DONALD BEASLEY INSTITUTE



Disabled Person-Led Monitoring of the UNCRPD

My Experiences, My Rights: Standard of Living

Preliminary Report

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

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

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

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

Quotes: Participant quotes are presented as originally written, with minor edits to spelling and punctuation applied only to enhance readability and accessibility. All identifying information has been removed to preserve anonymity.

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.

Content warning: This report covers content that can be distressing to read. Please take care as you read through the report.

Project Artwork: Ebenezer Shodavaram, Studio2.

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1 Whakatakika / Introduction

Globally, research shows that disabled people experience higher levels of financial hardship and material deprivation than their non-disabled peers (Basson, 2017; Mitra et al., 2017; Morris et al., 2022). Material deprivation refers to the lack of financial resources necessary to meet basic living standards, such as food, housing, and healthcare (Morris et al., 2022). Researchers have also identified factors that can alleviate or exacerbate financial hardship and material deprivation, such as specific disability needs, geographic location, life stage and household composition (Antón et al., 2016; Cullinan et al., 2011; Mitra et al., 2017; Zaidi & Burchardt, 2005). Despite these insights, hardship continues to disproportionately affect disabled people around the world.

In 2008, the New Zealand Government signed and ratified the United Nations Convention of the Rights of Persons with Disabilities (UNCRPD), followed by its Optional Protocol in 2016. With this commitment came the obligation to uphold Article 28 – Adequate standard of living and social protection, which includes disabled people's right to adequate food, clothing, housing, and social protection (United Nations, 2006). However, variations in how State Parties interpret this right and implement measures to uphold it can significantly impact disabled people's standard of living (Basson, 2017). For example, the 2023 Household Disability Survey found that 62% of disabled people in Aotearoa New Zealand had at least one unmet need (StatsNZ, 2025a), while disabled people and people with health conditions account for 53% of main benefit recipients (Welfare Expert Advisory Group, 2019). More recently, the Ministry of Social Development's latest report on child poverty highlighted the stark over-representation of disabled children in material hardship, with disabled children facing twice the risk of hardship compared to non-disabled peers, and accounting for 21% of children in material hardship and 25% of those in severe hardship. At a household level, nearly 60% of children in material hardship, and 67% in severe hardship, live with at least one disabled person in their household (Ministry of Social Development, 2026). Research further shows that many tākata whaikaha Māori and whānau hauā struggle to afford basic necessities,

with significant out-of-pocket living expenses pushing their overall cost of living beyond their income (Cram et al., 2024). Compounded by a cost-of-living crisis (Sim, 2025; Vatsa & Renwick, 2025) and changes to funding and support packages (Citizens Advice Bureau, 2025; Donald Beasley Institute, 2025c; The Fairer Future Coalition and Disabled Persons Assembly, 2024), qualitative and quantitative findings have sparked deep urgency and concern throughout communities across Aotearoa (Gray & Stratton, 2024; Sim, 2025).

In response, the New Zealand DPO Coalition selected standard of living as a focus topic for the 2025 - 2027 cycle of Disabled Person-Led Monitoring of the UNCRPD in Aotearoa. Disabled person-led monitoring operates under the mandate of UNCRPD Article 33.3, which says that civil society, in particular disabled people and their representative organisations, shall be involved and participate fully in the monitoring process (United Nations, 2006). Since 2018, the DPO Coalition has contracted the Donald Beasley Institute (DBI) to conduct monitoring research on their behalf. Between 2018 and 2025, the DBI completed three research cycles, with each topic emerging from the findings of the last. The initial cycle examined the right to adequate housing (Donald Beasley Institute, 2020a; 2020b), in which the right to the highest attainable standard of health emerged as a closely intertwined issue, prompting it to become the second focus topic (Donald Beasley Institute, 2022a). During the health and well-being cycle, participants highlighted disability supports and services as fundamental to upholding their human rights, establishing the third monitoring focus. In that third cycle, participants consistently raised systemic challenges surrounding income support, the extra costs of disability, and how inadequate assistance exacerbated existing inequities (Donald Beasley Institute, 2025a; 2025b; 2025c; 2025d; 2025e; 2025f). In response to these financial pressures and the broader economic climate (Weston, 2022), the DPO Coalition selected Article 28 as the fourth focus topic, including disabled people’s perspectives on standard of living, cost of living and the cost of disability.

This report presents the findings from Phase 1 of the monitoring cycle: an accessible online questionnaire that invites disabled people and their supporters to share their

experiences regarding standard of living, cost of living and the cost of disability. Key findings highlight the impacts of inadequate income, escalating daily expenses, attitudinal barriers and the rising cost of living, as well as participants' aspirations for financial security and dignity. After outlining and discussing these initial insights, the report lays the foundation for the delivery of Phase 2, which will explore key findings in greater depth through qualitative interviews and focus groups.

2 Te Aramahi / Methodology

Approved by the New Zealand Health and Disability Ethics Committee (2025 FULL 23672), this monitoring cycle takes place across two distinct data-collection phases using the Disability Rights Promotion International (DRPI) methodology. Originating in Canada, the DRPI framework was developed to establish a holistic, human-rights-based system for monitoring disability rights globally. Importantly, the DRPI methodology ensures that monitoring processes are led by disabled people themselves, while building the capacity of disabled human rights monitors. Specifically, it aims to:

- Provide a voice to marginalised populations;
- Enhance public awareness by documenting abuses and violations;
- Reinforce a collective identity amongst the disability community, and
- Support efforts to achieve social justice (Disability Rights Promotion International, n.d.).

2.1 Phase 1: Data Collection

The purpose of Phase 1 was to engage as many diverse disabled people and their supporters as possible in the monitoring process and to identify which specific topics within the overarching theme they wanted to be prioritised. This approach was designed to reflect the deep diversity of disabled communities in Aotearoa and to recognise that the cost-of-living crisis affects individuals and whānau in different ways. To do this, an accessible online questionnaire was designed to gather disabled people’s perspectives on the standard of living, the cost of living and the

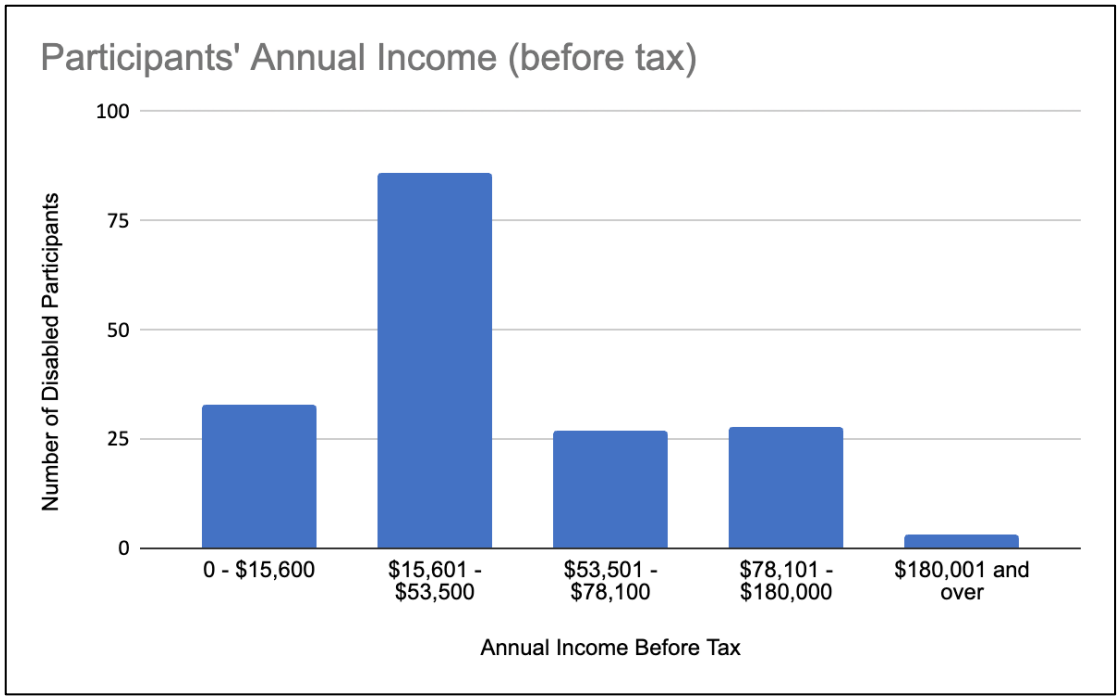
cost of disability, as well as their human rights experiences under Article 28 of the UNCRPD (the full questionnaire framework can be found in Appendix C).

