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Disabled Person-Led Monitoring of the UNCRPD

My Experiences, My Rights: Disability Supports and Services

Report 2 – Consultation and Engagement

**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 Organisation Coalition (DPO 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: Kāi Tahu dialect has been used when writing in te reo Māori. This means the ng is replaced with a k (for example, whakarongo is changed to whakaroko).

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, at the request of the Disabled People's Organisation (DPO) Coalition, the DBI started a third cycle of disabled person-led monitoring to explore whether the New Zealand government is realising disabled people's rights under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The DPO Coalition chose disability supports and services as the topic to be monitored. When DBI started this monitoring cycle many changes were happening in the disability sector. For example, Whaikaha - Ministry of Disabled People (the Ministry) was established in July 2022. In March 2024, restrictions were placed on some disability support services and funding and, after an independent review in August 2024, the new Ministry experienced further changes.

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, family, whānau, aiga and close supporters' feelings and views about the Government's engagement and consultation with the disability community about the Ministry, and the March 2024 changes. The findings also highlight participants' hopes and dreams for the Government's consultation and engagement processes with the disability community in the future.

Key Research Findings

Whaikaha - Ministry of Disabled People

Under Te Tiriti o Waitangi, the Government has an obligation to consult with tākata whaikaha Māori. The Ministry created a partnership between disabled people, tākata whaikaha Māori and the Crown called the 'Tripartite Partnership'. Disability sector leader participants felt there was active involvement and close consultation between disabled people, tākata whaikaha Māori and the Crown through this Partnership when the Ministry began. However, engagement with disabled people was reduced

or stopped soon after its establishment, either due to personal reasons or because of changes in the Ministry. These changes impacted Māori and Pacifica leaders from the disability sector, who felt their perspectives were reduced or lost. Some leaders believed the Ministry was not prepared to genuinely partner with the disability community. Participants highlighted that it was common for the Government to decide what the disability community needs and how their needs should be met. When consultation processes took place, participants felt that most decisions had already been made. Disability sector leaders said that system transformation should be designed and led by disabled people, instead of just consulting disabled people about it. They also said consultation that happens after decisions are made is not consultation.

Changes to Purchasing Rules and Equipment and Modification Services

Participants highlighted a lack of consultation regarding the 18 March 2024 changes to Purchasing Rules and Equipment and Modification Services (EMS). The changes negatively impacted many people in the disability community. Participants felt the changes did not consider the needs of people with intersectional identities such as Māori and Pacific disabled people. The Ministry said some disabled people had been consulted but there was not enough time for consultation with the wider disability community, fund holders, and service providers. There was no accessible information about the changes until late April 2024, which left some participants unsure about what the changes meant for them. Service providers and fund holders also experienced confusion due to the lack of communication. Many participants found out about the changes through social media. On the other hand, some participants said the announcement was the first time they learned about supports they are entitled to. Following the changes in March, an independent review of the Ministry was initiated, which also lacked consultation.

The sudden changes caused a lot of distress in the disability community. Participants shared feelings of despair, panic, and concern for their future support needs. The lack of consultation and engagement meant that disabled people were less trusting of the Ministry and the Government.

Hopes and Recommendations

Participants provided recommendations for effective engagement and consultation with the disability community, including:

- Building the capacity of tākata whaikaha, whānau hauā, turi Māori, and disabled people so they can participate in engagement and consultation fully and effectively.
- Early and regular engagement and consultation.
- Ensure engagement and consultation is genuine and not tokenistic.
- Consult and engage with a wide and diverse range of disabled people and disability organisations.
- Provide government officials with disabled person-led training and education on their obligations under the UNCRPD, including how to effectively engage and consult with the disability community.

2 Whakatakika / Introduction

In 2021, the Donald Beasley Institute was contracted by the Disabled People's Organisation Coalition (DPO Coalition) to conduct a cycle of Disabled Person-Led Monitoring on the progressive realisation of disabled people's human rights with respect to disability supports and services. Soon after the project was commissioned, the establishment of Whaikaha – Ministry of Disabled People (the Ministry) was announced, along with the news that Disability Supports and Services (DSS) would transition from the Ministry of Health to the new Disability Ministry.

In the first of a series of monitoring reports,¹ disability sector leaders together with disabled people and their families, whānau, aiga and close supporters shared their perspectives on the structure and operations of the Ministry, as well as their fears, hopes and recommendations for the new Ministry (Donald Beasley Institute, 2025). Despite initial challenges, many participants noted a cautious optimism about the new Ministry's potential, including its ability to deliver DSS using a social and human rights approach.

