



Women
With
Disabilities
Australia
(WWDA)

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NDIS Review

“What People Told Us”

Volume 2:

The Depth Interviews

with

 **articulous**

Advocacy for Inclusion with support from Women with Disabilities Australia and funding from the Australian Government. Produced with assistance from Articulous.

Acknowledgment of Country

The drafting partners respectfully acknowledge Aboriginal and Torres Strait Islander peoples as the First Australians. We recognise their cultures, histories and diversity, and their continuing connection to the lands, waters and seas of Australia and the Torres Strait.

We acknowledge the Traditional Custodians and Traditional Owners of the many lands where we meet, work, learn and connect. We pay our respects to all Elders past, present and emerging.

Executive Summary

The following report summarises findings from a series of depth interviews conducted by Canberra-based Disabled Peoples Organisation, Advocacy for Inclusion (AFI), as part of their consultation and engagement activities for the NDIS Review. These interviews were summarised and collated with the assistance of Articulous, which provides writing services. The project was conducted with funding support from the Australian Government through Women with Disabilities Australia.

These depth interviews were undertaken as part of a multi-phase engagement strategy to provide input to the NDIS Review initiated by the Australian Government. They focussed on the NDIS market and the NDIS workforce but also touched on many other issues. This report focuses on providing a summary and a set of policy recommendations from the depth interview process. However, the stories also speak for themselves and AFI will be launching a volume of confidentialised stories speaking to experiences and hopes for the NDIS in the ACT to coincide with the 2023 UN International Day of People with Disability in December 2023. This volume should also be read in conjunction with the report of the Appreciative Inquiry, which focuses on customer experience.

Five interviewees spoke about their individual experiences with the NDIS and associated services. A set of narrative stories were then prepared to best highlight these experiences authentically. These stories will be shared with the general public to share people's lived experience of the NDIS – their lows, highs and hopes for its future.

Several key themes emerged through the interview process, including:

- The overwhelming experience associated with submitting an initial NDIS application
- The inconsistency and frequent unfamiliarity of NDIS staff with clients and their requirements
- The labour-intensive process of identifying viable and beneficial treatment activities that are within the scope of current funding
- The life-changing nature of home and vehicle modifications
- The day-to-day relief of having access to support work
- The inadequate quality and supply of support workers
- The benefit of working with caring, competent support workers

Based on the experiences shared by interview participants, the following recommendations have been made to improve how people can access and utilise the NDIS:

- Implementing executive summaries/one-page applications for individual modifications
- Establishing a central repository for requesting information and responses to queries for NDIS staff
- Increasing the provision of staff trained to provide support service recommendations
- Implementing mandatory hygiene and health and safety modules for support workers
- Establishing a central directory of allied workers and accessible vendors

Throughout the interview process, participants shared honest and authentic stories, demonstrating the difficulties associated with not having their needs adequately addressed by the NDIS. They also expressed their hopes for the future of the NDIS, in which participants are supported to 'dream big' and reach their full potential to participate in society.

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Background

Project Overview

As part of the NDIS Review consultation process, Advocacy for Inclusion (AFI), a Canberra-based Disabled Peoples Organisation, was contracted by Women with Disabilities Australia to hear feedback from people with disability about the NDIS, focusing on listening to ways in which the NDIS can improve. Depth Interviews were conducted with five individual users of the NDIS located in Canberra, with the intention of facilitating discourse about the challenges associated with the scheme and users' overall access to disability services.

The interviews covered a broad scope of discussion topics, having been strategically designed to unearth rich insights about an individual's experience of disability. Lines of questioning pertained to the following subjects:

- Initial contact with the scheme
- Initial and subsequent rounds of application
- Collaboration with GPs, specialists and allied health providers
- Satisfaction with funding package
- Use of support services
- Sources of information about service providers and agencies
- Satisfaction with services and providers
- Availability of supports
- Use of unregistered providers
- Cost of services
- Goals of individual plan
- Support network available

Participants

This project was facilitated by Advocacy for Inclusion – an agency providing individual, self and national systemic advocacy services for people with disabilities in the ACT. Narrative writing support was provided by a contracted consultant, working on behalf of Articulous Communications.

Five individuals were engaged by AFI to participate in 2-hour depth interviews about their experiences as a user of the NDIS. Each participant was approached directly by the project facilitators and was offered to participate voluntarily. Participants were paid for two hours of their time and advised that they could withdraw their participation at any time.

