Women with Disabilities ACT and Advocacy for Inclusion

NDIS Review Submission

Joint survey report

8 September 2023

Survey details

The survey was launched on the 11th of August 2023, and closed on the 8th September 2023. The survey was run over Google Forms.

There were two options available: participants could choose to upload a free-form audio or video response, or fill out a written survey form. All participants chose to fill out the written form.

In total we received 19 responses. All people self-identified as being a person with a disability or disabilities, and residing in the ACT and surrounds.

Demographics

The majority of respondents identified as female (14) [see figure 1]. There were several age groups covered by our respondents, from 25-65+ [see figure 2]. 6 respondents identified themselves as being LGBTQIA+ [see figure 3]. 2 respondents identified themselves as Aboriginal, and one as from a migrant background.

13 respondents were current NDIS participants.

Figure 1: Gender of respondents

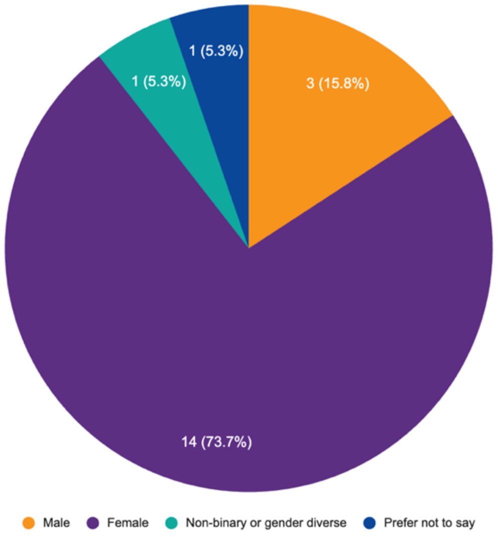


Figure 2: Age of respondents

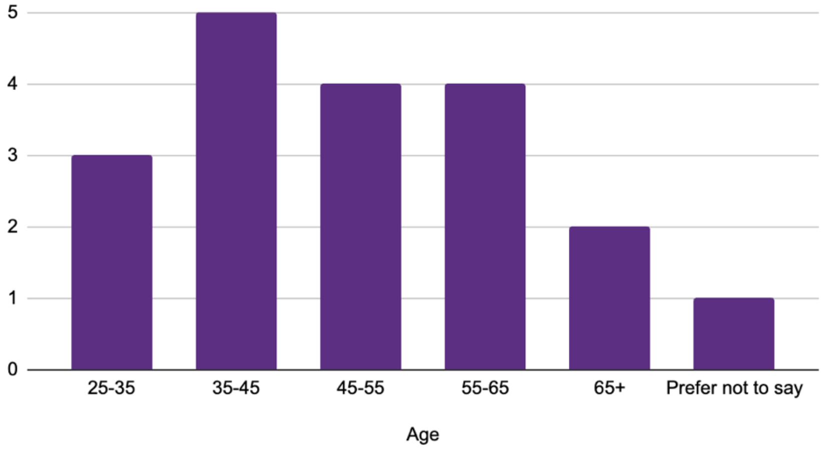


Figure 3: Identified as LGBTQIA+

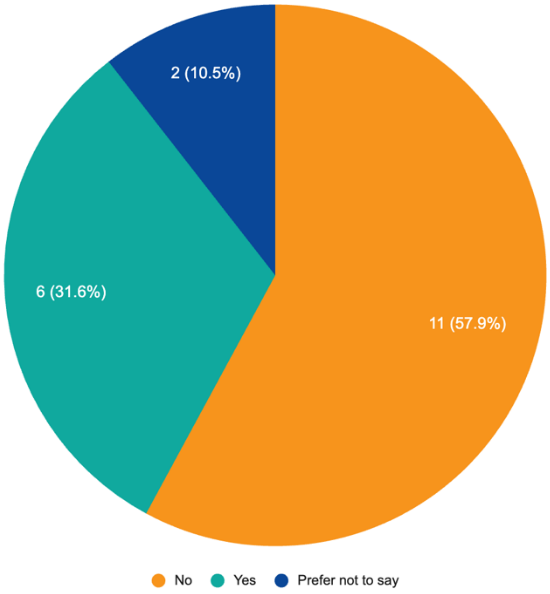
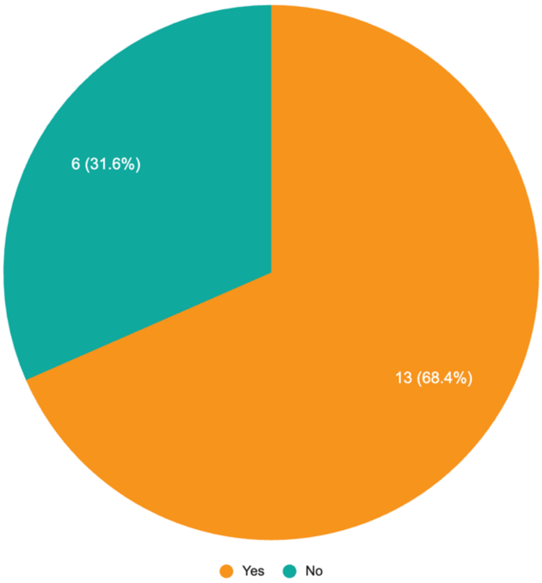