However, less than two years after the new Ministry's establishment, the New Zealand Government began to make significant and unsolicited changes to policy and legislation that directly impacted disabled people and their communities. For example, on 18 March 2024, the Ministry announced changes to Disability Supports and Services (DSS) and Purchasing Rules and Equipment and Modification Services (EMS) (Whaikaha – Ministry of Disabled People, 2024a). Then, in August 2024, following an independent review, the Cabinet announced a reduction in the new Ministry's functions and the transition of DSS to the Ministry of Social Development (MSD) while removing Whaikaha – Ministry of Disabled People from the auspices of MSD. These changes, amongst others, led to distress within the disability community and sector, with many accusing the Government of making decisions 'about us

¹ This report is the second 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.

without us’ - that is, decisions that directly impact disabled people and their families without engagement or consultation (Brown, 2024).

As has been accurately highlighted by many in the disability community, this approach directly contradicts Article 4.3 of the United Nations Convention on the Rights of Persons with Disabilities, which states that “in 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 [the New Zealand Government] shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations” (United Nations, 2006). The necessity of consultation is reiterated in the New Zealand Disability Strategy 2016-2026, which repeatedly states that “Disabled people are consulted on and actively involved in the development and implementation of legislation and policies” in all key outcome areas (Office for Disability Issues, 2016).

This report explores participant reflections on the Government’s recent engagement and consultation with disabled people and their families, whānau, aiga, and close supporters, as well as their representative organisations. It begins with findings related to the establishment of the Ministry, before the changes to Purchasing Rules and EMS are discussed. The impact of the lack of effective engagement and consultation is explored before recommendations for upholding Article 4.3 of the UNCRPD and effective engagement and consultation processes are presented.

3 Te Aramahi / Methodology

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.²

Phase Two: Focus groups

The second phase of this research comprised 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. The monitoring team also conducted a series of targeted focus groups with harder-to-reach and intersectional populations to ensure that people known to experience challenges in accessing supports and services were included in this research. Each focus group consisted of two to six participants and was 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%)

² 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'ilimalo³, Pasefika disabled people 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/or 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%, whānau and close supporters 20%)

In total, 29 interviews/focus groups⁴ 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 Articles 9, 19,

³ Tagata refers to a person or people, and sa'ilimalo is the pursuit of success in Samoan. This is a strength-based language to refer to Pasefika disabled people. The word is developed with an intention that other Pasefika nations can use their respective words with the same meaning.

⁴ If a person indicated they preferred individual interviews for accessibility reasons, this was arranged.

and 21⁵ of the UNCRPD, and following their experiences of DSS, the establishment of the Ministry, and EGL.

Phase Three: Nation-wide questionnaire

The third phase of this monitoring research was centred on a DRPI monitoring questionnaire. 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 to reflect on the establishment of the Ministry 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 - 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 disability.⁶

⁵ 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.

⁶ 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 and experiences with government engagement and consultation processes. Findings have been categorised according to two key milestones or events that occurred within the timeframe of the monitoring cycle and that were talked about most by participants: the establishment of Whaikaha – Ministry of Disabled People, and the 18 March 2024 changes to Purchasing Rules and Equipment and Modification Services (EMS). Disabled people’s recommendations for ensuring effective government engagement and consultation processes with the disability community are also discussed.

4.1 Whaikaha – Ministry of Disabled People

On establishment, a key aim of the Ministry was to build a true partnership with tākata whaikaha Māori and the disability community (Whaikaha, no date a).⁷ Disability sector leaders who participated in this cycle of monitoring felt that in the beginning, there was active engagement between the Government and disabled people:

In the past year [2022 - 2023] based off the organisation that I'm with. We've had a lot of communication with Whaikaha. And, like we've had certain meetings and catch ups with Whaikaha to make sure that they're still able to present information in the way that needs to be presented, and they'll have involvement and communicated well. (Disability Sector Leader 08-02)

One focus group participant reported that Government had been particularly good at consulting with young disabled people:

Whaikaha, I have a really good relationship with them [...] they give us a lot of consultations that our young people could be a part of to

⁷ 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.

actually make change with the right people. So that's where they actually do really, really well. They empower young people with just actually extending any sort of opportunity, any sort of contribution that literally regards what they're passionate about. (Pasefika Focus Group)

However, according to disability sector leaders, the new Ministry's level of engagement with disabled people either reduced or completely ceased soon after its establishment. While some said the lack of engagement was due to their individual circumstances, others attributed it to changes within the structure of the Ministry, whereby advisory roles were discontinued. When this occurred, participants said that communications about the changes were either unclear or absent. As highlighted in the quotes below, the impact of these changes was felt most acutely by disabled leaders from Māori and Pacific communities:

From my perspective, compared to a year ago, I was fully immersed in [groups]. And now, absolutely nothing. So it's gone quiet. (Disability Sector Leader 16-02)