Questionnaire responses were collected between December 2025 and January 2026. Research documents and the questionnaire were made available in alternative formats and languages (NZSL, Easy Read, Te Reo Māori, Braille, large print, and audio), and participation was open to all disabled people aged 18 and over, as well as their family, whānau, aiga and close supporters. Participants were required to provide their informed consent before participating. If a disabled person needed support or accommodations to complete the questionnaire, this was arranged by disabled monitors.

2.2 Phase 1: Participants

In total, 184 participants completed the questionnaire. This included 121 participants who identified as female, 35 as male, 18 as non-binary, two as takatāpui, four as 'other', and four chose not to disclose. There were 31 participants aged between 18 and 30, 141 participants between 31 and 64, nine participants were older than 65 years, and three chose not to disclose. Thirty-five participants identified as Māori, 146 participants as Pākehā, one as Fijian, eight as Cook Island Māori, six as Samoan, two as Niuean, 20 as 'other' ethnicities, and one chose not to disclose their ethnicity. Of the total, 146 participants identified as disabled (including tākata whaikaha Māori and whānau hauā), 13 as neurodivergent, 80 as having a chronic health condition(s), 13 as tākata turi/Deaf, and 38 as family members, whānau, aiga or close supporters of people with multiple and complex disabilities[1].

[1] The total equates to more than 184 as participants often registered multiple disabilities and identities.



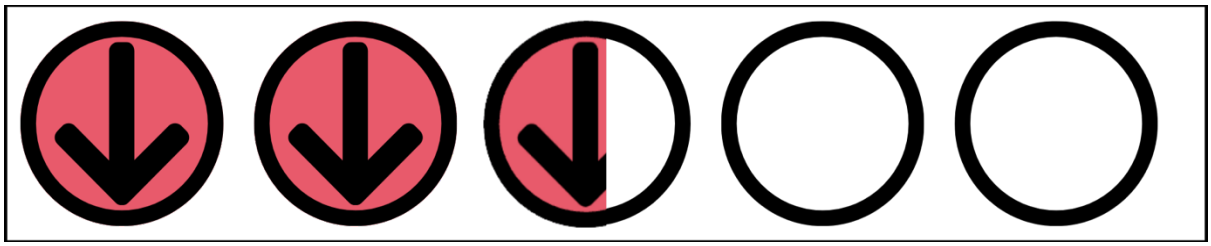
Thirty-three participants shared that their annual income before tax is between $0 - $15,600, for 86 participants it is between $15,601 - $53,500, for 27 participants it is between $53,501 and $78,100, and for 28 participants, it is between $78,101 - $180,000. Only three participants shared their annual income before tax is over $180,001.

2.3 Phase 1: Analysis

Once data collection was complete, Braun and Clarke's six-step thematic analysis was used to analyse the data (2006). This began with data familiarisation, generating initial codes, and searching for, reviewing and defining themes. This process produced five themes: income; cost of living; impacts of rising costs and declining standards of living; government attitudes; and hopelessness, dignity and aspirations. The data were then re-analysed within disability and identity cohorts, including disability types, age, ethnicity and gender. This enabled us to begin to identify any issues specific to different cohorts within the disability community.

3 Kiteka / Findings

Outlined below are five key themes that emerged from questionnaire responses contributed by disabled people and their supporters. While a small minority of participants noted they are currently managing despite a reduced standard of living, **over half of the participants (56%) reported an actual decline in their standard of living over the past five years[2].**



The following key themes examine the impacts of inadequate income and escalating daily costs, their consequences for participant well-being, and participants' aspirations for a financially secure and dignified standard of living.

3.1 Income

> **"I live in government-enforced poverty via the Supported Living benefit. No, they are not allowing us an adequate standard of anything." (Disabled participant)[3]**

The first key theme from the data related to the adequacy of income, which many participants said was a primary concern. Over 80 participants reported inadequate or unstable employment income, inadequate welfare or disability funding, loss of employment/income, depletion of savings, debt and reliance on partners or whānau due to insufficient personal income. As a result, many participants felt limited in their ability to afford essential items they *needed*, let alone the things they *wanted*. Within this finding, precarious employment, low benefit and disability funding levels, and

[2] There were 144 substantive responses to the standard-of-living question, with 80 coded responses (56% of those who answered that question) describing an actual reduction in living standards, choice, participation or ability to meet needs.

[3] To maintain participant anonymity, distinctions in quotes are made only between disabled participants and family members, based on their primary self-identification, without detailing other demographic identifiers. It should be noted, however, that some disabled participants also identified as family members.

compromised savings were identified as sub-themes that significantly impacted the adequacy of a disabled person's income.

3.1.1 Employment

In Aotearoa, it is estimated that at any given time, non-disabled people are twice as likely to be employed as disabled people. For example, in the months leading up to Phase 1 of data collection, data showed that only 38.2% of working-age disabled individuals were employed, compared with 78.5% of non-disabled individuals (StatsNZ, 2025b). Participants felt the impact of employment-related challenges deeply, citing unemployment, underemployment, workplace inaccessibility, ineligibility for disability support and the minimum wage exemption as influencing factors. For example, while participants acknowledged that securing employment is difficult for all people, they emphasised that it is becoming increasingly challenging for disabled people, particularly those whose impairments or health conditions preclude them from working.

> "As my mobility gets worse, I can no longer manage by picking up casual employment to help with extras." (Disabled participant)

Participants who were employed also shared their challenges. For example, one participant reported that, despite being employed, their income was insufficient to cover all their needs.

> "Normally I can't pay for everything I need, even though I work 30 hours a week. Normally I don't have enough money for all supplements or non-funded medication costs, so I normally have to go without it." (Disabled participant)

Some participants reported that their employment status impacted their ability to access much-needed means-tested disability support, and not having enough income to pay for it privately. One disabled participant noted the direct and indirect costs associated with maintaining their employment status, while another described the personal cost of needing to take unpaid leave beyond their sick leave entitlements due to disability.

