



**Australian Federation of
Disability Organisations**

NDIS participant experience in Rural, Regional & Remote Australia

**Submission to the Joint Standing Committee on the
National Disability Insurance Scheme**

12 March 2024

Primary author/s:

Rebecca Rudd
Coordinator – Policy & Submissions

Reviewed & approved by:

Ross B. Joyce
Chief Executive Officer

Table of Contents

ABOUT AFDO	3
ACKNOWLEDGEMENT	4
1. INTRODUCTORY COMMENTS	5
2. SURVEY METHODOLOGY AND RESPONDENT DEMOGRAPHICS.....	6
3. PARTICIPANT EXPERIENCE OF NDIS PROCESSES	8
4. NDIA PERFORMANCE IN RURAL, REGIONAL, AND REMOTE AREAS	15
5. PARTICIPANT CHOICE AND CONTROL OF NDIS SERVICES AND SUPPORTS.....	19
6. CONCLUDING COMMENTS.....	24




AFDO consents to the publishing of this submission inclusive of email contacts.



AFDO Ltd. 2024

- **CC BY-NC-SA:** AFDO provides materials it has developed under a Creative Commons Licence.
- This license allows reusers to distribute, remix, adapt, and build upon the material in any medium or format for non-commercial purposes only, and only so long as attribution is given to the creator (AFDO). If you remix, adapt, or build upon the material, you must license the modified material under identical terms.

CC BY-NC-SA includes the following elements:

- BY  – Credit must be given to the creator
- NC  – Only non-commercial uses of the work are permitted
- SA  – Adaptations must be shared under the same terms

About AFDO

The Australian Federation of Disability Organisations (AFDO), a Disabled Peoples Organisation (DPO) has been a respected & recognised national peak in the disability sector for over twenty years.

Our vision: That all people with disabilities must be involved equally in all aspects of social, economic, political and cultural life.

Our mission: Using the strength of our membership-based organisations to harness the collective power of uniting people with disability to change society into a community where everyone is equal.

AFDO's thirty-six member organisations represent disability specific & cross disability communities with a total reach of over **4 million** Australians.

Our Members:

Advocacy for Inclusion Inc. - ACT	Arts Access Australia
Autism Aspergers Advocacy Australia	Blind Citizens Australia
Brain Injury Australia	Deaf Australia
Deafblind Australia	Deafness Forum Australia
Disability Advocacy Network Australia	Disability Justice Australia
Disability Resources Centre - Vic	Down Syndrome Australia
Enhanced Lifestyles - SA	Physical Disability Australia
People With Disabilities WA	Polio Australia
South West Autism Network - WA	Women With Disabilities ACT
Women with Disabilities Victoria	National Mental Health Consumer & Carer Forum
Advocacy WA	All Means All
AED Legal Centre - Vic	AMAZE - Vic
Arts Access Victoria	Aspergers Victoria
Disability Advocacy & Complaints Service - SA	Explorability Inc - SA
Multiple Sclerosis Australia	Leadership Plus - Vic
National Union of Students - Disabilities Dept.	National Organisation for Fetal Alcohol Spectrum Disorder
TASC National Limited	Star Victoria Inc
Youth Disability Advocacy Service - Vic	Tourettes Syndrome of Australia

Acknowledgement

AFDO acknowledges Aboriginal and Torres Strait Islander people as the traditional custodians of the land on which we stand, recognising their continuing connection to land, waters, and community. We pay our respects to the peoples of the lands on which these operate and to their respective Elders past and present. We also pay our respects to the traditional owners of all lands on which we operate or meet around the country.

AFDO acknowledges people with disability, particularly those individuals that have experienced or are continuing to experience violence, abuse, neglect, and exploitation. We also acknowledge their families, supporters, and representative organisations and express our thanks for the continuing work we all do in their support.

1. Introductory comments

The Australian Federation of Disability Organisations (AFDO) thanks the Joint Standing Committee on the National Disability Insurance Scheme (the Committee) for their consideration of this submission.

This submission is primarily informed by a recent survey undertaken by AFDO examining the experiences of National Disability Insurance Scheme (NDIS) participants in rural, remote, and regional Australia.

In line with the Terms of Reference provided by the Committee, this submission will address:

- a. the experience of applicants and participants at all stages of the NDIS, including application, plan design and implementation, and plan reviews;
- b. the availability, responsiveness, consistency, and effectiveness of the National Disability Insurance Agency in serving rural, regional and remote participants; and
- c. participants' choice and control over NDIS services and supports including the availability, accessibility, cost and durability of those services.

The NDIS aims to provide support and services to people with disability across all of Australia, ensuring they have choice and control to access these supports and services to live their life on an equal basis with others.

AFDO wishes to state its strong support for the continuing operation of the National Disability Insurance Scheme maintaining the choice and control of all participants. We acknowledge that whilst the NDIS has been instrumental in transforming the lives of many participants, there are still ongoing challenges, particularly for those current participants or those accessing the Scheme who reside in rural, remote, and regional areas.

These issues include limitations on choice and control, difficulties accessing services, lack of services and inequitable provision of funding in comparison with those in most capital city metropolitan areas or major regional cities.

In summary, the findings of the AFDO survey underscore the complexity and inadequacies of the current NDIS system in meeting the needs of participants living in rural, remote, and regional Australia, reinforcing the critical need for urgent reform to ensure equitable access to services and supports for all participants, regardless of their geographical location.