[W]e had a very strong partnership model. And we were developing that as a partnership, co-governance kind of model, a tripartite approach. So we wanted to be sure that D/deaf sign language that they gave it the title, as well as the Māori title, and then the Pākehā title, and that was the tripartite. And the partnership was that Māori as Treaty partners will be sitting alongside other disabled in an equity role, it's gone. (Disability Sector Leader 10-02)

When asked why this might have occurred, some leaders speculated that the new Ministry was unprepared to genuinely partner with the disability community. For example, according to one participant, the reduction or termination of engagement was because the Ministry did not have plans in place for continued engagement beyond the establishment process, despite the Ministry's expressed aims and commitment to the UNCRPD:

Because Whaikaha did not feel ready to partner with the community. They did not feel that with their millions of dollars, and their hundreds of

staff that they had the infrastructure to partner with community. So they cancelled the Community Reference Group, and the Better Outcomes Partnership Board, they cancelled it. (Disability Sector Leader 09-02)

Throughout the interviews, participants highlighted that even though the role of Government is to serve and meet the needs of communities, it was not uncommon for Government to determine what the disability community needs were and how to meet them. For example, when communities were engaged, it was often through a consultation process. However, by the time consultations took place, most decisions had already been made on the community's behalf. Disability sector leaders stressed that to transform the disability supports and service system successfully, the system itself should be designed by disabled people, and disabled people should lead the transformation rather than simply be consulted. In doing so, decision-making power would shift from the duty bearer (Government) to rights holders (disabled people and their communities):

It's the hope that Whaikaha as a ministry will realise that they have a very minor functional role in this. My hope is that they get to a place where they realise the most impactful thing they can do is invest in communities to have conversations for themselves. So that's one thing I hope for. (Disability Sector Leader 09-01)

As was highlighted in the first in this series of Supports and Services monitoring reports,⁸ participants appreciated and valued the new Ministry's focus on the Tripartite Partnership between disabled people, tākata whaikaha Māori and the Crown (Donald Beasley Institute, 2024). Tākata whaikaha and whānau hauā Māori leaders highlighted that this approach embodies Te Tiriti o Waitangi and the Crown's obligation to consult with tākata whenua (Hickey, 2024). However, as cautioned by Dr. Huhana Hickey (2024, p. 9) in her submission to the Health Services and

⁸ Report 1 entitled 'Disabled Person-Led Monitoring of the UNCRPD My Experiences, My Rights: Supports and Services Report 1 - Whaikaha - Ministry of Disabled People (Donald Beasley Institute, 2024); the current report on consultation and engagement; and forthcoming Report 3 on disability supports and services and Report 4 on 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.

Outcomes Kaupapa Inquiry (Wai 2575), consultation that occurs after decisions have been made are not effective: “Effective engagement goes beyond notification, and in our view, beyond consultation [...] simply calling a hui and informing Maaori of a proposal does not meet the minimum standard of consultation, and certainly does not amount to effective engagement.”

As summarised by a disability sector leader:

I do think there has been generally an appreciation that disabled people need to be consulted on significant aspects of policy work. And I think they have slowly been a shift base by seeing it as a kind of nice to have like, well, we'll get to them if we can, to more of a, “No, disabled people are a population group that we need to talk to. And so we should align ourselves with their schedule, for example, rather than putting these into ours.” So I think there has been some progress on that. Obviously, there's always more that people can do. (Disability Sector Leader, 05-02)

4.2 Changes to Purchasing Rules and Equipment and Modification Services

Regarding consultation, the second key event discussed by participants was the 18 March 2024 changes to the Purchasing Rules and Equipment and Modification Services (EMS). Participants primarily reflected on the lack of Government consultation, how the changes were communicated, the impact of the changes, and how the changes failed to consider intersectionality.

4.2.1 Consultation

Following the 18 March 2024 changes to Purchasing Rules and EMS, monitoring participants were invited to a further round of focus groups⁹ to discuss how their access to supports and services were or could potentially be affected by the changes. During these focus groups, participants repeatedly noted the absence of Government consultation processes and engagement with disabled people and their representative organisations when making decisions. For example, one participant noted they found out about the changes via social media:

There was no consultation with the community at all, even with the equipment and modification services. And I was alerted to it on just a Facebook post. (Follow-up focus group, disabled person)

Following the social media announcement, Whaikaha - Ministry of Disabled People shared another post stating that some members of the disability community had been consulted in the lead-up to the changes to the Purchasing Rules and EMS.¹⁰ However, the post also indicated that the limited timeline for implementing the changes did not provide the opportunity for robust engagement with the wider

⁹ Follow-up focus groups were not organised according to the same themes as previous focus groups, but were conducted as tākata whaikaha and disabled people; family and whānau; and people unaffected by the changes.