> “To maintain employment, we have borne the cost of all our accessibility needs. To maintain health, we have borne most of our health costs, and these costs keep rising, so we go without.” (Disabled participant)

> “The cost of disability for me is the extended sick leave I must take and using all of my sick [leave], meaning I end up using annual leave or leave without pay.” (Disabled participant)

A final key point raised regarding employment was the Minimum Wage Exemption scheme, which permits certain employers to pay disabled workers below the minimum wage if their impairment is deemed to affect their productivity (Ministry of Social Development, 2024). Despite being identified as an unaddressed human rights violation by the United Nations Committee on the Rights of Persons with Disabilities (2022), the scheme remained active throughout the monitoring period. Multiple participants highlighted how policies, such as the minimum wage waiver scheme, can directly undermine disabled people's standard of living and financial independence.

> “Continuing to allow disabled workers to be paid less than minimum wage under the minimum wage exemption scheme.” (Disabled participant)

3.1.2 Financial Assistance and Welfare

Another major factor contributing to inadequate income was low levels of state financial assistance and welfare. When asked whether the New Zealand Government is meeting its obligations under the UNCRPD, many participants shared their experiences as beneficiaries. Participants agreed that current levels of state financial assistance and welfare do not enable disabled people to achieve an adequate standard of living and, specifically, have not kept pace with inflation.

> “There’s no way anyone could afford to rent a small unit alone on the disability benefit. There would be no money left for food, clothes or bills. Disabled people are not getting adequate

resources to afford good food, clothing and housing."
(Disabled participant)

"Since [...] 2019 the benefit for her has risen from just over $100 a fortnight to $118 a fortnight. No, I don't believe this is commensurate with the cost of living. That amount only barely covers her fuel to take her to school, never mind the doctor or the hospital for any appointments." (Family participant)

Some participants spoke about the restrictive nature of what the disability allowance can cover.

"A lot of treatments are unfunded and I've had to fight WINZ in order for the bare minimum to be added to my disability allowance. I haven't even asked for every cost to be covered." (Disabled participant)

"Weekly physio, doctors are now monthly not three-monthly. Disability allowance doesn't come close to covering half of the outgoings." (Disabled participant)

Participants who received benefits said they are not able to save for unexpected costs, which caused significant anxiety about the future.

"I got chronic fatigue, and went from working full time to now being on a Supported Living Benefit, and working 5 hours a week. I am good at managing money, and am lucky enough to have a little bit of savings, but worry about the affordability of my life going forward all the time." (Disabled participant)

Strict thresholds on how much participants could earn while receiving a benefit also prevented them from gaining much-needed additional income. Consequently, many were stuck on a benefit and unable to break the cycle of financial hardship. This was particularly relevant for participants who were unable to secure full-time work due to

a lack of employment opportunities that accommodate disabled people's access needs and energy levels.

> "With the only other option being temporary additional support, which also has a maximum, which you can apply for, also if you work the threshold for disability allowance is far too low income [other]wise there have not been extra provisions and there are no options for extra support to address these inequities - owning a home, living a life e.g. holiday, outings have not been possible since Covid." (Disabled participant)

3.1.2.1 Relationship Status

A specific challenge raised by women participants in particular was the impact of relationship status on disabled people's eligibility for financial assistance. Many reported being deemed ineligible for Work and Income (WINZ) support because their partner's income exceeded the income threshold, even when that income was insufficient to cover basic living costs for two people, or where finances were not shared. This finding is particularly concerning given the risks associated with a disabled person being financially dependent on a partner, including power imbalances, domestic violence and abuse. Forced financial reliance risks stripping disabled people of their autonomy, leaving many feeling trapped in relationships due to a lack of independent income (Goulden et al., 2026).

> "I have just had to stop working permanently due to disability and cannot access government help due to my partner working." (Disabled participant)

These restrictive eligibility criteria meant that some disabled participants felt unable to enter a relationship without giving up their financial independence.

> "I can't date someone without potentially losing my benefit income." (Disabled participant)

Participants repeatedly stressed that current benefit settings deny disabled people relationship equality and directly undermine their human rights, such as those

articulated under Article 23 of the UNCRPD – Respect for Home and the Family. As one disabled participant summarised,

> "We do not have relationship equality yet, disabled people cannot survive at the mercy of their partner choosing to share their income with them once their relationship is recognised. It is discriminatory and puts disabled people at great risk. Any income thresholds are not rooted in current reality." (Disabled participant)

3.1.3 Disability Funding

The third income-related sub-theme centred on disability funding, with many participants highlighting the shortcomings of funding packages for disability support services. Key issues included strict eligibility criteria, funding packages that did not cover basic needs, and a persistent gap between what a needs assessment recommended and what was actually funded. Several participants shared that they were ineligible for DSS support funding and equipment because they failed to meet criteria or their disability was not recognised. As a result, individuals and families went without, or bore the financial burden of paying for essential disability equipment out of pocket. A small number of participants obtained basic items through charitable providers like Blind Low Vision NZ.

> "My teen does not qualify for government assistance for medical costs, including wheelchairs. We have to pay for it all ourselves. The custom wheelchair will be $25k, and we are crowdfunding for it. I pay their medical insurance. They can't use public transport and the Total Mobility subsidy isn't enough to allow them out of the house. They are isolated and struggling. I am struggling as a full-time carer with a full-time job and being disabled myself." (Disabled participant)

Other participants noted they were shut out of essential support because they earned above the threshold for means-tested assistance, such as household management, which requires a Community Services Card (Disability Support

Services, 2026). Consequently, some participants were left unable to meet their basic needs and had to resort to fundraising to acquire necessary disability equipment and support.

> “[We’re] unable to access home support despite being assessed as needing it. Am concerned that my partner's MS may progress to needing modifications to the house and worried that won't be able to get help with it.” (Disabled participant)

And finally, as has been highlighted in previous monitoring reports (Donald Beasley Institute, 2025a; 2025b; 2025c; 2025d; 2025e; 2025f), many participants emphasised the ongoing financial strain caused by recent and proposed changes to Disability Supports and Services.

> “There have been and continue to be too many cuts to funding etc., which is taking a toll.” (Disabled participant)

3.1.4 Savings and Debt

Finally, participants noted the long-term impacts of inadequate income. Beyond precarious employment and limited financial support across welfare and disability services undermining their ability to save or contribute to KiwiSaver or retirement funds, the rising cost of living had forced many to dip into existing savings just to cover day-to-day expenses.

> “Over the years I have also been having to chip into my savings such as KiwiSaver, and market shares to cover at least essential costs.” (Disabled participant)

> “[The cost of living is] increasing with inflation [and] reducing value of retirement nest egg.” (Disabled participant)

Going into debt to cover essential needs was also a concern, especially for participants without access to savings or retirement funds

> “There is no want beyond what you need, because there are no extra funds without going into debt.” (Disabled participant)

In summary, participants described compounding barriers to securing adequate income across employment, state financial assistance, and disability support services. These systemic shortfalls caused material hardship that eliminated savings, compromised long-term security and caused persistent psychological distress, which ultimately eroded their standard of living,

3.2 Cost of Living

> **"It has become increasingly difficult to meet the costs of basic daily living. We have gone from living week to week to living day to day since 2021 and have had to cancel GP visits because we can't afford it." (Disabled participant)**

The second key theme highlights how the rising cost of living has reduced participants' standard of living, with many reporting severe levels of financial and material hardship. The section below explores the specific challenges participants raised across different life areas - from housing, food, utilities and clothes, to transport, healthcare, and disability-specific costs.