This research project and the writing of this submission have occurred contemporaneously with AFDO's ongoing work in relation to its response to the Final Report from the Independent Review into the NDIS. AFDO's response to this Review Recommendations is currently being finalised with input from AFDO's extensive Membership organisations and will be released shortly, incorporating the learnings contained within this submission. This forthcoming work will address all aspects of the NDIS, including the issues encountered by rural, regional, and remote participants, and will provide further insights to the work of the Committee.

2. Survey methodology and respondent demographics

2.1. Methodology

AFDO conducted an online survey over a two-week period in February 2024 using the online platform SurveyMonkey seeking responses from those located in rural, remote and regional Australia.

We utilised a purposive sampling method, with the survey distributed to AFDO's internal database of NDIS participants and their families and carers. A mixed methods survey design was used, with a combination of multiple-choice questions, Likert scales, and open text questions. The resulting data was analysed using both quantitative and qualitative methods.

In total, 63 individual responses were recorded, including both NDIS participants and those answering on behalf of an NDIS participant. While the highest concentration of respondents were from New South Wales and Victoria, all States and Territories excluding the Australian Capital Territory were represented.

2.2. Respondent demographics

Of the 63 total respondents:

- 50.7% (32) identified as NDIS participants completing the survey on their own behalf.
- 49.3% (31) identified as someone answering on behalf of an NDIS participant (presumably this group would comprise family members, carers, or support workers).

Gender:

- 60.3% (38) of respondents identified as female.
- 38.1% (24) of respondents identified as male.
- 1.6% (1) of respondents identified as non-binary.

Age:

- 12.7% (8) of respondents were under 18 years of age.
- 12.7% (8) of respondents were aged 18-25 years.
- 9.5% (6) of respondents were aged 26-35 years.
- 22.2% (14) of respondents were aged 36-50 years.
- 42.9% (27) of respondents were aged 51-65+ years.

Rural, regional, or remote:

- 47.6% (30) of respondents lived in a rural area.
- 3.2% (2) of respondents lived in a remote area.
- 55.6% (35) of respondents lived in a regional area.

Location:

- 31.7% (20) of respondents lived in New South Wales.
- 11.1% (7) of respondents lived in Queensland.
- 30.2% (19) of respondents lived in Victoria.
- 4.8% (3) of respondents lived in South Australia.
- 4.8% (3) of respondents lived in the Northern Territory.
- 15.9% (10) of respondents lived in Western Australia.
- 1.6% (1) of respondents lived in Tasmania.

Aboriginal and/or Torres Strait Islander status:

- 4.8% (3) of respondents identified as Aboriginal and/or Torres Strait Islander.
- 96.8% (61) of respondents did not identify as Aboriginal and/or Torres Strait Islander.

Culturally and linguistically diverse (CALD) status:

- 4.8% (3) of respondents identified as CALD.
- 95.2% (60) of respondents did not identify as CALD.

LGBTQIA+SB status:

- 6.3% (4) of respondents identified as LGBTQIA+SB.
- 93.7% (59) of respondents did not identify as LGBTQIA+SB.

3. Participant experience of NDIS processes

3.1. Application process

When asked which statement most closely matched their **experience of applying** for the NDIS:

- 12.7% (8) respondents indicated that they found the application process straightforward and did not require any assistance to complete the application.
- 36.5% (23) respondents indicated that they found the application process somewhat complex and required assistance.
- 30.2% (19) respondents indicated that they found the application process to be quite challenging.
- 34.9% (22) respondents indicated that they found the application process to be confusing and stressful.

Respondents were also given the option to expand on their experience of the application process in an open text question. From these responses, a number of key themes emerged.

3.1.1. Complexity and stress:

Many respondents perceived the application process to be overly complex and stressful. Specifically mentioned were the lengthy and tedious administrative processes, lack of clarity in terms of requirements, and difficulties in obtaining the requisite paperwork and documentation.

"It took years of work to apply for it... Horrific, stressful, arduous; made me more sick and disabled."

"I have found applying for the NDIS [to be] a very long, tedious, drawn out process, and the follow up from the NDIS is slack and unreliable."

"As a carer & nominee for my 30yo adult son with high intensity multiple complex disabilities PLUS a professional disability education facilitator (& volunteer advocate) at a local, state & national level it was a HUGE & time-consuming task to gather, check & correct all evidence reports from 20+ disability related specialists... 180km from our family home!"

3.1.2. Lack of understanding and flexibility:

Respondents criticised the NDIA for failing to understand individual circumstances or consider the diverse needs of individual applicants. This was exacerbated by a perceived lack of flexibility in the system and the utilisation of a "one size fits all" approach that could not accommodate specific needs.

"There was no allowance for differences. It was like a one size fits all and my particular needs were not understood. There was no flexibility for adaptations or to consider things differently."

"They don't listen to the situation the client is in, don't consider the clients address or disability..."

3.1.3. Lack of accessibility and poor communication:

Respondents mentioned accessibility issues, most commonly being unable to access required services due to lack of availability in their area. Lack of interpreting services and difficulty understanding documents that were provided only in English were also noted. Communication barriers with NDIA staff were also mentioned, with some feeling that their concerns were not heard or understood.

"I was not offered an interpreter and I struggled to understand the English documents."

"My mother is my legal guardian and is answering these questions for me. I have significant intellectual disabilities and would not be able to undertake this survey by myself - or be able to navigate the NDIS system."

"Major difficulties accessing clinicians to confirm diagnosis and fill out forms. Caused huge delays."

"NDIS/NDIA had little if any understanding of my particular disability. For example - I had to lodge complaints in order to get them to email me instead of phone - I am deaf and lodge complaints in order to get the information I needed."

