down to the different attitude that people have, and of course we cannot control how people think and feel but it's really important that we have a cultural change when it comes to how people not just people who have disability themselves, but how people outside of this community views disability as well. [...] I think this is the area where the Ministry can help the day to day average person with a disability. (Women Focus Group)</i>

Whaikaha - Ministry of Disabled People is a “one-stop-shop” for disability information and support.

I wish to have one shop you go to to talk with someone with all of your needs. (Home and Community Support Focus Group)

6 Kupu Whakamutaka / Concluding Remarks

This report is the first in a series of monitoring reports detailing the perspectives of disabled people and their family, whānau, aiga and close supporters about Whaikaha - Ministry of Disabled People; government consultation with the disability community; disability supports and services; and Enabling Good Lives. The report has detailed the reflections of disability sector leaders on the structure and functions of Whaikaha - Ministry of Disabled People, and highlights the frustration, fear, optimism and hope felt by disabled people and their family, whānau, aiga and close supporters regarding the establishment of the new Ministry.

It is important to note that data and evidence detailed in this report were collected amidst the launch of Whaikaha - Ministry of Disabled People (July 2022), a change of government (October 2023), and changes to Purchasing Guidelines (March 2024), but prior to the independent review of Whaikaha - Ministry of Disabled People (August 2024), the subsequent transition of DSS to MSD (October 2024), and any other changes that will occur as a result of the independent review.

Monitoring participants shared a wide range of frustrations and fears regarding Whaikaha - Ministry of Disabled People, many of which were also reflected in the findings of the independent review. However, there was a significant lack of alignment between participants' hopes, aspirations and recommendations for the new Ministry and Cabinet's response to the independent review (Cabinet, 12 August 2024). This monitoring research has very clearly shown that participants wanted supports and services to be delivered by a ministry that is committed to equity, Te Tiriti o Waitangi, the UNCRPD, and the Enabling Good Lives approach. Participants wanted a ministry dedicated to disability matters - one that would succeed and thrive. Participants wanted Whaikaha - Ministry of Disabled People to have the time and investment needed to get it right for disabled people and their family, whānau, aiga and close supporters.

As this monitoring research has shown, many disability sector leaders, disabled people and their family, whānau, aiga and close supporters feel uncertainty around the New Zealand Government's commitment to its obligations under the UNCRPD.

At the time of writing this report, the future of Whaikaha - Ministry of Disabled People was hanging in the balance. It is now crucial that the Government demonstrates commitment to the Articles contained within the Convention, by closely consulting with and actively involving disabled people in the development and implementation of legislation and policies, and in decision-making processes, including decisions about the future direction of Whaikaha - Ministry of Disabled People (Article 4.1 and 4.3). As summarised by the quote below, now is the time for “doing”:

[W]hen I got the announcement that Whaikaha was going to be established, I was happy! And I still am happy because you know, at least we have a legit voice at government level, or sort of, at that level to be really create us a pathway for our voice to be heard. I just hope that Whaikaha doesn't get lost in all the other voices that happen. It's only a new ministry compared to all the other ministries that are out there. But the issues are not new. Our concerns are not new. The solutions that we have are not new. So I think it's just time to start doing more of the doing and less of the talking. (Pacific Focus Group)

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