3.2.1 Housing

Over 40 participants spoke about housing insecurity, including affordability, homelessness or risk of homelessness, unsuitable/inaccessible or substandard housing, inability to move because of cost, and dependence on others for secure housing - issues that had already been raised during the 2018 - 2020 cycle of Disabled Person-Led Monitoring on the right to adequate housing (Donald Beasley Institute, 2020a; 2020b). For example, many participants reported significant increases in housing-related costs over the past five years, sharing that rising rents, rates, and insurance left them feeling uncertain about the future. A lack of accessible and affordable housing forced many into less-than-ideal living situations, with some waiting long periods to access public housing. Crucially, many available homes remain inaccessible and fail to meet their access needs.

> “I haven’t moved out because housing is too expensive and whilst my needs are basic it’s hard to find something in my budget. I’ve been waiting for a state house for years.” (Disabled participant)

Participants who had housing that met their needs said they spend more than half of their income on housing, which puts them under significant financial pressure.

> “Because of how my disabilities affect me, I am unable to cohabitate and live close to people. I live out of town in a standalone house with no one around me. That is very expensive and it is not really a luxury but a necessity. I think it's unfair that I have to pay up to 70% of my income on housing and work full-time even though it is killing me.” (Disabled participant)

> “The cost of living has definitely increased. My husband and I have a healthy income but with increased housing and food costs, this makes it hard and we very much live week to week.” (Disabled participant)

As these quotes highlight, even when employed, rising housing costs compromise disabled people’s ability to live securely and safely.

3.2.2 Food

Affordability of food was another key concern. While not all participants answered every question, 42 participants described insufficient food, skipping or reducing meals, an inability to afford appropriate or nutritious food, needing food grants/kai parcels, or having to choose food over other essentials. For example, some participants shared that they often had to choose between essential staples such as meat, produce, and dairy, and weigh a balanced diet against simply having enough to eat. As a result, many feared for their long-term health.

> “[D]ue to food costs I am unable to eat the food that would be best for my health.” (Disabled participant)

Food affordability was particularly concerning for participants with specific dietary needs, as specialised products for allergies and intolerances further increased their grocery budgets.

> “With ARFID and IBS I have very limited and expensive food options. I can only afford to eat one meal a day, if I'm lucky two.” (Disabled participant)

Another factor impacting food budgets was disability-related fatigue, which left some participants with limited energy to prepare meals. Consequently, they often relied on pre-prepared options or takeaways, significantly increasing their overall food costs.

> “I have to spend an uncomfortable amount weekly on things like ordering food because I am unable to reliably stand in the kitchen and prepare meals.” (Disabled participant)

According to participants, food insecurity had a unique and compounding effect on disabled people's health, wellbeing and energy levels, which directly exacerbated the day-to-day impacts of their disabilities.

3.2.3 Utilities

Many participants highlighted rising utility prices as impacting their everyday standard of living.

> "Power and water have increased in cost even though usage has gone down." (Disabled participant)

> “Our heating costs rose significantly (wood to burn) as we had to keep our house warm year round for our daughter. The fire was alight all day and night, for nearly 11 months of the year. We ran 2 heat pumps to warm her bedroom.” (Family participant)

For example, some participants said they were forced into a difficult trade-off: go without adequate heating or cooling, which often worsened their health, or absorb exorbitant power bills to stay well.

> “Power costs have increased to the point where even with the energy payment, I am not able to afford heating in winter causing other health issues.” (Disabled participant)

> “Increase in electricity costs for heating because if I get cold I end up sicker.” (Disabled participant)

To save money, some participants tried doing household chores manually rather than using electricity. However, given the energy limitations associated with their disabilities, this extra physical strain left them fatigued and unable to manage other daily tasks.

> “I’ve had to stop using my tumble dryer to save electricity. Hanging the washing uses energy I don’t have, so I have to sacrifice other tasks.” (Disabled participant)

As summarised by one participant, the daily realities of being disabled often meant consuming more power than non-disabled people, compounding the impact of rising costs.

> “Direct and indirect costs have increased. We use more power in this house than the average two-person household, mainly due to my use of the computer as it is my primary communication tool.” (Disabled participant)

3.2.4 Clothing

The ability to afford appropriate clothing was another challenge raised by multiple participants. For instance, one participant explained that they struggled to afford warm clothing, making it difficult to manage through the winter months.

> “I don’t use my heating or heat pump due to it being expensive. It's hard to afford extra clothing because the money we get is not enough on a benefit.” (Disabled participant)

While limited government assistance for clothing was available, this was often treated as a loan that had to be paid back, creating further debt risk.

> “Clothing etc. is harder to access, and despite being a cost that is usually loaned/paid back to MSD.” (Disabled participant)

Notably, clothing affordability was identified as a challenge for particular disability cohorts, such as neurodivergent participants, who required specific materials or fits to accommodate sensory needs.

> “[A]s part of my neurodivergence, I have a lot of sensory issues, so I have a hard time wearing a lot of fabrics, so I have to pay way more for soft cotton and bamboo clothes, polyester makes me itch really bad. And the cost of decent non-polyester clothes has gone up quite a bit.” (Disabled participant)

3.2.5 Transport

A further area of concern for participants was the increasing cost of public and private transport.

> “It has always been expensive but now more so. I limit trips to town to once a week due to cost and the physical impact going out has on me.” (Disabled participant)

Several participants shared that they relied on private cars or taxis rather than public transport due to energy constraints and accessibility needs. However, escalating costs such as petrol, registration, and vehicle maintenance forced them to stay home and limited their ability to participate in the community.

> “Transport costs have also increased. Travelling to Deaf events, hospital appointments, or community activities often requires more time and planning because accessible public transport is limited. Petrol prices have gone up sharply, and so has parking. This means that simply participating in the Deaf community or attending important meetings costs more than before.” (Deaf participant)

As this participant highlighted, the prohibitive cost of transport directly restricted their ability to engage with their community, a barrier that other participants linked to the broader psychosocial impacts of a declining standard of living (for further examples, see section 3.3.4).

3.2.6 Healthcare

Healthcare services were also identified as an area of escalating costs. Even where services exist, many participants reported that high fees and limited availability created significant barriers, leaving them unable to access pain relief, mental health support, and other essential treatments.

> “[I want to have] access to medical needs at an affordable price without a ridiculous wait time (took me 18 months to access MHAIDS psychiatrist while actively suicidal and so far [I have] treatment resistant depression).” (Disabled participant)

One participant described feeling that healthcare costs are continually rising with no end in sight, noting that even routine access to repeat medication requires weeks of financial planning.

> “It is getting higher and doesn't seem to stop. The simple things of seeing the doctor for repeat medication have become so much I have to plan weeks in advance to be able to pay it.” (Disabled participant)

Another participant highlighted that medications may only be partially subsidised or lose funding over time, while non-funded treatments like acupuncture remain entirely out of reach, sometimes requiring them to borrow money just to afford necessary pain relief.

> "It's true that I do feel that I have higher costs, and I have become used to not being able to access some treatments that do help alleviate my pain levels (like acupuncture etc.) as they are not fully subsidised. Currently the pain medicine that I am on is not cheap (around $60 per script) so that might not be a long term solution as I had to borrow money last time to be able to get it." (Disabled participant)

In summary, participants' experiences showed that health costs are not isolated expenses. They form part of a broader picture where increasing needs and reduced funding create a cycle of financial hardship, debt and deteriorating wellbeing. As one participant summarised, these mounting costs and declining health create a difficult cycle to break.