3.1.4. Frequent delays and rejections:

Many respondents described significant and repeated delays in the application process, including long waits for internal reviews and challenges in accessing necessary services. Rejections were also a common issue, with some feeling that decisions were inconsistent or arbitrary, leading to increased stress and exacerbation of physical and mental health conditions.

"I was rejected 3 times, each for a different reason although my application remained much the same. The inconsistency made me feel like the process was either a lottery, or that the assessors had decided from the start to reject most people with psychosocial disability and therefore that the reason(s) were trumped up. Extremely stressful (and time consuming) and made my disability much, much worse."

"It took years of work to apply for it. I was too sick to do it myself, my parents had to do it for me even though I was an adult. I was knocked back the first time even though I was the same level of disability I was when I was accepted on my second application."

3.1.5. Importance of support and coordination:

Support from external organisations and professionals was crucial for many participants in navigating the application process. Some respondents highlighted the importance of having knowledgeable support coordinators or advocates to assist with applications and understanding the system's complexities.

"Without the assistance of my mental health social worker and kind support coordinator - I would have been lost. Local Area Coordinator were useless and simply did not care. Frightening experience."

"The main thing was being denied support coordination. This is needed as services in my area change all the time."

3.1.6. Systemic issues within the NDIA:

Several respondents criticised perceived systemic issues within the NDIA, including insufficient training and qualifications of employees, arduous bureaucratic processes, and lack of transparency in decision-making. Concerns were raised about the capacity of the NDIS to effectively support people with disability, and many respondents cited a need for improved services and resources.

"Always having a different Planner means a lot of repetition and going over history that can be very traumatic to discuss. Not knowing what is on record makes it more difficult and knowing that the Planner does not understand the issues with living remotely... Not having had access to an experienced and knowledgeable Support Coordinator has been the biggest issue."

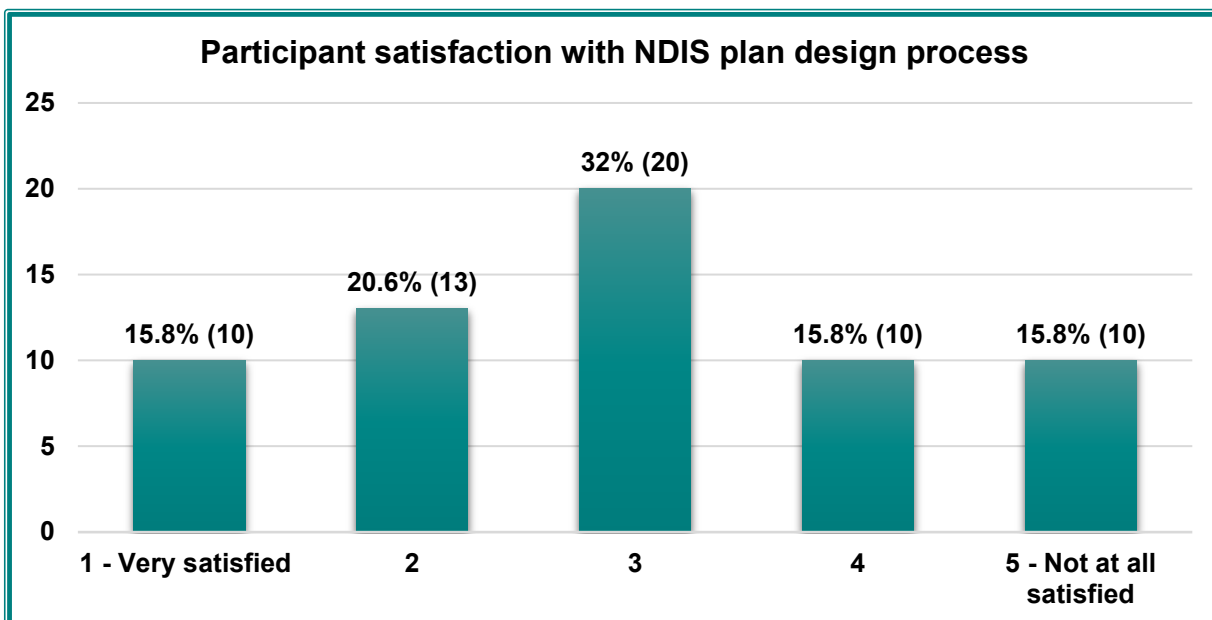
"There are shortages in a number of support services, particularly Allied Health, accessing open employment, and housing support services. As a result, I have not been able to utilise all of my plan budget each year, achieving approximately 70% expenditure and not receiving all of the support services I need."

"The system doesn't want us to be on the NDIS and does everything it can to not approve us. Horrific, stressful, arduous, made me more sick and disabled."