Figure 4: NDIS Participants

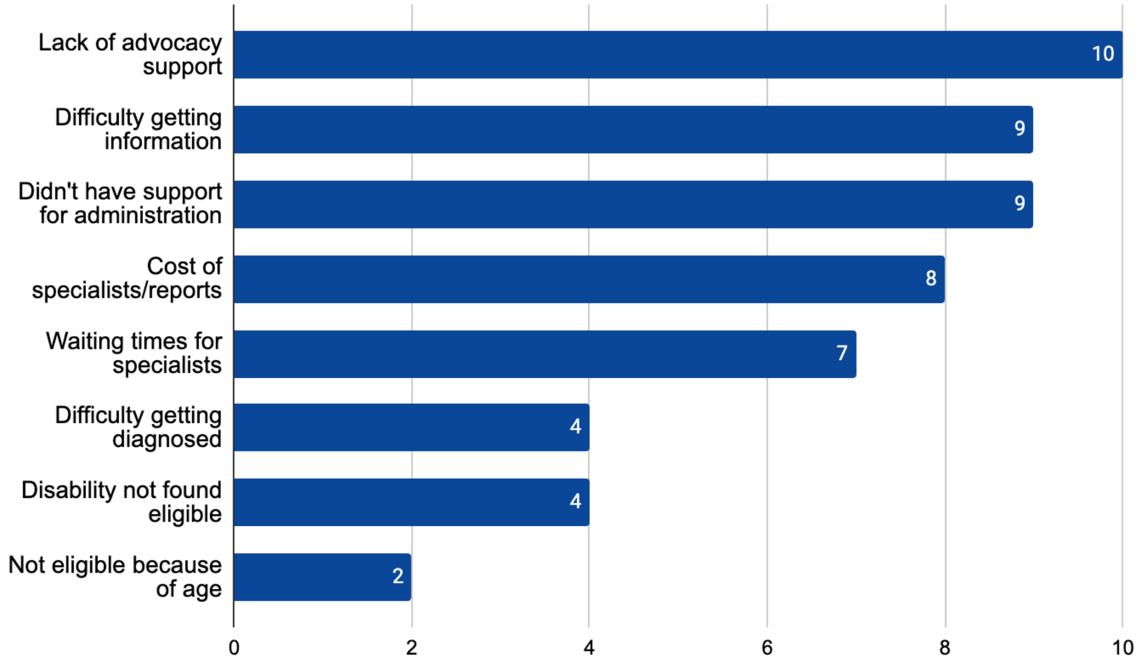


Getting onto the NDIS

Nearly all respondents reported issues getting onto the NDIS [figure 5], with over half telling us that they experienced a lack of advocacy support (10). Other commonly reported issues were difficulty getting information (9), a lack of support for administration (9) and the cost of accessing appropriate specialists or obtaining reports (8).

Some respondents told us that their specific diagnoses caused issues for getting onto the NDIS, including autism, autoimmune diseases, and chronic pain. Specialists for some disabilities do not produce reports that meet NDIS requirements, making it difficult or impossible to get onto the NDIS. One respondent reported having to pay to be re-diagnosed under new criteria, to be recognised by the NDIS.

Figure 5: Issues encountered getting onto the NDIS



For respondents with multiple disabilities, they reported issues getting all their disabilities recognised for the NDIS. They struggled to get all their support needs included in their plans. Other reported that OTs and assessors provided incorrect information about their disabilities in reports, impacting the usefulness of their plans.