> "Before becoming sick my increased costs included psychiatrist, therapist, medicine and food. Now it's a lot more medical appointments and medicine, other more health specific food/supplements, body temperature issues means constant heater or fan use. Unable to work as much = increased transport use. There's a whole heap of stuff I would like to access for my health but can't afford." (Disabled participant)

3.2.7 Disability-Specific Costs

Finally, participants often associated rising expenses with being disabled. While escalating costs for accessible housing, specialised food and clothing, transport, utilities, and healthcare were shared across the different demographics[4], there were

[4] Following initial analysis, responses were thematicised across participant cohorts, including ethnicity (e.g., Māori and Pasefika), disability type (e.g., learning disabilities and Deaf), age, and gender identity.

key differences between cohorts regarding disability-specific expenses. These unique findings are summarised below.

For example, neurodivergent participants highlighted additional expenses linked to adult diagnoses and accessing sensory-friendly activities. They also noted the hidden, downstream costs of managing untreated symptoms, including what some termed the ‘ADHD tax’, as well as expenses resulting from impulsive decisions, difficulty maintaining focus and memory lapses.

> “Difficulty in getting diagnosed with a disability for neurodivergence or to get treatment as an adult unless [you] can self-fund, hidden costs and extra expenses e.g. ADHD tax or propensity to impulsivity and injury from poor decision making or inattention” (Disabled participant)

Family members of people with multiple and complex disabilities highlighted a critical shortage of practical, affordable support and respite care. One participant explained that even when carer support funding is approved, the rates are too low to cover the real cost of a support worker, which leaves families without adequate help.

> “The most pressing need for me is the need for respite. I get a little carer support funding but it's only $80 a day which is not enough to pay a carer since I have no family nearby to volunteer.” (Disabled participant)

Blind and low vision participants highlighted how some assistive technologies cost more, not because they offer better quality, but simply because they are accessible. Several participants described this mark-up as a ‘disability tax’.

> “[T]o get tactile appliances without a touch screen is more expensive even though the technology is older. Examples are microwave, oven, washing machine. I found a washing machine with Braille on it when mine broke but it is about $600 more expensive than the ones with touch screens that are not tactile. I use a very light cane because of [a] shoulder injury, when this

> broke I could not get the one I needed for free under the free cane scheme and needed to pay $298 for a white cane I can use with a bad shoulder." (Disabled participant)

D/deaf participants reported challenges accessing consistent and affordable communication supports, such as interpreters, devices, reliable internet and assistive technology. These barriers left some participants isolated from their community and forced others to absorb the expense of essential equipment.

> "Since 2021, the cost of disability has increased in many ways for me and my family. As a Deaf person, I rely on communication access, technology, and accessible services to participate fully in daily life. However, these essential supports have become more expensive or harder to access. One indirect cost is the increased need for reliable technology and internet for communication. I depend on video calls, interpreters, and relay services, and these all require strong internet, good devices, and sometimes paid upgrades." (Disabled participant)

Participants with multiple disabilities also highlighted how intersecting needs compound their expenses. For example, one participant noted the higher price tag of specialised equipment.

> "The cost of intersectional disability needs is more. For example, being Deafblind, equipment is more specialised and expensive." (Disabled participant)

In summary, across all disability types, the message was clear: rising costs are perpetuated by increasingly disabling systems. As one participant eloquently summarised, the burden of these costs does not lie with disabled individuals. Rather, removing access barriers and addressing funding gaps is a fundamental obligation of the New Zealand Government as a State Party to the UNCRPD.

> "The true cost of disability is hidden in the fabric of this disabling society. Access issues mean we may need paid help for

everything from accessing information to running simple errands, whereas a truly inclusive and universally-designed world may offset some of these costs. Meantime, it is the duty of governments to bridge the gap properly." (Disabled participant)

3.3 Impacts of rising costs and declining standards of living

"I can't do anything else but stay home because I can't afford to go out and enjoy life or buy things that I may need to better my health or pay for more education to help me get into new employment once my health improves. I feel like a prisoner within my own home because of my lack of funding support and freedom to do more fun activities in my life that would improve my mental health and well-being plus have a better outcome." (Disabled participant)

The fourth key theme addresses the impacts of the rising cost of living for disabled people in Aotearoa. Participants detailed how escalating costs were directly eroding their standard of living, including straining natural supports, restricting personal choice, forcing increased compromise, and degrading psychosocial wellbeing.

3.3.1 Natural Supports

One of the impacts of the rising cost of living described by participants was the need to increasingly rely on natural supports (unpaid whānau/family and close supporters) in order to meet rising daily costs. Some participants who were financially supported by their whānau recognised that without this support, their standard of living would change dramatically. Others who relied on natural supports said it negatively affected their ability to make choices, how they lived their lives and their standard of living.

"[My standard of living is] average, I am not able to move out of my family's home due to cost, if I moved out of home I'd be living pay check to pay check." (Disabled participant)

Similarly, another participant described having no choice but to rely on natural supports, and the safety risks associated with it.

> "Since becoming sick, my standard of living has completely dropped. I have to live with family in an abusive relationship as I can't afford to move out while relying on WINZ job seeker medical, my only other option is to become homeless." (Disabled participant)

As reported by this participant, and has been highlighted by national and international research, dependency and forced reliance on natural supports, as well as inadequate income can increase the risk of disability violence and abuse (Donald Beasley Institute, 2022b; Plummer & Findley, 2012).

3.3.2 Choice and Compromise

Relatedly, participants described how the rising cost of living has restricted their ability to exercise choice and control in daily life, and forced them to compromise on both basic needs and personal wants. For example, many participants shared that their income only covered the bare necessities, forcing them to forgo discretionary spending on things they 'want' and, at times, even to reframe essential needs as unaffordable luxuries.

> "I'm not able to buy anything beyond the basics that I need. I don't get to choose how I live." (Disabled participant)

> "The cost of living means there is less means to buy what we want or have freedom and dignity to live our lives. It means sacrifices have to be made - clothing for example is harder to access now." (Disabled participant)

As described earlier, other participants described being unable to eat the food they wanted, going without food, being unable to afford supplements and non-essential medications, not being able to leave the house, and being unable to change their

living situations. Participants routinely described making agonising trade-offs between fundamental human needs, such as choosing between transport or food, or deciding whether to pay utility bills or eat.

> “I struggle with daily living as I live in a substandard situation. I do not have extra money to fix my circumstances and have to prioritise bills over how much can be spent on groceries.” (Disabled participant)

> “We had not enough money for food or medicine, not enough money for transport, we often had to skip meals.” (Disabled participant)

3.3.3 Participation and Isolation

Several participants noted that their standard of living and wellbeing had steadily declined due to cutting back on leisure activities and pulling away from community participation. Participant experiences highlight that the government is not upholding disabled people’s human rights under Article 19 – Living independently and being included in the community and Article 30 – Participation in cultural life, recreation, leisure and sport of the UNCRPD.