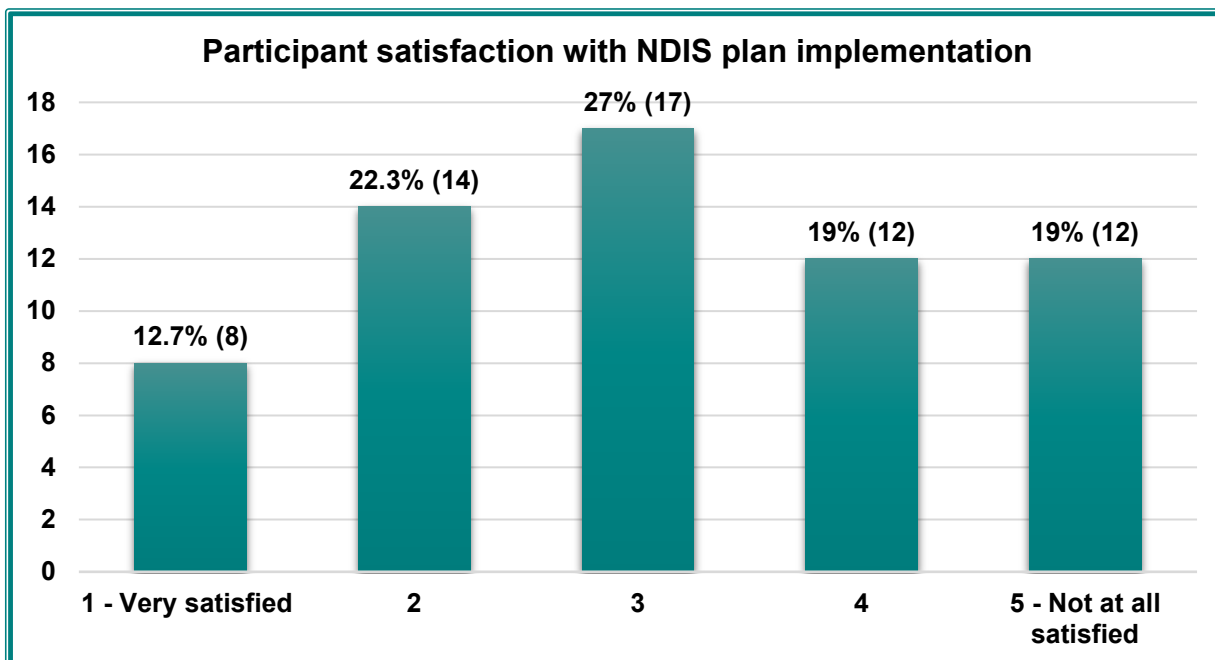
"They only follow policy which is miles apart from legislation - I don't think anyone at the NDIS understands the legislation as they abuse it."

3.2. Plan design, implementation, and review

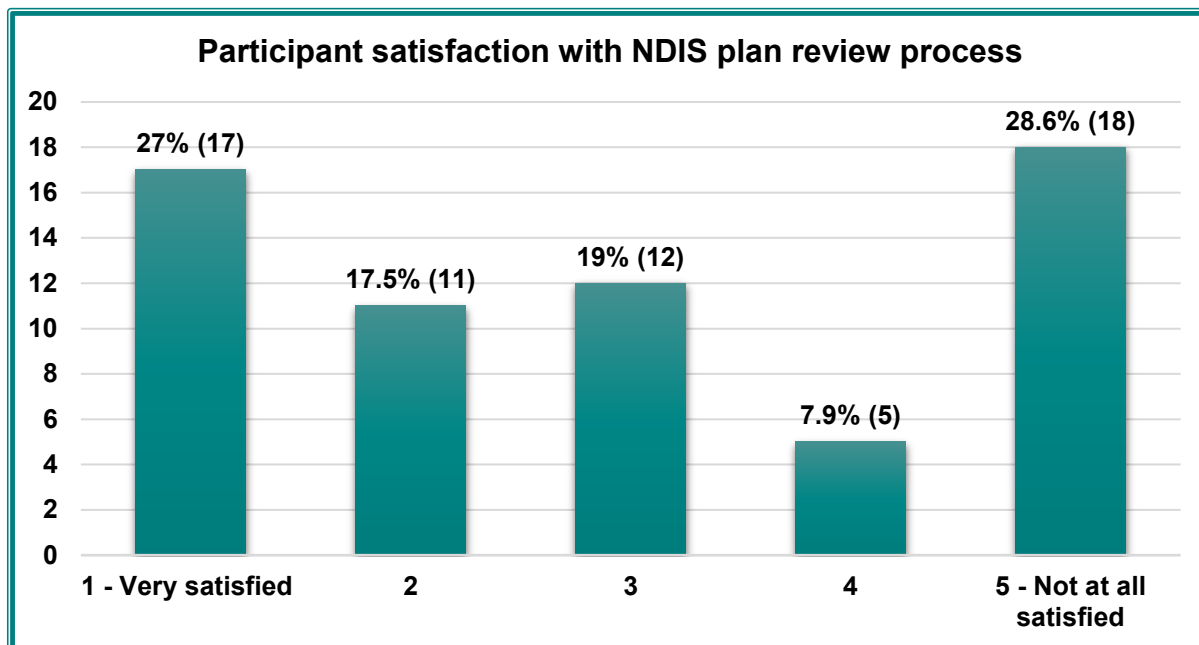
When asked to rate their experience of **designing their plan** on a scale of 1 to 5, with 1 being “Very satisfied” and 5 being “Not at all satisfied”, respondents had an **average rating of 3.0**.



When asked to rate their experience of **implementing their plan** on a scale of 1 to 5, with 1 being “Very satisfied” and 5 being “Not at all satisfied”, respondents had an **average rating of 3.1**.



When asked to rate their experience of **having their plan reviewed** on a scale of 1 to 5, with 1 being “Very satisfied” and 5 being “Not at all satisfied”, respondents had an **average rating of 2.9**.



Respondents were then given the option to further expand on their experience of having their NDIS plans designed, implemented, or reviewed in an open text question.

- As in the previous section, respondents once again noted the frustratingly **slow, exhausting, and highly stressful nature of NDIS processes**, particularly the plan review process. Many delays in receiving decisions – or, indeed, any response at all – from the NDIA were likewise reported, causing significant inconvenience and further compounding anxiety for many.
- Similarly, respondents once again noted a **lack of understanding and communication** from NDIA staff. Issues related to communication barriers were once again highlighted, and many reiterated their feeling that staff did not understand and adequately account for their needs.
- As in the previous section, many respondents expressed dissatisfaction with the **"one size fits all" approach**, feeling that their individual needs were not adequately considered or addressed in their plans. Complaints were again made about the inflexibility of the system, particularly its failure to recognise and accommodate diverse needs.