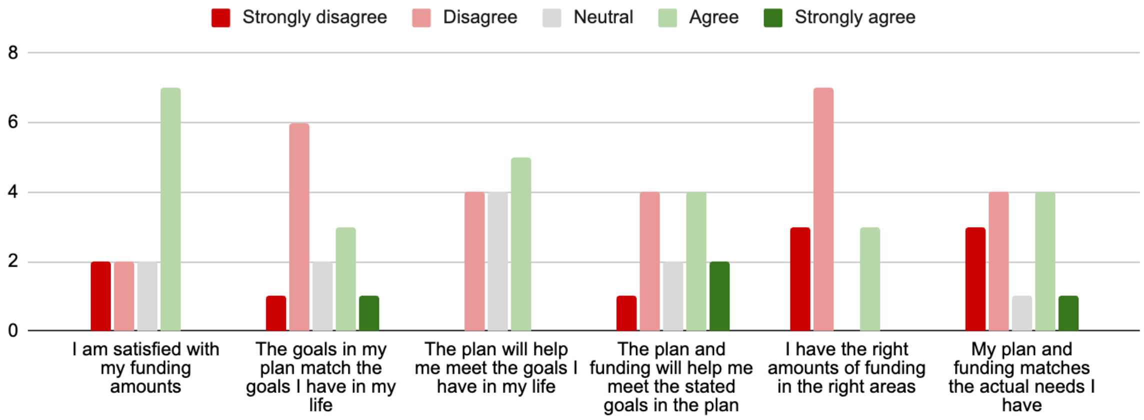
Some respondents found it difficult to prove eligibility as their diagnosis was not understood by the NDIS, and they considered it medical rather than a disability.

Other respondents told us that they were over the age limit for NDIS supports. For people with disabilities who were above 65 when the NDIS was introduced, they never became eligible for the supports they needed.

One respondent commented that people who apply for the NDIS often already struggle to manage and pay for supports and services. Attempting to navigate the system to get onto the NDIS can aggravate these struggles and can be a barrier preventing people from getting onto the NDIS in the first place.

NDIS Packages

Figure 6: NDIS Packages



Whilst most respondents were satisfied with the funding amounts in their packages [see figure 6], many reported that the goals in their plans did not match the goals they had in their lives, and that their plans may not help them to meet their goals.

Most felt that they did not have the right amount of funding in the right areas, and many felt that their plan and funding did not match their actual needs.

Some reported having experienced funding cuts to below what they needed to function during their time on the NDIS. Others delayed or forewent their reviews because of the risk of losing funding, missing out on the chance for additional supports. Some participants received incorrect or no information about funding from the NDIS, and did not know that in a two-year review cycle, the funding also went over two years.

Respondents reported that the NDIS did not provide enough support to meet their goals. One respondent wished to travel with their family, but were limited by the costs of accessible travel. NDIS would not fund accessible travel arrangements like plane seats that lay down, accessible accommodation, or additional days and accommodation in travel to accommodate their disability. Another’s goal was to live in supported independent living nearer their family, but their coordinator was not proactive in securing places when they became available. They mentioned feeling controlled by their support coordinators – ‘I think they want me to stay here to be dependent on them instead of my family’.

One respondent was asked to change their goals. Another received such a small amount of NDIS funding that the cost of going to disability programs was not fully supported, and they could only attend once per week. In general, respondents mentioned that the NDIS problematically assumes improvement is a goal and that ‘a few sessions here or there will make your condition or disability magically go away’.

Those who designed their own plans reported higher satisfaction with the NDIS and that their goals were well supported.