> “I often have to say no to optional purchases such as buying food while socialising or buying tickets to concerts. This feels like a lower standard of living as I am missing out on culture, enrichment, and building my social connections.” (Disabled participant)

> “I haven't been on a holiday away since before the pandemic hit. I used to like going on little getaways occasionally, and loved to travel. That does not happen anymore. I liked being able to treat myself and my friends to things we enjoyed (like going to the movies or buying flowers for their birthdays), now I can't afford it.” (Disabled participant)

> “I used to play various blind sports but it's too expensive to travel, replace equipment and I had to stop. Which has been hard on my wellbeing. Same with a gym membership (stopped in 2023). It's harder to get out and exercise, the gym was an accessible space for me.” (Disabled participant)

As one Pasefika participant described, the rising cost of living had created ripple effects across their entire family. They shared the pain of pulling back from family gatherings due to being unable to contribute:

> “We don’t offer to have our grandchildren visit us because we don’t have food for them and we rarely attend family gatherings because we don’t have anything to contribute to the lunch/dinner.” (Disabled participant)

3.3.4 Psychosocial Impacts

Many participants described the psychosocial impact that the rising cost of living had had on them. Participants indicated they struggled to meet essential costs and described feeling stressed, anxious, lonely and overwhelmed by their circumstances.

> “And makes me more stressed out and lack sleep due to thinking what's going to happen to me if things don't improve.” (Disabled participant)

> “Financial stress and insecurity is very stressful, ongoing, and not good for mental health (ADHD is worse with stress and anxiety).” (Disabled participant)

Forced to prioritise basic necessities over discretionary spending, many participants reported withdrawing from social and community life, leading to isolation. The cumulative expenses of accessible transport, club fees, and disability-related access costs made ongoing participation in community activities financially impossible.

> “Fewer organisations can afford interpreters, means my access to wider community is curtailed.” (Disabled participant)

> “I've given up clubs and interest groups as they want donations and fees to attend.” (Disabled participant)

Combined, the mental, emotional and social pressures of financial hardship compound over time for disabled people, reinforcing existing administrative data that highlights high levels of psychological distress experienced by disabled people in Aotearoa (Health Quality & Safety Commission Te Tāhū Hauora, 2026; Ministry of Health, 2023). As summarised by one participant:

> “This all adds up to add [an] extra burden on my health and stress and limits me more.” (Disabled participant)

3.4 Government Attitudes

> **“I think disabled people are being treated as an afterthought, and, as well, you should be thankful you have your basic needs met and shame on you for asking for stuff that makes your life better, not just tolerable.” (Disabled participant)**

The fourth key theme centred on how the attitudes of those in positions of power directly affect disabled people. Participants consistently reported that government officials and public servants lacked both the disability literacy required to champion meaningful change, and the willingness to act. Consequently, participants characterised decision-makers as uncaring, indifferent to disabled people's lived realities and inclined to view disability as a burden—attitudes identified as directly contributing to a declining standard of living.

For example, some participants felt that government officials did not care about the realities of living with a disability in Aotearoa.

> “They are not interested in quality of life issues. [They] operate from a scarcity-based social policy model.” (Disabled participant)

> “I feel that this Government doesn't care about disabled people at all which has impacted on my health and well-being.” (Disabled participant)

Other participants said they felt ignored by the government.

> “[T]hey are not listening to us when we are asking for help.” (Disabled participant)

> “They are not listening to us and they are continuing to use people with impairments as political footballs.” (Disabled participant)

Participants also reported that negative attitudes towards disabled people also extended to frontline public servants operating at the community level.

> “ACC is corrupt and horrifying to deal with, requiring repeated legal intervention to receive the barest minimum of services. WINZ is a dangerous, upsetting and accusatory environment full of uneducated judgemental desk staff that are rude and ignorant. I often go without supports and benefits that I am legally entitled to and have proof I need as it is too upsetting to fight repeatedly for them.” (Disabled participant)

Many participants said they also felt the government viewed them as an economic burden, an attitude they believed directly informed policy decisions affecting disabled people’s standard of living.

> “I feel like I am a burden to the NZ Government when needing anything to do with my disability.” (Disabled participant)

> “[T]hey are attached to neoliberal mindsets where the people worthy of their support are the tiny minority *they* deem

incapable of working sufficiently to earn their way." (Disabled participant)

"Because traditionally disabled people are not business owners or money makers and the current government views money as a metric of value." (Disabled participant)

One participant reasoned that due to a lack of disability representation within government agencies, income policies were being designed by non-disabled people without considering the lived realities of disabled individuals.

"Why is there not any employment equity for disabled people in government departments? Because until we have equitable representation and equitable income options, we will never have equitable lives and living conditions (affected by policies designed by solely able bodied people for inclusion of only able bodied people in communities & levels of society)." (Disabled participant)

Ultimately, participants viewed negative and discriminatory government attitudes as contributing to their financial and material hardship. These attitudinal barriers undermine disabled people's financial security, obstruct access to adequate income and exacerbate the pressures of the rising costs-of-living. As summarised by one participant:

"We feel like we are 3rd class citizens." (Disabled participant)

3.5 Hopelessness, Dignity and Aspirations

"I think the disability community has so much to teach the human race and I hope we'll be given the opportunity to do so because what we have to contribute to the world can only make life and living beautiful." (Disabled participant)

The final key theme explores participants' aspirations for the realisation of Article 28 of the UNCRPD – Adequate standard of living and social protection. However, these aspirations must first be considered alongside a strong sense of scepticism, with many participants expressing disbelief that immediate, meaningful change to disabled people's living standards would occur any time soon. When asked whether the Government was meeting its Article 28 obligations, 131 participants responded with answers that indicated no, not adequately, only to a limited extent, or otherwise clearly indicating that the obligations were not being met, about 96% of people who answered that question (137 total responses)[5].



As highlighted by one participant, while "radical change" is needed, " in reality I know we will, at best, have some gradual change over decades." Other responses reflected widespread hopelessness regarding current and future living conditions, underscored by recurring reports of social isolation, eroded trust in public systems and severe impacts on the standard of living. This sense of hopelessness is a direct consequence of ongoing structural barriers that left disabled people feeling disconnected, unsupported and resigned to an uncertain future. As summarised by one participant:

> "I would hope that the standard of living would improve but I have very little hope of it doing so." (Disabled participant)

Even amidst widespread scepticism, however, some participants still shared their aspirations for an improved standard of living for disabled people in Aotearoa, including more dignified lives, adequate income and supports, choice and control, the realisation of basic human rights and a shift in government attitudes.

[5] There were 137 substantive responses to the question asking whether the Government was meeting its Article 28 obligations. 131 participants were coded as saying no, not adequately, only to a limited extent, or otherwise clearly indicating that the obligations were not being met (about 96% of people who answered that question).

3.5.1 A Dignified Life

Some participants framed their circumstances through a lens of relative gratitude, attributing their “small mercies” to luck when comparing themselves to others. This is a form of adaptive preference, whereby people who are facing long-term structural barriers (such as poverty, ableism, or social inequality), adapt their aspirations to what seems realistic. A minor improvement or basic accommodation is celebrated as a “small mercy” rather than recognised as a basic human right or standard entitlement (Sen, 1992, p. 55)[6].