In addition to the above issues, several new themes emerged:

3.2.1. Unprofessionalism and lack of respect:

Respondents mentioned encountering unprofessional behavior from Planners and Local Area Coordinators (LACs), including a lack of respect, both in general and in regard to their lived experience expertise; poor knowledge and understanding of disability; and a lack of professional decorum. Many instances of feeling dismissed or not listened to during the planning or review processes were reported.

"LAC and planners were terrible at each stage - not professional, not respectful, lacked knowledge about [my] particular disability, didn't listen, conveyed [that] my disability and its impact was less important than others."

"Our local LAC had very limited professional or life experience with disability... This I know has been an ongoing issue for my community."

"My voice was not represented in the first plan. Told my story, only to find myself portrayed with infantilising language in my own plan!"

"LAC had obviously not read/understood my plan. I ended up with the impression I knew more about the process than they did. In the end the LAC couldn't advise me on some basic conditions."

3.2.2. Inadequate support and advocacy:

The lack of support from NDIS representatives, particularly LACs, was highlighted by several respondents, in addition to minimal or entirely non-existent access to disability advocacy services. Many respondents stressed the need for more disability advocates to assist in navigating the NDIS system effectively.

"There has been no support at all from the LAC... No one from NDIS has ever contacted me to support me to implement my plan."

"I needed my support coordinator to handle much of the review process because the stress made me fall apart. Without her I would have been railroaded and ended up with an unsatisfactory plan that materially disadvantaged me. But she was accused of acting like an advocate. I don't see why people who can't cope with the process emotionally should be denied advocacy."

"We need more disability advocates funded as I wouldn't have understood [the] NDIS system without her"

3.2.3. Concerns with review process:

Concerns were raised regarding the review process, namely the lack of transparency, ever-changing and inconsistent rules, and the stress of potentially having one's support package reduced. Respondents felt that reviews were often unnecessary and time-consuming, and many avoided seeking any amendments to their plan out of fear of retribution through a reduction in their allocated funding.

"The reviews have not been a pleasant experience. I felt as though I was having to justify my needs, to the degree of pleading my case."

"Plan reviews are very difficult. As my age and needs change, it's like starting the whole process over again to have my new needs met... Life is tough enough already but if I don't get this right my quality of support and quality of life is seriously impacted."

"We're too scared to demand a review, even though a lot of the info in my plan is no longer correct, because it actually has the right amount of funding for me now. Everyone we know has had their funding cut."

3.2.4. Issues with plan implementation

Difficulties in implementing plans, including the challenge of finding suitable service providers in their area and coordinating complex supports, were mentioned by numerous respondents. Multiple instances of plans being grossly underfunded or not reflective of participants' needs were reported.

"... they never listen to clients' needs or cater for distance and living areas. No services out this way being isolated and no funding or help at all."

"... can't use all of the plan because of the restrictions and hoops you have to go through to access what I need. I am too sick to jump through so many hoops."

"... lack of support to coordinate complex and overwhelming implementation."

"They ignored my goals and made up their own. There was less than half the amount of funding that I needed... No one has ever contacted to check if I'm okay, or to help me understand or implement my plan."

4. NDIA performance in rural, regional, and remote areas

4.1. General experience with the NDIA

Respondents were first asked about their general experience of dealing with the NDIA from where they lived, and directed to check all boxes that apply.

- **14.3%** indicated that they found NDIA to be **easily available**.
- **7.9%** indicated that they found the NDIA to be **responsive**.
- **12.7%** indicated that they found the NDIA to be **consistent in their dealings** with them.
- **6.3%** indicated that they found the NDIA to be **effective in meeting their needs**.
- **11.1%** indicated that they found the NDIA to be **effective at answering their questions**.
- **66.7%** indicated that they found the NDIA to be **none of the above**.

4.2. Availability, responsiveness, consistency, and effectiveness of the NDIA

When asked whether they found NDIA staff to be **easily available** when needed:

- **14.3%** (9) respondents answered "**Yes**"
- **46%** (29) of respondents answered "**No**"
- **39.7%** (25) of respondents answered "**Sometimes**"

When asked whether they found NDIA staff to be **responsive** in their dealings with them:

- **23.8%** (15) of respondents answered "**Yes**"
- **31.7%** (20) of respondents answered "**No**"
- **44.5%** (28) of respondents answered "**Sometimes**"

When asked whether they found NDIA staff to be **consistent** in their dealings with them:

- **15.9%** (10) of respondents answered "**Yes**"
- **49.2%** (31) of respondents answered "**No**"
- **34.9%** (22) of respondents answered "**Sometimes**"

When asked whether they found NDIA staff to be **effective in answering their questions and meeting their needs**, including communication and accessibility needs:

- **14.3%** (9) of respondents answered **"Yes"**
- **52.4%** (33) of respondents answered **"No"**
- **33.3%** (21) of respondents answered **"Sometimes"**

Respondents were then asked to provide any further comments on issues they had encountered while dealing with the NDIS that were related to living in a rural, regional, or remote location. Key themes identified include:

4.2.1. Communication barriers:

Frequent communication barriers were reported, including difficulties in reaching NDIS representatives by phone, limited access to support staff, and inconsistent or delayed responses. Many respondents noted their inability to meet with NDIA staff in person due to their location and expressed concern about the subsequent reliance on telecommunication. This was of particular concern to those who had difficulty with verbal communication and was often further exacerbated by a lack of translators and another accessibility supports.