¹⁰ “These changes are being implemented now, effective from 18 March 2024 in line with our statutory responsibility to work within our budget each fiscal year. They will be in place while we complete work to consult with disabled people, tāngata whaikaha Māori, family and whānau and our providers as we work towards the long-term settings” (Whaikaha - Ministry of Disabled People Facebook page, 19 March 2024).

disability community, funding hosts, or service providers. For example, one participant noted their confusion around how the changes affected people using Individualised Funding (IF), and noted that funding host agencies were not consulted either. This, along with inadequate accessible information, meant that details were interpreted inconsistently by funding hosts and service providers:

I would say that it [was] the same for the IF process as well. They [funding agents] weren't consulted either. And they are just basing it around their interpretation. So every IF hosts have appeared to be interpreting it differently but the fact that there [was] no visual aid to back up what Whaikaha has released, like apart from Easy Read, for a lot of autistic individuals we need visual aids as well, and this just no visual aid is like a car or a plane go with the crossfire. (Follow-up focus group, disabled person)

The gaping discrepancy between expected and actual consultation processes highlights a critical failure by the Government, which negatively impacted the well-being and rights of disabled people and their family, whānau, aiga and close supporters. Participants said they wanted a more inclusive and accessible decision-making framework that aligns with the UNCRPD and NZDS. As articulated by one participant, the decision to make changes to the Purchasing Rules was made without proper consultation or a clear understanding of the consequences on the disability community and disability sector:

They've axed it right so that's really against all our human rights because they've axed it like you said without consultation, without, you know, knowing the effects of what it's actually going to have on some of the people you know. (Follow-up focus group, disabled person)

A statement published by the DPO Coalition in September 2024 confirmed that the lack of consultation with disabled people and their representative organisations continued beyond the 18 March 2024 announcement.¹¹ Following an independent

¹¹ As the peak body of disabled-led organisations, the DPO Coalition holds the role of consulting with the government on important matters for the disability community (Whaikaha, no date c).

review of the Ministry, which also lacked consultation and engagement with the disability community, Cabinet made a unilateral decision to restructure the role and function of the new Disability Ministry (Minister for Disability Issues, 2024). As summarised by the DPO Coalition:

The DPO Coalition expresses its grave concern that the Government has failed disabled people by not meeting its obligations to engage with them prior to making substantial decisions about the future role of Whaikaha and the provision of Disability Support Services (DSS). Te Tiriti o Waitangi obligations on the Government to engage with Tāngata Whaikaha Māori have not been met. Obligations to engage with organisations that represent disabled people in line with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD | Disability Convention) have not been met. The fundamentals to work with disabled people and whānau which assisted the establishment of Whaikaha have not been met (DPO Coalition, 2024, p. 1).

4.2.2 Communication

Following the 18 March 2024 announcement, the changes to Purchasing Rules and EMS were implemented immediately. However, information about these changes was not available in te reo Māori or accessible formats (NZSL, Easy Read, Braille, audio, and large print) until late April 2024. The absence of accessible information in alternative formats contradicts Article 9.1 of the UNCRPD, which states that: “States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications” (United Nations, 2006). The delivery of inaccessible information also goes against the Government’s own Accessibility Charter, which requires “ensuring that all information intended for the public is accessible to everyone and that everyone can interact with our services in a way that meets their individual needs and promotes their independence and dignity” (Ministry of Social Development, 2018).

This meant that many disabled people and their family, whānau, aiga and close supporters could not access information about the changes and did not know whether their supports and services would be impacted or removed. This led to panic, frustration and concern for livelihoods (Davison, 2024; John, 2024). During the follow-up focus groups, participants emphasised the inadequacy of communication methods. In particular, neurodivergent and D/deaf people raised concerns about the accessibility of vital information about their human rights and supports and services:

So obviously, Whaikaha, the government in general did not consider that because we weren't consulted, nor were the Purchasing Guidelines particularly accessible for a lot of people, also weren't in plain language, because in any way because there was so much confusion, equal participation or acknowledging diversity? (Follow-up focus group, disabled person)

Participants shared how the lack of accessible information impacted them and the wider disability community:

And you know, still to this day¹², there is no alternative formats, no Easy Read, no New Zealand Sign Language interpretation of it or anything like that. And that's not okay, for a new Government, a new Ministry to be in place, that is for disabled people, they should be, you know, releasing the same information and other alternative formats at the same time. (Follow-up focus group, disabled person)

Other participants highlighted that not only was there an absence of accessible formats, but the available information was difficult to understand:

I just want to reiterate. You have to do a lot of reading because any changes are buried in the detail. I don't think that's an accident either. What I would have done if I was updating information was saying okay, here's a summary of the update. If you want to read it in full go here instead of just burying any updates. On the surface you look and it doesn't look as if there's been any updates at all even though they put a