Project Methodology

Depth Interview Process

The NDIS Review Depth Interviews were 2 hours in duration and scheduled following liaison with the participant to find a suitable time slot. Each interview began with a casual conversation to establish rapport with the participant and ensure that they were comfortable to continue.

Participants were advised that the interviews were being recorded and that a transcription was used to capture a conversation record. It was emphasised that the recording and transcriptions would not be shared externally and were being used to aid in the process of producing project outputs, which would be deidentified before release.

In each interview, the lead interviewer explained to the participant that they were entitled to:

- Stop the interview at any time, for any reason
- Take a break whenever they wish
- Receive payment for two hours of their time, regardless of whether the interview is shorter in duration or ceases entirely
- Refrain from answering any questions
- Redact information post-interview
- Clarify or provide further information post-interview

Each conversation was productive and mutually courteous in nature.

Narrative Story Writing Process

Five narrative stories were produced from the testimonies of the individuals involved in the depth-interview process. Written in first-person, the stories are intended to provide an authentic and accurate overview of each participant's experience with the NDIS, with subject matter ranging from the process of application to the use of support services.

Verbatim segments of the recorded transcripts were used frequently, with entirely verbatim sections of text identified in quotation marks. For clarity and brevity, variations to the exact phrasing used by participants were made throughout each piece. However, it can be said that the stories reflect the accurate sentiment of participants and assume their authentic voice as often as practical.

Each story was intended to highlight 'light and shade' in the experiences shared by interviewees. Personal (but non-identifiable) details irrelevant to the NDIS were also included throughout for additional context.

Outputs

The following section provides a high-level overview of the outputs derived from the NDIS review depth interviews with participants. Beyond the production of five narrative stories outlining the experience of individuals on the NDIS in the ACT, the depth interviews yielded useful insights into key challenges associated with use of the NDIS and opportunities for improvement to the service.

Perceptions of the Disability Gateway

Participants were specifically asked to comment on their experiences using the Australian Government funded Disability Gateway, an online single point of contact established to inform people with disability about the range of supports available to them. The gateway is here:

Of the interviewees questioned on the subject, none were using the portal on a regular basis or had found the portal useful previously.

Some of the comments provided about disability gateway were as follows:

- "My GP mentioned that website. I've had a look at it, but I felt like it wasn't providing what I need and [didn't have] the right information for me."
- "I've heard of it. I don't think I've found anything yet through it."

Key themes

Conversations in interviews centred around several key themes including:

- **The overwhelming experience associated with submitting an initial NDIS application**, due to the volume and complexity of information required
- **The inconsistency and frequent unfamiliarity of NDIS staff**, resulting in the need for an individual to repeatedly share their story and advocate for the necessity of a requested service or modification
- **The labour-intensive process of identifying viable and beneficial treatment activities that are within the scope of current funding**, including physical therapy, occupational therapy, mental health programs and alternative therapies.
- **The life-changing nature of home and vehicle modifications**, providing participants with increased autonomy, independence, dignity and limiting their risk of injury
- **The day-to-day relief of having access to support work**, allowing an individual to participate more wholly in their community and reducing the caring load on partners and family members
- **The inadequate quality and supply of support workers**, resulting in instances of interacting with improperly trained or unhelpful workers, who do not add value to the lives of participants
- **The benefit of working with caring, competent support workers**, who provide meaningful assistance and support individuals with tasks that they are unable to complete themselves

Recommendations

The following key recommendations are based on the discussions, observations and outputs from each interview and are provided for consideration only.

According to interviewees, coordinators of the National Disability Insurance Scheme (NDIS) need to consider the implementation of:

- 1 Executive summaries/one-page applications for individual modifications,** negating the need for delegates and local area coordinators to comprehend irrelevant information when processing distinct requests. According to participants, the length and complexity of applications may contribute to the extensive wait time for approvals and the high anecdotal frequency of misunderstandings.
- 2 Central NDIA repository for request information and responses to queries (like a client records management system),** to limit the need for an individual to repeat information to multiple staff members. This is suggested as a strategy to create a more consistent and less stressful experience for NDIS staff and participants alike and reduce the overall time for requests to be processed.
- 3 Better information and referral** by reforming the Australian Government funded Disability Gateway with a more useful, interactive and continuously updated resource with quality information on goods, services, spaces, places, equipment and services. There should be mechanisms for consumers to review and comment on services. This new service should be managed and run by people with disability, sit with a DPO and be given ongoing funding as part of Tier 2 services
- 4 Provision of staff trained to provide support service recommendations,** either through the retraining of delegates and local area coordinators, or the appointment of a dedicated team. Participants frequently expressed the desire for increased guidance regarding the types of support services they could access, and which services would be the most beneficial considering their individual circumstances.
- 5 Mandatory hygiene and health and safety modules for support workers,** in addition to existing police checks and working with vulnerable people checks. Participants consistently cited witnessing dangerous or unhygienic practices performed by hired support workers.
- 6 Provision of central directory of allied workers and accessible vendors,** including builders, handymen, therapists and specialists. This would assist with locating individuals who are cognisant of disability requirements and willing to accommodate varied, specific requests.

Defining Comments

The table below is provided to summarise the key challenges identified by depth-interview participants. Comments are centred around the NDIS, in addition to general use of support and treatment services, and interactions with the general public.

CATEGORY/DEFINING FEATURES	EXEMPLAR COMMENTS (EDITED FOR BREVITY)
<p>INSUFFICIENT OR INEQUITABLE FUNDING</p> <ul style="list-style-type: none"> • Inequitable allocation of funds to individuals with similar conditions and levels of function • Denial of reasonable and potentially life-changing requests • Lack of objectivity • High variability of funding approvals and allocations between participants 	<ul style="list-style-type: none"> • “My brother is also on the NDIS and his plan is 2.5x bigger than mine, even though we have the same condition [and a similar level of function]. It feels like just luck of the draw.” • “The kind of plan you get feels solely dependent on your rapport with staff and whether they’re maybe having a good day or a bad day at the time.” • “You have to prioritise the important things [because your requests won’t all be approved].” • “We extended our mortgage by a significant lump to [account for] all of the other little things that they didn’t cover.” • “I would love for the NDIS to be more equitable for people from a disadvantaged or poorer socioeconomic background. I’m worried that there are people falling through the cracks because they don’t have family support or a strong level of understanding.”
<p>LACK OF CLARITY AND GUIDANCE</p> <ul style="list-style-type: none"> • Lack of direction or support navigating the NDIS system • Limited public knowledge of application process • Provision of highly generalised information • Provision of “unnecessarily” complex information (including sophisticated language and jargon) • Process requires information that is unfamiliar or inaccessible to all participants (e.g. licence number) • Process is intended to provide quality assurance measures that are not relayed to all participants 	<ul style="list-style-type: none"> • “The disability advocate that I met in 2019 was the first person who explained things to me. [They] explained the kind of language I needed to use and that I needed to have a functional OT assessment, which I didn’t have initially.” • “There’s some information available on the NDIS website, but it wasn’t clear what I need to do before I had my first planning meeting.” • “I turned up to the first planning meeting and I had no idea that you had to prepare.” • “It was very stressful. The form itself wasn’t telling me anything.”

(e.g. NDIS reference number to track application progress)

- “The NDIS basically has its own language and vocabulary, and different terms and nuances that you wouldn’t know unless you had done a lot of work with it or [were] on it.”
- “It took me a couple of years to feel like I knew how to navigate the system and who to ask questions to.”

LABOUR INTENSIVE REPORTING AND DOCUMENTATION REQUIREMENTS

- Extensive evidence requirements (e.g. \$7000 worth of reportage from an occupational therapist, 52-page+ total documents)
- Inclusion of irrelevant/repeat information in each request or application (excessive background information and history)
- Reluctance to submit change of circumstances due to administrative burden (e.g. after being impacted by long COVID-19)
- Highly pressurised planning meetings

- “We had some issues around getting the right evidence and things like that.”
- “It took several months to get everything sorted and then I was rejected the first time around, so I had to [provide] more documentation for a review of the decision.”
- “I wasn’t surprised that I was rejected, because my neurologist who has had a lot of patients on the NDIS has said that everyone gets rejected the first time anyway.”
- “I don’t think anyone reads the pages and pages of reports that people provide for reviews. I can tell that [the staff I speak to] haven’t read anything. There’s no effort to understand the situation and what I need.”
- “The amount of paperwork, energy and time that you need to do a review or [submit] a change of circumstances is a lot. It takes a lot out of you and for months you are stressed.”
- “I probably didn’t get a great plan because it [relied on] everything that I managed to remember or think about in the short meeting that I had with my NDIA planner.”