Communications and NDIS Supports

Figure 7: Communications and NDIS Supports

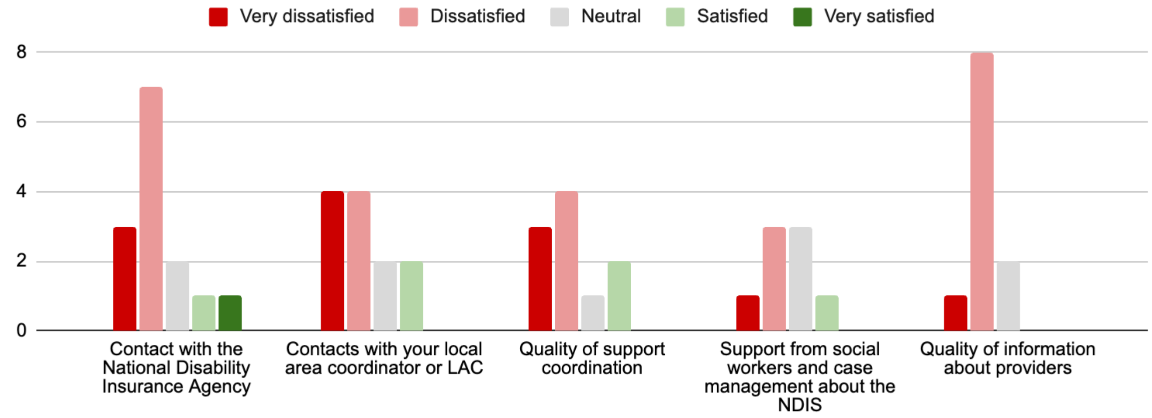


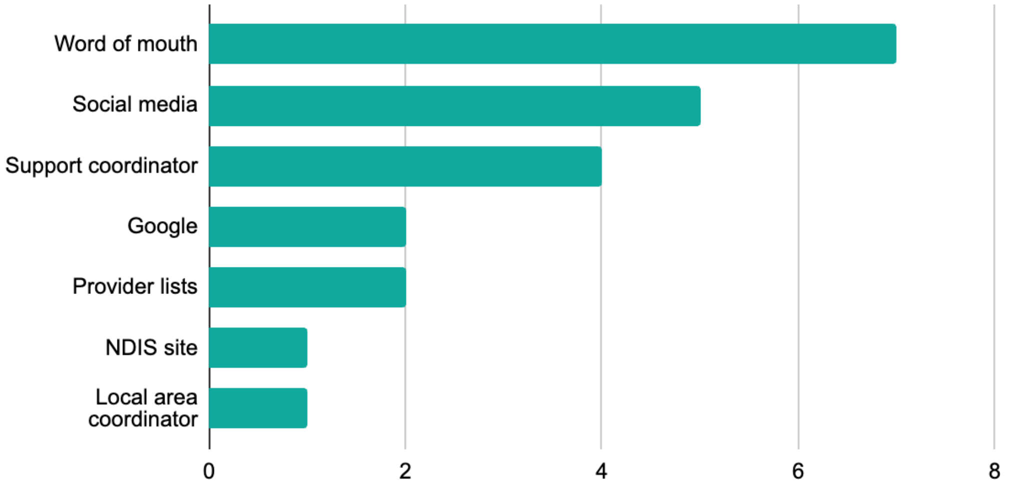
Figure 7 outlines the respondents’ satisfaction with their communication and support coordination through the NDIS. Many people reported significant issues getting in touch with the NDIA, reporting that it was impossible to contact them or have calls returned. Others reported that the NDIA staff were not well trained about different kinds of disabilities and didn’t understand what it was like for their clients. They reported not feeling respected by the NDIA staff, and having very little trust. One reported that the NDIS staff and website had conflicting and incorrect information. Another suggested that weak security on the NDIS systems and passwords left people vulnerable to theft.

Respondents reported significant issues with their experiences of support coordination. Those that had support coordinators reported high turnover rates (one had 4 coordinators in a 6 month period), being ‘ghosted’ by support coordinators or uninformed about changes in support, and finding it difficult to follow up with support coordinators about unfinished work. One respondent had a 15-month delay in getting wheelchair repairs due to ineffective support coordination.

Despite these issues, respondents reported that having support coordination was a highly necessary part of navigating the NDIS. Many found it hard to get a coordinator, with information not being available, or no services available to suit complex needs. One respondent said ‘the NDIS is impossible to navigate without support coordination (and I say this as someone with relatively high levels of privilege as an NDIS participant, e.g. a PhD-level education). I have no idea what the NDIA want or how they make decisions.’

Information and Choice

Figure 8: Finding out about services



Most respondents found out about services through word of mouth (7), their support coordinator (6) or social media (5) [see figure 8].

Many reported issues with finding information about services. Many respondents reported that provider lists and the Disability Gateway are poor and contain service providers that are no longer functioning. It was difficult for respondents to get information, and many needed a support coordinator to help. 12 respondents didn't find all the services they needed on the NDIS [see figure 9].

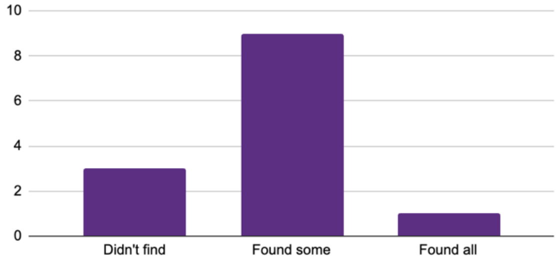


Figure 9: Did you find all the services you needed?