¹² This focus group was conducted two weeks after the 18 March 2024 announcement.

new date on it. So you have to read absolutely everything each time to see what tiny details have changed which is not good. (Follow-up focus group, disabled person)

The Government's lack of communication with the disability sector meant that service providers and funding hosts also scrambled for information and clarity. Participants experienced inconsistent communications between providers, which in some cases led to more confusion:

I got one, got email alerts from our hosts but our Individualised Funding hosts but I felt it was just regurgitated scrambling of which the information they were being fed there was, as far as I could tell, there was nothing really done well. (Follow-up focus group, disabled person)

To back up that, I think the most phenomenal thing to me was that it absolutely threw all of our connectors into an absolute disarray. No one knew anything about it before it came out on Facebook [laughs]. [...] It's still really confusing as to actually what it covers and what it doesn't cover. Everyone kind of has a different idea of what it covers or doesn't cover depending on who and where you get your supports from or um all that kind of thing. (Follow-up focus group, disabled person)

The announcement also drew attention to supports and services that many disabled people and their families did not know they were entitled to. For example, one participant who was a family member mentioned they did not know that IF could be used for equipment and assistive devices. Again, this called into question Article 9.1 of the UNCRPD, as this information should have been easily found and accessible:

I never knew that IF could pay for those sorts of things. (Follow-up focus group, family member)

Many participants found out about the changes through the media, which added to their uncertainty about how their access to supports and services might be impacted:

I haven't had any communication at all so that's why I find it quite scary as to what has been put in the media. (Follow-up focus group, disabled person)

The short answer is I wouldn't have a clue how it affects me because I've not been told. It's very hard to, you know, there's some things that are said in the media that won't be paid any more. (Follow-up focus group, disabled person)

Furthermore, participants shared that some of the media narratives portrayed disabled people and their family, whānau, aiga and close supporters negatively. Relating to Article 3 of the UNCRPD, which emphasises inherent dignity as a general principle of the Convention, participants shared how the media and Government constructed disabled people as passive recipients of care who get nice things “because [they’re] disabled,” while also construing their family, whānau, and carers as “just wasting money”:

I think I've been more annoyed at the way that the media has come out and spun it and then with no regard for the people like they might pretend to be on your side, but they've actually been very divisive in the way that they've reported it. (Follow-up focus group, family member)

4.2.3 Impact

As highlighted in the New Zealand Government's ‘Good Practice Participate - Benefits of Effective Community Engagement’ (Department of Internal Affairs, 2021, p. 1),¹³ “Improving community engagement can strengthen public trust in government, improve government transparency, enhance civic capacity and create more sustainable policies.” Importantly, active and effective relationships between government and disabled people and their families, whānau, aiga and close supporters can:

- Improve the quality of policies and services

¹³ Further Government resources for good practice and inclusive community engagement can be found at: <https://www.dpmc.govt.nz/our-programmes/policy-project/policy-methods-toolbox/community-engagement>

- Help solve complex problems
- Build trust and understanding
- Support active citizenship
- Ensure participation of Māori
- Measure progress more effectively
- Build staff skills

However, when community engagement and consultation processes are insufficient or absent, the impact on affected communities can be negative and wide-reaching. Detailed below are participant reflections on the practical implications of the Government's unilateral decision-making processes including reported psychosocial impacts.

4.2.3.1 Practical Implications

Article 19 of the UNCRPD requires the New Zealand Government to take appropriate measures so that disabled people have access to “full inclusion and participation in the community” (United Nations, 2006). In order to achieve this, adequate funding and resources are required. However, a lack of financial forecasting by successive governments of the investment needed for disability supports and services led to changes that restricted and reduced disabled people's enjoyment of Article 19 rather than its progressive realisation. One of the justifications for the 18 March 2024 changes offered by the former Minister for Disability Issues was a return to pre-COVID levels of investment (Smith & Palmer, 2024). However, as was highlighted by one participant, disability supports and services had never been adequately funded, including pre-COVID. As a result, the 18 March 2024 changes would exacerbate historical underinvestment:

[T]he Ministry made a comment like it was going back to pre-COVID levels. Well, the pre-COVID levels of spending on Disability Support Services was hardly, hardly adequate. Really. EGL was brought in to change, transform the system, because they constantly got bad reports from the monitoring group in accordance with the UNCRPD. So I mean, goodness. What it's gonna look like now? (Focus group, disabled person)

Moreover, the recent independent review of Whaikaha - Ministry of Disabled People exposed a significant increase in the number of people accessing disability supports and services over the past five years (Weaver et al., 2024). Successive annual budgets, however, have not factored in this increase. One participant described how the announcement implied that disabled people and their family, whānau, aiga and close supporters were being punished for the increased demand on disability supports and services, instead of increasing the budget to meet the needs of the growing community:

[W]e're all given budgets to work with. So how have they got so far off their budget, and then they're saying that, you know, more and more people now are becoming eligible for these services, but the funding is not there. But I was thinking, "well, whose job is it to pre-plan?" (Focus group, family member)

With regards to the practical implications of the changes, many disabled people accessing IF and variations of personalised budgets reported immediate restrictions on how they could spend their budgets. For example, prior to the changes, disabled people and their families, whānau, aiga and close supporters were permitted to spend their pre-approved budget on support worker travel, regardless of the purpose of the travel (for example, travel for work, to visit family, to network with other disabled people, or for leisure). However, the initial announcement enforced immediate restrictions on the use of pre-approved budgets for domestic and international support worker travel:

[N]ot having the ability to claim expenses for my support work and now when I travel for work, or anything, you know, outside the region is not okay. I call myself a 'disabled regional prisoner' now, 'cause that's how I feel. You know, and particularly when it comes to the AAC¹⁴ community in New Zealand is too small to hold AAC conferences in New Zealand, and we don't have the funding to do that. So now we've been stripped of our ability to go interact with the International AAC community, including, you

¹⁴ Augmentative and Alternative Communication.

know, going, when you're at these conferences, you know, people that make the speech generating apps and the technology are there at these conferences. (Follow-up focus group, disabled person)

As reported by participants in the follow-up focus group for family, whānau, aiga and close supporters, another immediate practical implication related to respite. Before 18 March 2024, it was possible for full-time carers to use their pre-approved budget to cover the costs and expenses associated with respite with a degree of flexibility. However, after 18 March 2024, this was no longer permitted, with budgets only covering costs or expenses directly related to the disabled person's care and support needs while the full-time carer took a break:

[A]ll the expenses we had submitted fit the criteria. But they didn't [approve it] [...] [I was] just trying to get like a respite couple of nights away while Dad was home, but Dad will be going back probably now before, you know, it's gonna be too late now anyway. But that all fit the criteria under the previous stuff. [...] they are restricting these rights, so much that the supports don't match what the family actually needs. It's not taking into account [...] rural families that have different, you know, there's different ways we probably need to use our support and services 'cause we don't have the array of options available to us in the city. (Follow-up focus group, family member)

As summarised by one participant, both the fear of losing choice and control and the actual loss had challenged their sense of personhood:

[W]hat I presume that I'm going to lose is the scary part because finally being able to access some funding that actually makes you feel like you're a person again and you can participate in community stuff and that you know. (Follow-up focus group, disabled person)

4.2.3.2 Psychosocial Impact

The sudden announcement of changes to the Purchasing Rules and EMS resulted in considerable distress within the disability community, with participants expressing

feelings of despair, panic, and concern for their future support needs. One participant emphasised the emotional impact of these changes:

[I]t certainly blew me away and put me in a panic I guess as to how it was gonna affect me. Because there was no control or no ready information from a lot of people. It was just thrown at us that this was going to be happening and I think it just threw a lot of people into despair. I know I had the initial feelings of despair and “oh my God, what's gonna happen to my situation and my support workers and the assistance that I need to get around and do things?” Because there was no consultation or anything like that, so it left me feeling really vulnerable. (Follow-up focus group, disabled person).

Participants also reported that the lack of consultation and engagement with the disability community regarding the changes had negatively impacted their levels of trust in the Ministry and wider Government. Feelings of distrust were heightened by the fact that participants had expected the new Ministry to advocate for the disability community within Government:

[I]t's disappointing cause, you know, we thought that the whole point of Whaikaha was to champion people with disabilities and to our needs and to help us to have accessibilities, not minimise accessibilities or limit the type of accessibilities we could have. (Follow-up focus group, disabled person)

I was really pleased that there'd been a Ministry for Disabled People. But I don't believe that they are really for us. And I can't, I can only say that because the set of behaviours demonstrated indicate that well, they just, you know, they're blowing the trust. How can we trust them? Like, how do we believe anything they say? (Follow-up focus group, disabled person)

For some participants, the announcement and subsequent communications reiterated their marginalisation in society by evoking feelings of devaluation and powerlessness:

[I]t was like, "just go back in your box, and you don't, we don't want you to be seen or heard you're irrelevant to society." (Follow-up focus group, disabled person)

We're getting treated like we're worth nothing, like we're not important. I just feel like we're not going to be able to survive out there if we want to go independent. Um why does everything have to be cut? It's not fair. It's like we don't matter. I just feel like we're secondary like citizens. It makes us feel like we're not [...] proper New Zealand citizens. (Follow-up focus group, disabled person)

Another participant noted the impact of the subtle but symbolic change in terminology from 'Purchasing Guidelines' to 'Purchasing Rules':