UNSATISFACTORY INTERACTION WITH AND BETWEEN LOCAL AREA COORDINATORS, PLAN MANAGERS AND DELEGATES

- Lack of clarity regarding roles and responsibilities
- Disconnect between local area coordinators and delegates
- Interaction with unfamiliar local area coordinators, plan managers and delegates, with low awareness

- “I don’t really understand the role of the local area coordinators. All they seem to do is forward emails higher up the chain to NDIA. They don’t offer any advice. They take weeks and weeks to even acknowledge an email before they forward it on.”
- “I think in the original model, the delegates were actually supposed to be [involved in] the planning process directly with the client and I think somehow, they got lost along the way. The role has [almost] been given

of an individual's needs and experiences (one individual was assigned a local area coordinator living in a different state)

- Single request or issue handled through a series of different planners and staff, rather than by one individual
- Insufficient knowledge of disability

LACK OF RELATIONSHIP-BUILDING WITH NDIS STAFF

- Impersonal interactions with staff members
- Inability to maintain consistent communication with a single staff member, or reach out to ask questions
- Consistent hand off to alternate staff members (potentially influenced by burn out in the field)
- Lack of NDIS staff with sufficient knowledge of disability, or the skills to know the types of support that an individual could benefit from
- Lack of support for email communication (which is often a preferred channel for accessibility when an individual is not well enough to talk on the phone)
- Technical issues over Zoom (resulting in talking to a black screen/not seeing anyone face-to-face)

LACK OF COMMUNICATION

- Insufficient communication post-meetings or between requests
- Lack of updates or evidence of progress

to the local area coordinators, who are an intermediary between the participant and the delegate."

- "[Your request will] go in isolation to a delegate who has not met you, and who doesn't know your situation."
- "I don't think I've had the same [local area coordinator] for more than six months."
- "The only time I hear from my local area coordinator is around a plan review and I don't have their email address. If I really need to ask them a question, I have to call someone higher up and I'm not even provided with their last name – only the first letter of their last name."
- "It's like they just have too much on. They don't have the time or capacity or resources to contact people."
- "I wish there was someone who you could contact and ask questions, and who could spend enough time to get to know you."
- "Sometimes they've rung me up and put me on the spot. They've almost threatened me saying that if I didn't talk to them that things weren't going to happen, and that I would really slow down the process."
- "They don't really help afterwards. You don't hear from them again or they will have turned over. All you get is that one hour and maybe an email and that's it."
- "There were a lot of gaps of time where I didn't hear anything from my support coordinator, and I didn't know what kinds of services I could access."
- "There will be months in between meetings where you don't hear from them, or you email and don't hear back."

SIGNIFICANT WAIT TIMES

- Extensive wait times for requests and modifications (e.g. 6 months, 1 year, 4 years)
- Wait times for appointments with specialists and in hospitals (e.g. 5 hours to be seen to)
- Increased cost of service and equipment due to inflation, exacerbated by significant wait times (e.g. \$1,800 addition expense on an item due to a 1+ year delay)

- "I'd been told prior to [my application] that the wait time for approval could be a couple of years."
- "It took a really long time [to get accepted]. I think it took 7 months for them to get back to me to say 'yes, you're accepted'."
- "It turns into a long winded very slow process where you have your planning meeting [and then your request] goes into the void, until 3, 4, 5 or six months later you get a verdict and it's maybe not the verdict you were hoping for."
- "I find that the equipment and things I need haven't caught up with my rate of decline because it takes so long to get anything through the NDIS."
- "My wheelchair doesn't meet my current needs, but I'm told that I need to wait five years at least before I can apply [for an electric model]."

MISTAKES AND MISHANDLING

- Funding assigned to the wrong spending bucket
- Funding mistakes requiring participants to wait for an individual plan to expire
- Repeated mistakes despite appeal and notification
- Portal incompatible with self-management (one individual waited 8 weeks for the portal to reprogram to be able control their own home modification)
- Loss of application lodged in person, with no record found

- "They actually gave me a huge chunk of money in my plan, but it was in the wrong bucket. Then they kept saying, 'no, you can't spend that because it's in the wrong bucket'."
- "We had to let that plan expire."
- "The portal couldn't cope with me having permission to control my own home renovations and it took [the NDIS] eight weeks to reprogram the portal. I couldn't actually access the funding that was sitting in there ready for me to do my own home modifications."
- "Considering the fact that I'd taken in it person, I just couldn't comprehend how they possibly could have lost it."