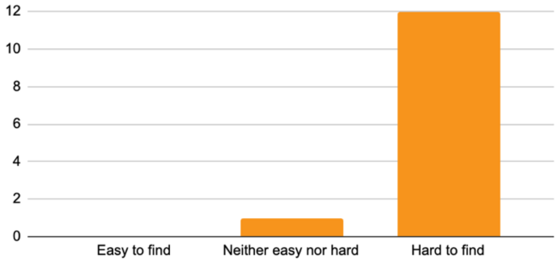


Figure 10: Was it easy to find services?

Several respondents reported that there was a huge time investment required to look for providers. Respondents had to call around to see if providers were taking on clients, were in the right location and were accessible. 12 respondents found it difficult to find services [see figure 10].

There were issues raised specific to Canberra – as a small city, respondents raised issues with conflict of interest, privacy, long waitlists, shortages of providers, and having no choice of competent providers. 11 respondents reported that it would be hard to find a new provider if needed [see figure 11]. 13 respondents didn't know anything, or only knew a little, about other providers [see figure 12].

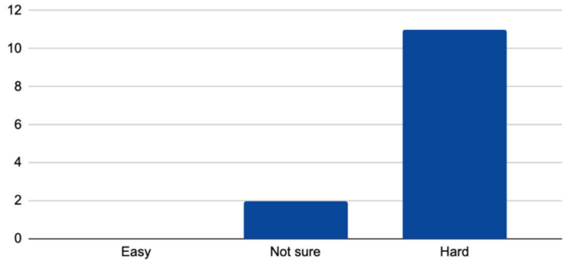


Figure 11: How easy would it be to find a new provider if you needed?

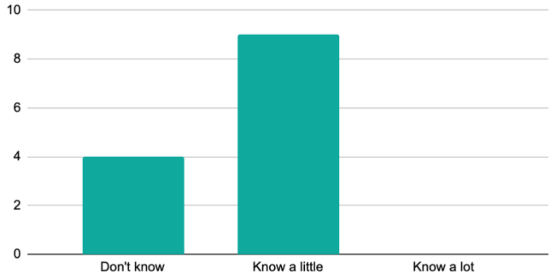
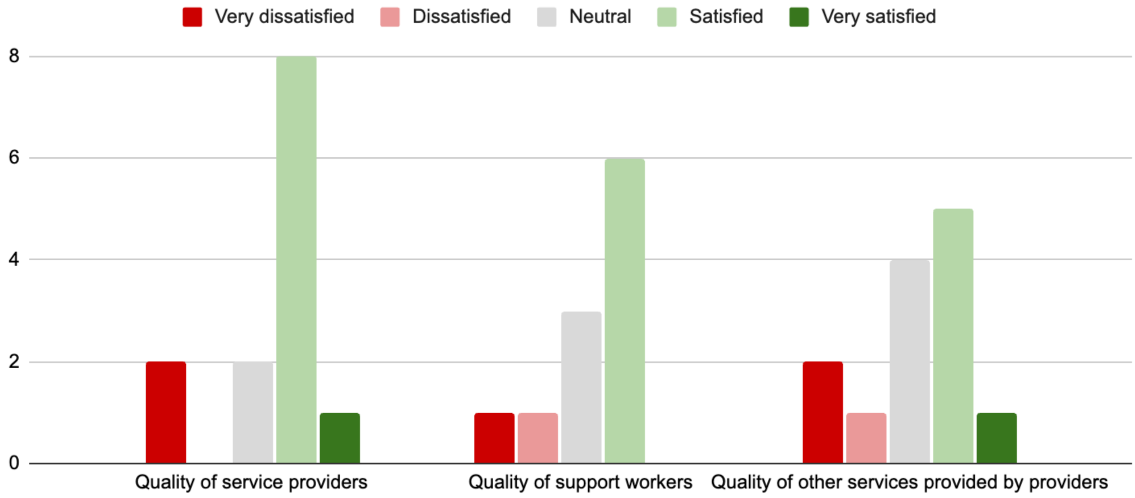


Figure 12: Do you know about other providers?