> “Even though I'm lucky to live in a warm, dry, accessible house, a lot of other disabled people in my position couldn't achieve this unless they had enough money/luck to be able to buy/modify a home.” (Disabled participant)

> “Again, we're lucky. The only reason we're lucky is we were able to buy a house and fix interest rates while things were manageable. The house opposite us was up for rent for twice what we pay in mortgage. It makes me sick. We would not be coping if we didn't have that luck.” (Disabled participant)

However, this framing implies that an adequate standard of living is an exception rather than a fundamental human right. The UNCRPD establishes that all disabled people possess inherent human dignity and are entitled to live with autonomy, independence and freedom from discrimination. It says that the New Zealand Government, as a State Signatory, must protect this dignity through equal rights, accessibility and inclusion in all aspects of life (UNCRPD, 2006). Participants said that for them, living a dignified life meant having the freedom, security and support to live well, rather than just surviving. It is more than subsistence, or having one's basic needs met. It means treating disabled people with respect, ensuring their basic needs are met, and supporting them to fully participate in their communities. For

[6] Forced gratitude and luck are themes that have been repeatedly raised throughout Disabled Person-Led Monitoring cycles (Donald Beasley 2020a; 2022b; 2022).

example, when asked what their hopes were for disabled people's standard of living in Aotearoa, one participant responded:

> "That they [disabled people] get the support[s] they need, when they need them. That they will be treated as valuable members of society." (Disabled participant)

Specifically, participants articulated that living a dignified life requires adequate income and disability supports, the ability to make informed choices and exercise control over their lives and having their human rights fully protected and upheld. One participant highlighted how Māori values can provide a useful framework for achieving this:

> "I think in a Te Ao Māori perspective it's about Mana - to have the ability to take care of yourself and whānau is about Mana enhancing. It's about connection to all elements like te taiao so that we can all flourish." (Disabled participant)

3.5.2 Adequate Income

As reported throughout the findings, many participants described financial hardship that prevented them from meeting their basic needs. Inadequate income and limited access to essential disability supports often forced participants to compromise on their needs, leaving them to choose between housing, food, or healthcare. Many aspired to a life where they had adequate income and so did not have to make these impossible decisions.

> "We deserve to be able to afford not just the basics, but also enough to live a good life." (Disabled participant)

> "That the majority aren't suffering in poverty and we have the resources and tools to thrive and look after ourselves to keep our health as good as it can be." (Disabled participant)

> "That we are able to access all of the same things as everyone else. A liveable income regardless of capacity to work, ability to

> access in home and community support regardless of income, ability to purchase a home, comfortably cover needs and some wants and save for retirement. We should be allowed and encouraged to build wealth through shares and current assets without being penalised when we need help." (Disabled participant)

Analysis of the responses shows that disabled people believed that financial security is fundamental to living a dignified life, with participants strongly emphasising that disabled people should not have to sacrifice one essential need for another.

3.5.3 Choice and Control

Participants also aspired to greater autonomy over their lives, including being able to decide where they live, the care they need and to participate in their communities without unnecessary barriers. As shared by one participant:

> "I don't want millions. I just want a life of dignity and a little freedom." (Disabled participant)

> "People should have enough to live and have choice over their lives." (Disabled participant)

As highlighted by one participant, not all disabled people or disabilities are the same. Choice and control means recognising the diverse needs disabled people have when it comes to an adequate standard of living.

> "There needs to be more flexibility/choice. Not all disabilities are visible or totally disabling. Some days are good for me and others are dreadful." (Disabled participant)

Importantly, participants' aspirations were not about having luxuries or more than non-disabled people have, but about being able to make meaningful choices and live independently.

3.5.4 Human Rights

Participants also emphasised the importance of disabled people being recognised as valued and equal members of society and as human rights holders. Under the Universal Declaration of Human Rights (United Nations, 1948), all people have the right to a standard of living adequate for the health and well-being of them and their family, including food, clothing, housing, medical care, social services, and security in the event of unemployment, sickness and disability. For one participant, their hope was simply for disabled people to be treated respectfully, rather than as a burden, and to have their basic human rights upheld:

> "That we are treated equitably and like important members of society - not like a stain that has to be 'dealt' with. That they [disabled people] don't have to risk their safety to be able to have somewhere to live. That they don't have to stop taking important medicine because they can't afford it. That they can't get a diagnosis merely because they can't afford it. That they don't have to skip meals to pay rent or medicine." (Disabled participant)

As demonstrated by this quote, this participant, and others, aspired to what most would consider the bare minimum for a good and dignified life: safety, choice and basic necessities.

3.5.5 Governmental Shift

Finally, participants said that for these aspirations to be realised, the New Zealand Government needs to make a major systemic shift. This involves changing the structures, systems and attitudes that have continued to create barriers for disabled people and diminish their standard of living. For example, various participants described the need for a Government that values disabled people as equal citizens, removes discriminatory practices, and provides financial stability alongside disability supports that enable them to participate fully in society. These shifts include policy reforms and the establishment of a universal basic income.

> “I believe that disabled people should have access to the services, supports and care that they need, no questions asked. I would like there to be an established trust-based economy of resources available for disabled people, provided by the NZ Government.” (Disabled participant)

> “I hope one day we will implement a universal basic income, which would really help unpaid carers and disabled people. There is so much paperwork accessing disability funding and the onus is on families to do all the research themselves about how to access it. It's so complicated. (Disabled participant)

Participants also called for the New Zealand Government to create and develop systems that are built on trust. Many said they do not feel that the New Zealand Government is doing enough to understand their lived realities, and that they do not feel heard. This is despite the Government’s efforts over the past five years to consult with the disability community on issues that matter to them[7].

> “For them to visit us, talk with us, live in our shoes and see for themselves how hard it is.” (Disabled participant)

One participant noted that they would like greater transparency around government spending to know where funds are being spent,

> “I would like to see a bigger breakdown of what the government spending is, how much is being sent to the healthcare industry, where money is being spent inside public healthcare and how it gets audited so that every dollar spent is used efficiently.” (Disabled participant)

In summary, while hopelessness was a theme underpinning questionnaire responses, participants outlined a clear vision for a dignified life grounded in adequate income and disability supports, autonomy and basic human rights.

[7] For example, see Donald Beasley Institute (2025c).

Achieving this, however, requires a fundamental shift in the government's approach to disability; one where disabled people are trusted as experts in their own needs, and where the state works in genuine partnership with disabled people, guided by transparency and consideration for their lived realities. As outlined by the UNCRPD, these aspirations are not extraordinary expectations but basic conditions that enable improved standards of living and dignified lives.

4 Kupu Whakamutaka / Concluding Remarks

This report presents preliminary findings from the 2025–2027 disabled person-led monitoring research cycle. Drawing on questionnaire responses from across Aotearoa, it details how disabled people and their whānau have navigated living standards, rising living costs and the extra cost of disability over the last five years. The purpose of this monitoring research is to understand whether, and to what extent, the New Zealand Government is upholding disabled people's rights under Article 28 of the UNCRPD.

Already, Phase 1 findings reveal a stark reality: disabled people and their whānau are experiencing severe financial and material hardship. Driven by precarious employment, restrictive welfare settings, changing disability support systems, eroded savings and pervasive attitudinal barriers, participants reported a sharp decline in their standard of living over the monitoring period. Furthermore, rising costs are affecting every aspect of their lives, including housing, food, utilities, clothing, transport, healthcare and disability-specific needs. As these essentials slip further out of reach, participants described how the resulting stress, isolation, and anxiety is taking a heavy toll. This relentless strain has damaged relationships with natural supports, restricted choice, forced daily compromises and degraded overall wellbeing. In the most severe cases, it has contributed to secondary or acquired conditions, malnutrition and unsafe living arrangements.