UNSATISFACTORY AND LIMITING RECOMMENDATIONS

- Offering to explore recommendations for unfeasible and unrequested modifications, while ignoring reasonable requests
- Offering to fund participants moving to an accessible home (as opposed to funding home modification) despite this being impractical

- "We went through the process [of requesting home modification funding] again and they came back and said, 'what about if you looked at actually moving to somewhere that was accessible rather than trying to make your house accessible?'"
- "They will approve certain things for certain people and not for other people because a request has to be part of your goals and whatnot."

- Inability to accept or approve treatments and modifications that do not align with a narrow interpretation of point in time goals (that may have since changed due to circumstances)
- Difficulty receiving support for secondary conditions or ailments (e.g., mental health support for an individual with a physical disability)
- Recommendations which do not align with the actual real world social, emotional and family circumstances of participants: (see example).

- "We explained [the type of accessible bed] we wanted and why two king beds wouldn't work because we were [planning to] fit a special base inside our existing queen bed frame. By limiting me to a king bed, I would be delegated to our spare room, because that's the only place we could put a king bed. It's a tight little angle and my partner couldn't hear me from that end of the house."

LIMITED HELP FINDING GOOD SUPPORT SERVICES:

- A lack of detailed and useable information in the NDIS provider lists
- Reliance on independent desk-top research and Google searching to find relevant support workers and services
- Reliance of Facebook, word-of-mouth recommendations and informal means to find relevant support workers and services
- Lack of guidance to additional support post hospital admission
- Inability for hospital staff to make formal recommendations

- "In the beginning I found it really hard, at least in the first year, to figure out what I need help with and where to get it and how to go about it."
- "One of my colleagues said, 'did you know that there are Facebook groups where you [can] learn a lot more stuff or ask questions?'"
- "I felt really lost in terms of figuring out like what I need, what's possible and how to get it."
- "She said 'here's a list of providers, I can't actually recommend any of them to you because I'm not allowed to'."

EXCESSIVE TREATMENT AND SERVICE COSTS

- High costs of essential treatments
- Inequitable pricing for NDIS participants compared to general population

- "I think that treatment costs a couple of hundred per week."
- "I'm spending a lot of money on my own alternative treatments [particularly those that haven't been approved]."
- "I understand that occupational therapists and physiotherapists take additional time with reporting and record keeping, but we need to stay vigilant and account for how they're actually spending money."
- "They jack up the prices when you're an NDIS participant."
- "[Providers] charge a lot more when they find out you're an NDIS"

participant. I complained and said 'I'm self managed, why am I having to pay \$40 more than the average person?'"

- "Once you mention the NDIS, people's eyes have those dollar signs in them."

EXCESSIVE MODIFICATION AND EQUIPMENT COSTS

- High costs of car or wheelchair modifications
- Over-charging and quoting (e.g. being quoted \$14,00 for new wheelchair batteries, while another provider was prepared to offer \$900)
- Attempts to withhold information (e.g., being told that an invoice would go straight to a plan manager)

- "I don't want to risk getting fresh quotes and going back for fresh approvals, because that triggers a whole review process."
- "I felt really uncomfortable about the fact that they thought they could just make up however much they were going to charge me and send it off to someone else."

LIMITED AVAILABILITY OF SERVICES IN THE ACT

- Lack of car modification services (e.g., one car modification specialist who is frequently booked out and unreachable, doesn't respond to emails etc.)
- Limiting stipulations imposed by only available services (e.g., refusal to modify car as it was second hand/too old)
- Lack of home modification services/builders specialised in accessibility
- Lack of specialist medical services (e.g., neurofeedback training)
- Long wait lists for specialist appointments (e.g., 6 months to see specialist OT)

- "I think there's just the one [brain training clinic in Canberra]. That's a single point of failure right there."
- "When I was first getting my hand controls fitted, we actually ended up going to Sydney to get them done by ParaQuad (now Forward Ability Support)."
- "I've been relying on Mable and Hireup. I wouldn't even know where to start if I wanted to use a registered provider for support work."