"It's almost all by phone which is fine while my mum is alive and advocating for me but as a non-verbal person, we worry how I can do that kind of stuff by phone."

"The call centre do not use interpreters and I get different answers all the time."

4.2.2. Logistical and financial challenges:

Respondents highlighted the additional costs and logistical challenges associated with living in rural, regional, or remote areas, such as the need to travel long distances for appointments and services. In many cases, this additional financial burden was not recognised in their plans, with insufficient funding being allocated for transport. Lack of local support options and the need to seek services outside the area were also mentioned as significant challenges, leading to financial strain and disruption to daily life.

"Travel needs to be a standard addition to funding for rural participants when a 45 minute drive to [access] services is normal."

"Access to support staff is difficult or support staff does not exist in our rural town. One of the biggest cost factors is transport as we access services out of area..."

"Transport is not taken into account. Travel for providers is extremely costly but there is no additional funding available to cover it."

4.2.3. Inadequate local knowledge and representation:

Many respondents expressed dissatisfaction with the lack of local understanding among NDIA representatives and stressed the need for more localised planning decisions that took the specificities of their particular location into account. Calls were made for better representation of local needs and interests within the NDIS planning and decision-making processes.

"Local NDIA team members should be responsible for planning decisions for local participants - what is the point of having a local office if all NDIA members work nationally and you can't even speak to a local representative?"

"People in the cities have no idea what it's like to live in a rural community with little or no services."

"Simply a person (with apparent lack of life skills or experiences) that sits in an office in a capital city (with no local knowledge) making decisions that severely impact a person's life. Absolutely no idea of what it is like to live in RRR areas and the huge lack of services and support."

4.2.4. Quality of NDIA staff

Many respondents expressed dissatisfaction with the quality of NDIA staff, particularly LACs. Complaints included reports of rudeness, dismissiveness, and a failure to recognise or understand participants' individual needs. Instances of receiving conflicting advice and a general lack of continuity in support provision were highlighted as significant issues.

"They are useless, different answer every time and nothing but bullied."

"... lack of knowledge of physical and mental health conditions / disabilities. No idea about comorbidity factors, poor listening skills, no empathy or compassion, not even aware of their own rules and regulations."

"They are ableist, rude, and dismissive."

"It's terrible. Every time we try to contact someone from NDIS it's a different person, and they all say different things. No one tries to help and no one follows up. I need emails and things in writing, and they never do that."

4.2.5. Need for systemic change:

Multiple respondents identified the need for systemic change within the NDIA in to address the unique challenges faced by individuals living in rural, regional, and remote areas. In particular, the need for better training of NDIA staff, additional means of communication, and fairer pricing structures that reflect regional differences were noted.

"Make training in all areas compulsory and give the NDIS participants money to purchase items if low income."

"It's not the client's fault in where they are living in rural areas, funding needs to be given for travel to therapist and the city appointments as resources in rural areas are non-existent. Parents shouldn't be left struggling to pay travel costs for the therapy they require in a rural environment. Need more therapists and social workers and support workers needed desperately."

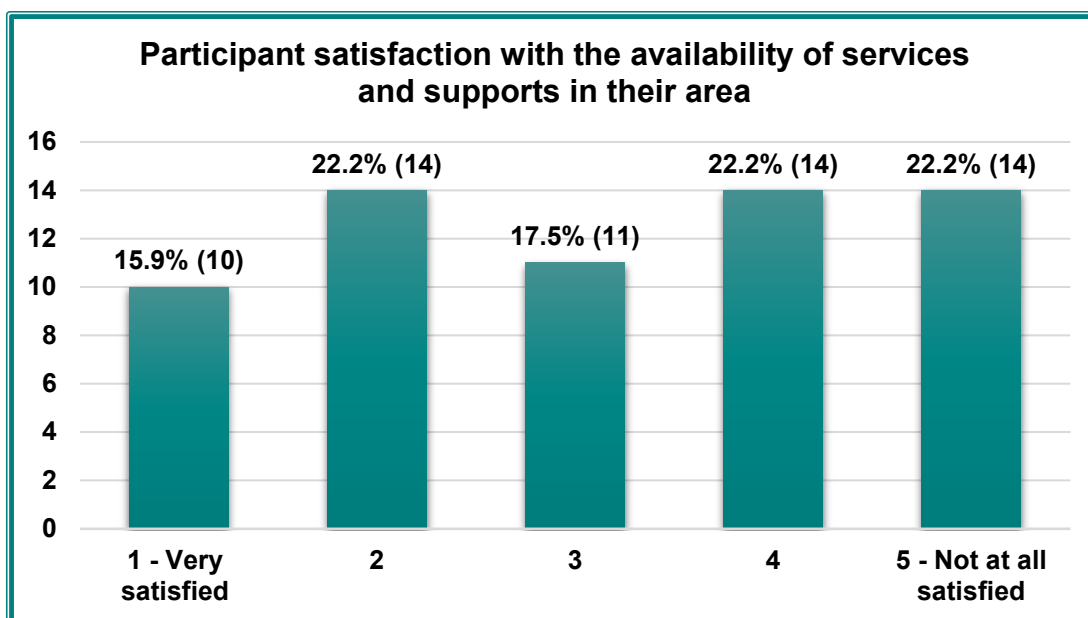
"... refusal to acknowledge or provide funding to satisfy rural needs. Also refusal to acknowledge that market prices vary across the whole country and have gone up dramatically since covid. The competition that is supposed to operate to keep prices down in the city simply doesn't operate in the country. Therefore, extremely difficult to find anyone who is willing to provide the services for the NDIS prices."