[W]e have read one thing in the change of document and by the way, I think it's even significant that they are now called 'Rules' instead of 'Guidelines'. That is an insult to our community. [...] because that implies to me, that implies that we can't now be trusted to follow guidelines so we have to have rules imposed on us. (Follow-up focus group, disabled person)

Many participants expected more changes in the future, which would further restrict their ability to participate in the community. For example, one participant feared that the lack of options and flexibility would force an even higher number of disabled people into residential and day services:

[I]t's not okay for disabled people just to be shoved into day services because we need to be able to join the community, you know, and not just day services, there needs to be a choice, choice and control. We don't have choice and control anymore. It's been taken away from us. (Follow-up focus group, disabled person)

As articulated in the quotes below, the 18 March 2024 changes did not align with the Government's commitment to the social and human rights models of disability and demonstrated a lack of understanding about disabled people's support and service needs:

[T]hey haven't taken the social model of disability into account at all [...] they don't understand our community at all, even to be a huge percentage of New Zealand, let alone our rarer communities who are fighting to even get funding in the first place. (Follow-up focus group, disabled person)

Following the publication of the new Purchasing Rules on the website of Whaikaha – Ministry of Disabled People, helplines were presented alongside the newly introduced Rules, which invoked further emotional stress for the disability community who already experience challenges when trying to access the intricate array of supports and services:

[T]hey have their audacity to tell us to contact 1737 or mental health services. And it's such an audacity because, especially for the neurodivergent population in the wider disability community, it is so hard to access mental health services. And so, you know, to get afford for them to say that when they already know the issues exist, it's just like a slap in the face. Yeah, and they kind of need to be pulled up on their behaviour. Maybe they need some behaviour support on how to appropriately respond to people that are distressed from their announcements that they suddenly made. (Follow-up focus group, disabled person)

4.2.4 Intersectionality

The final sub theme, that was consistent across the focus groups, drew attention to the impact of the changes on disabled people who live with multiple, overlapping and intersecting forms of discrimination:

By taking such a narrow, prescriptive focus, which are done through these changes, it's really basically as a station posed a one size fits all prescription for how you use, to use your money, it doesn't take into account family or whānau, it does not take into account cultural values around cooperation or mutuality say in terms of koha, which I think works for everyone regardless of what culture they are, identify with. And it also says it sees disability in a very narrow [...] there's no social model aspect to it at all. (Follow-up focus group, disabled person)

For tākata whaikaha and whānau hauā Māori participants, the failure to consult with the disability community exacerbated their existing challenges with disability supports and services. For example, one participant remarked that the lack of consultation reflects a broader pattern of imposing changes without adequate recognition of the consequences on Māori. This highlighted the need for culturally appropriate engagement in all policy-making processes:

So it was, like, no consultation but as Māori, you know, I'm used to that, no consultation with us, like, changes just happen and then you deal with it. (Follow-up focus group, disabled person)

In contrast, some participants said that the announcement was the first time disabled people in their communities had been informed about what Individualised Funding (IF) is and how it could be used. In particular, one participant said that this experience highlights the already inequitable access to supports and services for tākata whaikaha and whānau hauā Māori and other minority groups such as Tagata Sa'ilimalo and Pasefika disabled people:

So that's even getting bigger for Māori who already struggle to engage with our health system and when we're talking about like IF, individualised funding you know like [Participant] was saying, it's not for everybody. Not everybody knows how to manage that so even bringing in all these more complications and changes is just going to make it harder for disabled people to even want to use it. (Follow-up focus group, disabled person)

5 Tūtohi / Recommendations

Throughout the interviews and focus groups, and the questionnaire, participants emphasised the need to transform the disability supports and services system in a way that fosters dignity, promotes accessibility, and genuinely considers the needs and human rights of disabled people. Participants agreed this could only be achieved through effective engagement and consultation with disabled people and their family, whānau, aiga and close supporters, with the emphasis being on 'effective'. The following recommendations provide guidance on how this might be achieved in the future.

Build the capacity of disabled people so they can participate in engagement and consultation fully and effectively:

[T]here should be more opportunities for [younger disabled people] to engage in that you know, there's a lot of potential out there, but there's not enough of community voices that can be called on to keep pushing the, you know, the movement. (Disability Sector Leader, 13-02)

Build the capacity of tākata whaikaha, whānau hauā and tākata turi Māori so they can participate in engagement and consultation fully and effectively:

And so the system at the moment is not fit for purpose for Māori D/deaf, everything that's been provided for us is not appropriate. And so what we need is to have Māori D/deaf people who know, some of them say 'we don't know' and so we need to empower them, and really upskill them so that their knowledge, their experience, can be expressed in an appropriate way that they can stand strong and speak up for what they need. (Disability Sector Leader, 14-02)

Engage early and consult regularly:

But getting them [disabled people] in at that [early] stage to be like ok, we're gonna consult everyone and see what's actually going to work.