SERVICE DELIVERY CONSTRAINTS

- Lack of specialists (physios etc.) open on weekends for individuals who work
- Need to pay higher rates for support workers on the weekend (limiting for individuals who work)
- Lack of support workers willing to provide ad-hoc support

- "I have three to five medical appointments a week and a lot of the time I'm too unwell to drive. I can't plan for every special appointment. I need someone who can be there to fill all of those different strange variations."
- "I've had builders want to put up lots of handrails and stuff that's just not useful to me as a wheelchair user because it just makes extra barriers [and I don't] use rails."

- Lack of nearby support workers (i.e., many reside on only one side of Canberra – North Side)
- Inability to cater for unique disabilities and requirement (e.g., avoiding fragrances and the use of conventional cleaning products)
- Difficulty locating tradespeople with experience with disability (and who are willing to make accessible changes)
- Overabundance of short-term services, as opposed to long-term supports (need to seek extensions to remain with favoured providers)
- Inadequate transition from hospital stage of traumatic injury to long-term recovery
- “[My psychologist] had been seeing me for several years and she’d extended it several times. [The service] was tied to the hospital and people that had come out of rehabilitation.”

INADEQUATE QUALITY AND TRAINING OF SUPPORT WORKERS

- Lack of experience, qualifications or skills
- Inexperience completing necessary tasks (e.g. house cleaning and cooking)
- Health and safety concerns (e.g. inadequate hand washing)
- Food safety concerns (e.g. dropping food on the floor, picking it up and storing it in the fridge)
- Charging for additional hours unworked
- Arriving significantly late for appointments (e.g. 1.5 hours)
- Legal concerns around hiring unregistered providers (alignment with work health and safety requirements and workers compensation insurance, need for sole trader ABN)
- Difficulty working with unregistered providers (one individual reported having to write an invoice on a provider’s behalf)
- Inconsistency of workers (potentially due to high dropout rate in the profession, as workers seek stability and access to job benefits)
- Significant portion of support workers interested in ‘fun’ activities
- “Many don’t have any experience or qualifications or skills really.”
- “I feel like some [like] easy money. The aren’t in the role to help or make a difference in someone’s life.”
- “I’ve asked for assistance cooking and been sent a 20 year old who didn’t know how to cook.”
- “I feel like I’m constantly having to find new people.”
- “I’ve got some really lovely ladies who look after me but [need reminding about] really basic things about using soap when they’re washing their hands instead of just rinsing with water and [not emptying mop water in the kitchen after] mopping the bathroom and the toilet.”
- “[Support workers] have left open bladed scissors and knives in the bottom of the sink, which is dangerous for the next support worker who might reach into the sink and not know they’re there.”
- “There are people I have wanted to use who haven’t had an ABN, but an ABN is so easy to get as a sole trader.”
- “I need help with the actual things I can’t do myself, but there are a lot of people who don’t want to do the actual work.”

(going to gallery's, getting coffee etc.) as opposed to required tasks

- Not all physically strong enough (to assist with transfers, lifting and helping with a wheelchair)
- Miscommunications (one individual was denied taking their partner home from an appointment, despite them having been present on the journey to the appointment)

REDUCED AVAILABILITY OF COMMUNITY DISABILITY SERVICES

- Limited services for those not yet accepted to the NDIS
- Limited accessible community therapies and activities

- "I rang up a lot of community service and everyone asked, 'are you on NDIS?' All of the services were only for NDIS participants."
- "I do miss having a group environment for support."

PRINCIPLES OF NDIS:

- Emphasis on independent activities and progress
- Lack of support for trialling treatments and support activities
- Unclear community reputation, lack of clarity around access and potential means testing

- "The NDIS wasn't going to fund that sort of group activity, which is frowned upon because you're supposed to be out there doing your own individual stuff, but [that has] actually broken up some really strong friendships."
- "I thought [there would be] an income test to join the NDIS. I never looked into it when it was piloting or launching."