Quality of Service Providers

Figure 12: Service quality



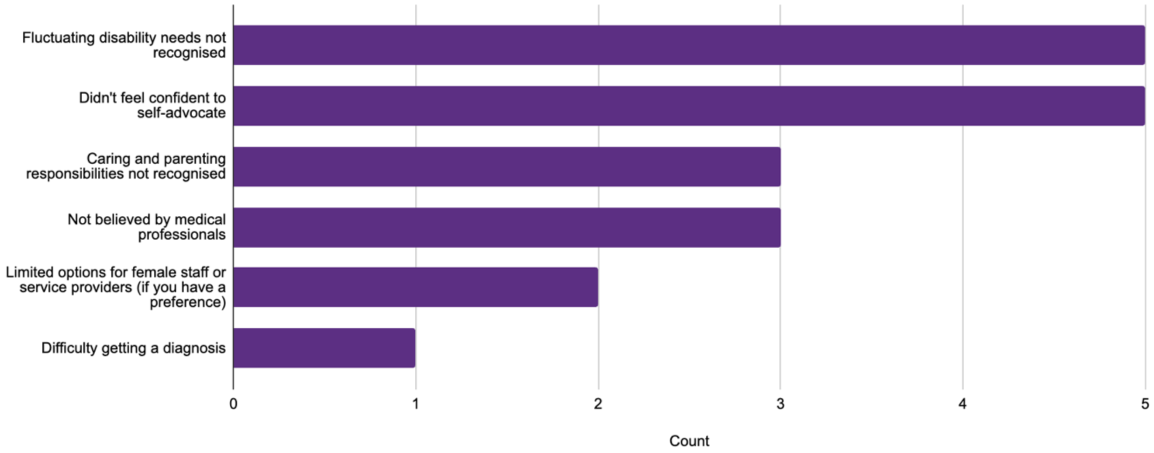
Respondents reported mixed experiences with service providers and support workers – ‘some are great and some are terrible’. Although many reported that it was hard to find appropriate staff, those that could choose and could find good workers found the experience ‘excellent’.

Many respondents reported issues with long waiting lists for supports in Canberra. Another issue is high staff turnover – losing staff means an interruption of the supports NDIS participants need to live and work.

Some respondents had specific issues with service providers that they were not assisted to address. For example: OTs quoting unnecessary repairs to wheelchairs that were expensive, OTs providing and charging for unusable equipment, cleaning companies overcharging, service providers stealing resources, support workers wasting food and damaging possessions. Respondents found it difficult to communicate these issues, with service providers not listening to concerns and refusing to admit fault. For example, when reporting that a support worker had stolen things, one respondent was told they were at fault and that ‘they should have stopped them’.

Women* with Disabilities and the NDIS

Figure 13: Gendered issues interacting with NDIS



Everyone who self-identified in our survey as a woman or gender diverse person with disabilities reported issues caused by their gender in their interactions with the NDIS. Common responses included that fluctuating disabilities needs were not recognised (5), not feeling confident or having energy to self-advocate (5), not being believed by medical professionals (4), having limited options for female staff or service providers (4), and not having caring or parenting responsibilities recognised (3).

Several respondents reported feeling uncomfortable in their interactions with the NDIS, including discussing domestic violence issues, and being asked intimate questions about how their disability affected continence.

One respondent reported that their Local Area Coordinator refused support for gardening as it was a ‘man’s job’, even though the respondent normally undertook this job prior to their disability.

Conclusion

On the whole, most respondents found it difficult to interact with the NDIS and reported difficulties in at least one part of the system – from being accepted on the scheme, to interacting with NDIA staff and LACs, finding service providers, and getting the supports they needed.

For some respondents, the bureaucratic processes outweighed the benefits of having the NDIS – ‘the burden of using completely defeats the purpose’. Some reported avoiding using the NDIS, or delaying interactions, due to the burden of interacting with the scheme. Others commented that the system ‘sets up an applicant and participant to fail’, and seems to be ‘designed to be as punitive and degrading as possible’. The time required to interact with the NDIS was commonly cited, with one person comparing setting up an NDIS plan to.a part-time job.

Others acknowledged the positive impact of the NDIS on their lives, saying it helped them to live independently and access supports. However, they acknowledge that the implementation of the scheme has been full of challenges, and that it is exhausting to fight for suitable supports. Contained in many responses was the sentiment ‘everything was and still is hard’.

In general, the survey echoed the findings of interview and focus group discussions conducted by both Women with Disabilities ACT and Advocacy for Inclusion, and points to a number of areas where the NDIS can improve its processes to offer better supports, independence, choice and control to people with disabilities.