"NDIS needs to understand the wide range of inequities between city/metro and regional/rural/remote and equalise it in some way, take this into consideration."

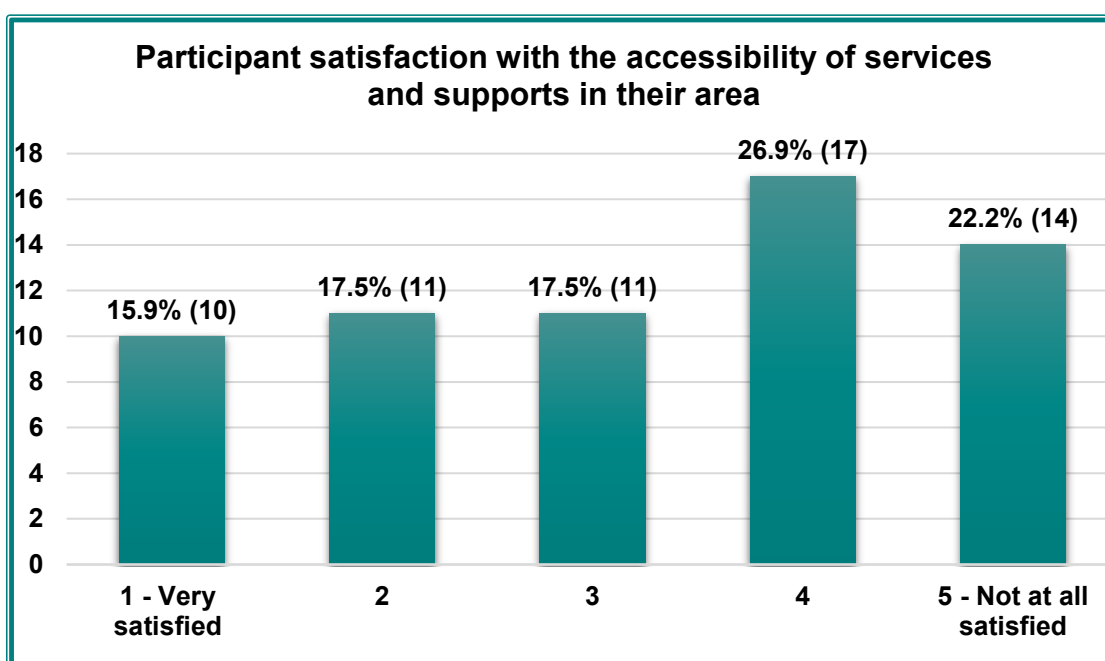
5. Participant choice and control of NDIS services and supports

5.1. Availability, accessibility, cost, and durability of services and supports

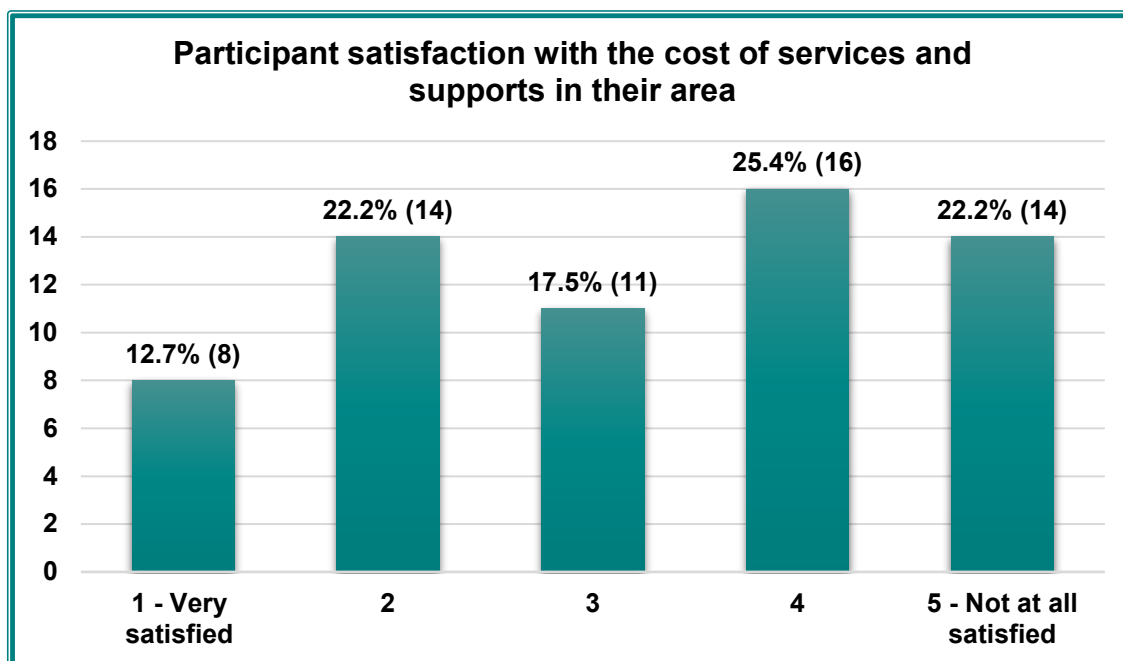
When asked to rate the **availability** of services and supports in their area on a scale of 1 to 5, with 1 being “Very satisfied” and 5 being “Not at all satisfied”, respondents had an **average rating of 3.1**.