COMMUNITY PRINCIPLES AND IGNORANCE:

- Lack of natural integration of people with disabilities in society
- Limited availability of wheelchair accessible housing
- Limited understanding from real estate agents about accessibility requirements
- Lack of supported living accommodation catered to couples
- Limited accessibility of group programs and group living situations
- Limited accessibility of community activities and group programs
- General inaccessibility (difficulty navigating steps, limited ramps, inability to reach shelves in supermarkets)

- "Certain things are frowned upon by the disability sector as far as group programs and group living situations go. There should be options for people that find that they may not be able to live independently or do things independently."
- "It'd be lovely if [community programs] were fully inclusive, and these situations weren't just for people with disabilities."
- "I had a lovely real estate agent who was trying to help, but she'd say things like 'you'll love this one. It's only got 3 steps at the front, and there's a little step from the living room into the family room'."
- "I'm fine with a 100% flat surface, but anything with gravel, slopes or steps is difficult to navigate. My freedom is restricted because I can't take my wheelchair everywhere I want to go."

- Exclusion from events (e.g., narrow aisles, high bar tables)
- Difficulties traveling (e.g., not receiving special assistance booked in advance, airline breaking wheelchair)

- "There was one venue I went to that said they had an accessible toilet, but my walker could barely fit down the walkway and you go down a slippery hallway [through a kitchen] and down uneven steps to access it."

PSYCHOLOGICAL IMPACTS:

- Emotional labour (need to advocate for oneself)
- Reluctance to rely on friends and family members (knowledge of carer and compassion fatigue experienced by partners and family members)
- Heavy research burden
- Heavy administrative burden
- Isolation and exclusion

- "I'm a fairly forthright person [with hand sanitising and mask wearing] because it's a matter of life or death for me."
- "You need to be your own advocate and really state what it is that you need to create those really firm boundaries."
- "[After hearing that my requested bed had been denied], I wrote a very distressed letter back."
- "I'm reluctant to ask friends for assistance beyond small tasks. I try to leave their support for actual emergencies when I desperately need something."
- "I think my research brain gets used up at work. I can't be doing more research after or I don't end up exploring or doing anything."
- "By Friday I feel quite relaxed because I've done a lot of appointments and gotten through it. On Monday's I think 'oh my god, how am I going to get through all this again'."
- "Between managing medical appointments and managing support workers it does feel like a full time job."
- "I wasn't able to engage with people as well as I [could] have because my walker couldn't fit down the walkway between the bar and the tables."
- "At the end of the night I ended up sending an email to the board president saying, 'this was what my experience was'."

Compelling risks and consequences

Across the course of the depth interview process, participants shared several compelling anecdotes demonstrating the hardship and discomfort that has resulted from not having their needs adequately addressed by the NDIS.

Regarding wait times and rejected approvals for home modification, participants spoke of the physical discomfort and social embarrassment associated with living in an inaccessible home. Specific examples included:

- Inability to shower more than 1-2 times per week
- Inability to stand up from the toilet without assistance
- Repeat incidents of incontinence, resulting from not being able to navigate a step into the bathroom,
- Inability to sleep in an inaccessible bed, requiring an individual to sleep in their armchair for 12 months,
- Inability to welcome visitors with disability to the home, resulting in meetings with friends and colleagues being held in an outside driveway or the back seat of a car
- Long-term injury caused to the back and shoulder of an individual's partner due to assistance with transfers

The experience of interacting with inadequately trained or inexperienced support workers was consistently shared by participants. In their cooperation with support workers, interviewees reported witnessing health and safety violations and unsanitary practices.

Specific examples included:

- Encountering broken glass that was not properly disposed of
- Encountering sharp knives left in water in the sink
- Witnessing mop water being emptied in the kitchen sink, following mopping of the bathroom floor
- Witnessing food being dropped on the floor and placed back in the fridge for consumption
- Witnessing individuals taking off their masks to sneeze

Participants spoke of being cancelled on by support workers at the last minute, or hiring individuals who did not arrive for their shift entirely. One interviewee spoke of a support worker who frequently 'tacked on' 30-minutes of additional work time either side of their shift and another reported witnessing 'spot cleaning' as opposed to house cleaning or gardening to a sufficient standard. Frequent cancellations and tardiness of up to 90 minutes was also reported.

Four of the five individuals interviewed mentioned feeling exploited financially by service providers due to their status as NDIS participants. One participant shared their experience of having a partner denied the opportunity to sit in on a drive home from an outing (despite the support worker having accepted their presence in the car on the journey to the destined). Some participants also spoke of miscommunications with support workers.