Because you can't just say disability is one thing. We are all so incredibly complex with our own cultural and spiritual needs. And if you're not actually taking those on board at the inception of something, it's gonna be not actually speaking for all of us. (LGBTQIA+ Focus group 01)

I think the ideals [of Whaikaha] are refreshing, and I hope their work is able to continue according to those, with regular consultation and inclusion of the sector in key roles. (Questionnaire participant)

Ensure engagement and consultation is genuine and not tokenistic:

[There is a] lack of genuine engagement, pretence from people in positions of power to come across as "good people" or "doing good". (Questionnaire participant)

Consult and engage with a wide and diverse range of disabled people and disability organisations:

The disability consultation system is not working for us. [...] Whaikaha needs to set up a better disability consultation system, where Whaikaha has a relationship with all. [...] More disabled organisations need to be involved in order to gain trust, transparency and confidence in the system. (Disability Sector Leader 12-02)

And one of the challenges is outside of the DPO Coalition trying to reach a broader range of people. Because obviously, like the DPO is one section of a very diverse community. And I think, generally people kind of see the DPO Coalition, it's the kind of, you know, one and done, like, we've talked to the disabled people, because we've talked to the DPO Coalition kind of thing. [...] they [Government] kind of rely on the disabled people using their own personal networks to connect Government with different communities, which is obviously not best practice or ideal. (Disability Sector Leader 5-02)

[...] they don't include people like me when they're doing consultation. (Ministry of Education supports and parents of disabled children focus group 01)

Provide government officials with disabled person-led training and education on how to effectively engage and consult with the disability community:

So I still think there needs to be some capability building around how Government engages with disabled people more broadly. And hopefully Whaikaha in the future will be able to support other Government agencies to do that, because I think that should be one of their roles, is to, as the kind of central agency, to kind of connect different agencies with different parts of the community as well. So hopefully, that can happen. (Disability Sector Leader 05-02)

Provide government officials with disabled person-led training and education on their obligations under the UNCPRD:

[Disabled people] should have training with these people in Whaikaha and teach them a lesson. Teach them it's just not right. This is the UN Convention. They have to stick by what the UN Convention says. (Focus group participant, disabled person)

In summarising their hopes for the Government's engagement with disabled people and their family, whānau, aiga and close supporters, one questionnaire participant reflected:

I hope that people who engage with Whaikaha can and feel listened to, even if the outcome is not what the person desires.

6 Kupu Whakamutaka / Concluding Remarks

This report has provided insight into disabled participants' perspectives on the New Zealand Government's recent consultation and engagement processes with the disability community when making decisions about disability matters, supports and services.¹⁵ It is the second report in a series detailing the perspectives of disabled people and their family, whānau, aiga and close supporters about Whaikaha - Ministry of Disabled People; government consultation and engagement; disability supports and services; and Enabling Good Lives.

The findings began with participants' reflections on the Government's consultation and engagement with disabled people and their family, whānau, aiga and close supporters in the lead-up to and the launch of Whaikaha - Ministry of Disabled People. Disability sector leaders indicated that the Government's engagement with the disability community had started strongly and positively, but declined soon after the new Ministry's launch in July 2022.

A second key event discussed in relation to consultation and engagement was the 18 March 2024 changes to Purchasing Rules and EMS. Participants reported the announcement came as a surprise, given that no prior consultation or engagement had taken place. This impacted participants in a variety of ways, including confusion about the changes due to inaccessible and inconsistent communications; immediate practical implications for disabled people's involvement in their communities; negative psychosocial impacts such as distress, frustration, panic and fear; as well as further marginalisation of disabled people with intersecting and overlapping marginalised identities. Participants then shared recommendations for future consultation and engagement processes in line with expectations set out in the UNCRPD and New Zealand Disability Strategy 2016 - 2026.

¹⁵ 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 before the independent review of Whaikaha - Ministry of Disabled People (August 2024), the subsequent transition of DSS to MSD (October 2024), and any other forthcoming changes that will occur as a result of the next phase of the independent review.

This monitoring report has reinforced the importance of effective consultation and community engagement with disabled people and their family, whānau, aiga and close supporters. Participants emphasised the need for early and effective processes, with the meaning of 'effective' being defined by rights holders (disabled people) rather than duty bearers (Government). In doing so, not only will the quality of policies and services be improved, complex problems be solved, and trust and understanding built (as outlined in 'Good Practice Participate - Benefits of Effective Community Engagement' (Department of Internal Affairs (2021))), but the Government will also successfully fulfil their obligations as set out in the UNCRPD and New Zealand Disability Strategy 2016 - 2026.

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