While some participants expressed gratitude for their current circumstances, the framing of basic economic security as a stroke of luck rather than an inherent right

signals failure at the highest level. Many participants also shared that while they prioritised meeting their basic needs, disability-specific needs often remain unmet, and that their experience is not equitable to those of non-disabled people. Participants aspired to a life of dignity, adequate income, choice and control and where their fundamental human rights are met. However, fulfilling the promise of Article 28 requires a fundamental shift in how the New Zealand Government views and responds to disability. It obligates the Government to move beyond fostering mere subsistence and to actively guarantee disabled people the financial independence, self-determination and dignity to which they are entitled.

In Phase 2, this cycle of monitoring will delve deeper into the most pressing issues identified through these questionnaire responses. For example, the impact of relationship status on disabled people's access to financial assistance and welfare, and the experiences of disabled people employed under the minimum wage exemption and those who have used retirement savings and KiwiSaver to cover everyday costs associated with disability. In doing so, the aim is to enrich the evidence base feeding into New Zealand's United Nations reporting cycle, while equipping disabled people with the knowledge and tools needed to immediately advocate for the full and meaningful implementation of Article 28 in Aotearoa.

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Appendix A - Kā Whakamārama / Glossary

Cost of Living: The money needed to cover basic cost of living, such as housing costs, utilities, food, communication and transport (Immigration NZ, n.d.).

Disability: “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (Article 1, United Nations, 2006).

Learning disability: An alternative term to describe intellectual disability. It is the term preferred by self-advocates with learning disabilities in Aotearoa New Zealand (Milner, Mirfin-Veitch & Conder, 2013).

Means-tested: A means-tested payment refers to a financial benefit or subsidy that is only granted if your financial situation (your "means") falls below a specific threshold.

Multiple and complex disabilities: Also referred to as high and complex needs, this terminology includes individuals who have multiple disabilities including sensory disabilities, physical disabilities, severe intellectual disability, or serious and ongoing medical conditions; behaviours that may require a very high level of support; a lack of appropriate services or policies to meet their intensive support needs; and who often are unable to voice their needs in appropriate forums due to their severe intellectual and learning disabilities (Complex Care Group, n.d.).

Psychosocial Disability: “[T]he functional impact and barriers which may be faced by someone living with a mental health condition. A psychosocial disability arises when someone with a mental health condition interacts with a social environment that presents barriers to their equality with others” (NSW Health, 2023, para. 2).

Standard of living: There are various definitions for this term. For the purpose of this report, standard of living is the comparison of disabled people's standard of living with their non-disabled peers, as reported through self-measurement.

Whānau hauā me tāngata/tākata whaikaha Māori: Whānau hauā refers to Māori disabled people and their whānau. Whānau hauā acknowledges that the experience of disability is a collective whānau experience (Hickey & Wilson, 2017). Tākata whaikaha Māori is a more recent term for Māori disabled people, and tāngata/tākata whaikaha refers to the determination and ability of Māori disabled people (Ministry of Health, 2018).

Appendix B - Foundational Documents and Models

This monitoring project is underpinned by the UNCRPD (specifically Article 28 – Adequate standard of living and social protection), Te Tiriti o Waitangi, the New Zealand Disability Strategy 2026-2036 and Enabling Good Lives (EGL). Further models and frameworks identified through the integrative literature review as crucial to disabled people's experiences of Article 28 and the cost of living, standard of living, and cost of disability, included Te Whare Tapa Whā, the Fonofale Framework, the Human Development Model for Disability and Health, and Distributive Justice.

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

The UNCRPD is an international agreement that sets out what governments must do to ensure that disabled people have the same rights as everyone else (United Nations, 2006). Article 28 – Adequate standard of living and social protection is especially relevant to this monitoring cycle:

Article 28 of the UNCRPD

1. States Parties recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability.
2. States Parties recognize the right of persons with disabilities to social protection and to the enjoyment of that right without discrimination on the basis of disability, and shall take appropriate steps to safeguard and promote the realization of this right, including measures:

    a) To ensure equal access by persons with disabilities to clean water services, and to ensure access to appropriate and affordable services, devices and other assistance for disability-related needs;

b) To ensure access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programmes and poverty reduction programmes;

c) To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care;

d) To ensure access by persons with disabilities to public housing programmes;

e) To ensure equal access by persons with disabilities to retirement benefits and programmes. (United Nations, 2006)

Enshrined in Article 28 of the UNCRPD is disabled people's right to a standard of living, measured by access to adequate food, clothing, and housing, and the improvement of living conditions. Disabled people who live in poverty also have the right to access State assistance in situations of poverty to help with disability-related expenses (Mont, 2023).

Te Tiriti o Waitangi

Te Tiriti o Waitangi is the founding document of Aotearoa New Zealand. It sets out the agreement between Māori and the Crown, including disabled people, on how to exist in peace and partnership. Te Tiriti o Waitangi guarantees Māori tino rakatirataka (self-determination) and the same rights and protection as other citizens. However, Māori, including tākata whaikaha and whānau hauā continue to experience inequity, including in standards of living (Carm et al., 2024). This inequity is compounded by the intersecting oppressions experienced by tākata whaikaha Māori and whānau hauā.

New Zealand Disability Strategy (NZDS) 2026 - 2030

The New Zealand Disability Strategy establishes cross-government agreement on advancing disability rights nationally. The vision for the strategy is: “New Zealand is an equitable and accessible place for all disabled people and their whānau – where disabled people thrive, contribute, and choose the lives they want to lead ” (Whaikaha - Ministry of Disabled People, 2025a, p. 2). Importantly, it calls for barrier-free access to employment and an accessible and healthy home. The NZSD serves as a guideline for how government agencies should address disability-related issues.

Enabling Good Lives (EGL)

The Enabling Good Lives (EGL) is a co-designed set of eight principles and funding model aimed to improve disabled people’s lives. It gives disabled people and their whānau genuine choice and control over their lives and support systems. However, self-determination cannot exist without economic security. To bring EGL principles to life, Article 28 of the UNCRPD must be treated as an actionable mandate rather than an aspirational goal. True inclusion requires ensuring an adequate standard of living, fully offsetting the extra costs of disability, and insulating disabled people from the cost-of-living crisis.

Appendix C - Questionnaire Framework

Cost of living is the amount of money a person needs for basic expenses like housing, food and health care.

- What has been your experience of cost of living since 2021?

There are many definitions of ‘‘standard of living’, but some common ones can include:

- A person’s ability to access decent living standards such as clean water, air and education;
- The ability to buy things people want beyond what they need; and
- The freedom to choose how people want to live their lives (Barreiro-Gen, 2019).

- What has been your experience with the standard of living since 2021?

Disabled people often experience direct and indirect costs due to their disability. Direct costs include medicine, equipment, technology and home support. Indirect costs include things like increased use of electricity for heating and machines, increased cost for accessible/suitable housing, and increased costs for transport and food (Weston, 2022).

- What has been your experience of the cost of disability since 2021?

Article 28 of the United Nations Convention on the Rights of Persons with Disabilities says that the New Zealand Government should “recognize the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability.”

- Do you think the New Zealand Government is doing this? Why? Why not?

What issues related to cost of living, standard of living, and cost of disability, do you think are most important for this monitoring research to investigate in greater depth?

- What is your hope for disabled people's standard of living in Aotearoa New Zealand?

After this questionnaire, the monitoring team will do more in-depth interviews and focus groups with disabled people, based on the specific issues identified in this questionnaire.

Would you like to be contacted about being interviewed or part of a focus group? (please circle one)

- Yes
- No

This is the end of the questionnaire.

Thank you for taking the time to share your experiences and thoughts.



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