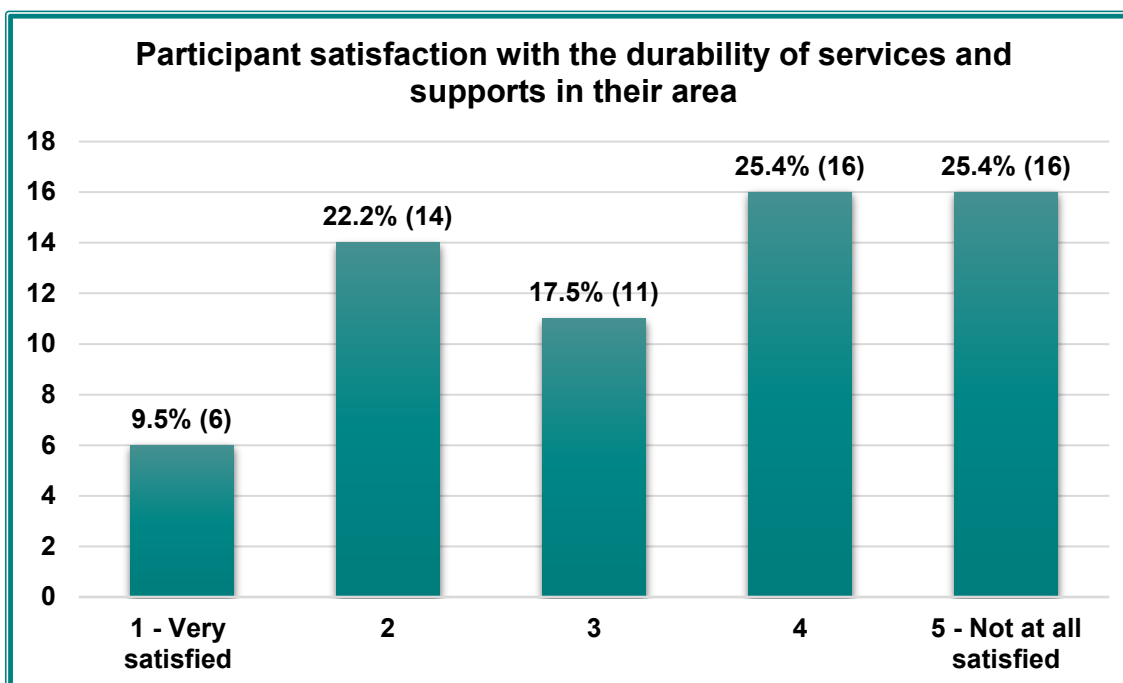
When asked to rate the **accessibility** of services and supports in their area on a scale of 1 to 5, with 1 being “Very satisfied” and 5 being “Not at all satisfied”, respondents had an **average rating of 3.2**.



When asked to rate the **cost** of services and supports in their area on a scale of 1 to 5, with 1 being “Very satisfied” and 5 being “Not at all satisfied”, respondents had an **average rating of 3.2**.



When asked to rate the **durability** of services and supports in their area on a scale of 1 to 5, with 1 being “Very satisfied” and 5 being “Not at all satisfied”, respondents had an **average rating of 3.3**.¹



¹ For the purposes of this survey, durability was defined as “how well supports and services last, or are likely to last, where you live.”

5.2. Participant perception of their degree of choice and control

Respondents were then given the option to further expand on the degree of choice and control they were able to exercise when accessing services and supports in their area. As with the two previous open text questions, several themes were reiterated:

- **Lack of local services** resulting in long waitlists, limited access to specialists, and scarcity of support staff.
- Being forced to **travel long distances** to access necessary services, resulting in **financial strain** and **logistical challenges**.

In addition to these, several other key themes emerged:

5.2.1. Inequity in access and funding

Multiple respondents highlighted the disparity between rural, regional, and remote areas and urban centres in terms of access to services and provision of funding. Many again referenced the higher transport costs associated with accessing services in these areas, stressing the need for NDIS plans and funding to take this increased financial burden into account. In addition, some respondents identified NDIS price limits as another factor restricting their choices and preventing them from accessing a wider pool of services.

"The services and supports I need are mostly at a distance - I have to travel, and the other aspect of living regional with no car is that public transport is not as good as [in] the city... Transport funding is not included to help with accessing services if you are regional/rural/remote, and this adds to the inequity and lack of access with city participants vs participants in other areas."

"Very limited in options. [Being] restricted by NDIS price limits means that I miss out on a wider pool of services."

"Long waiting lists for therapy services, providers are often hours [of] driving away, rural providers have a high turnover of therapists so continuity can be very hard and dependent on luck."

5.2.2. Inability to exercise choice and control:

Despite the emphasis placed by the NDIA on the importance of participant choice and control, many respondents expressed feeling that their options were severely limited, and that they lacked any true agency in regard to their NDIS plans and funding. This sense of impotence is further exacerbated by frustration with arduous bureaucratic procedures, a lack of responsiveness on the part of NDIA staff and service providers, and difficulties with accessing support when needed.

"The availability of service providers in regional and rural areas is extremely poor. This means that a) travel funding for services providers is needed; b) difficulty in accessing services at all; c) there is little or no choice in practice; and d) durability is a huge issue. If something is unsatisfactory, I am loathe to raise it because there is usually no alternate service provider available."

"I do not have choice and control particularly with allied health, which is so hard to access, and again, always the language barriers."

"There is not a lot as most times you take what you can get."

"Little choice of service providers and those that are available do not understand their role or function. Simply see me as a cash cow. No understanding of my conditions, goals and aspirations. Poorly run and organised, support workers not qualified or experienced, poor attitudes... No flexibility to suit our changing needs. Leaving me little to no choice or control."

5.2.3. Reliance on unregistered providers:

Due to the shortage of registered providers in many rural, regional, and remote areas, as well as dissatisfaction with the quality of services offered by many registered providers, many respondents were either forced to rely on unregistered providers or preferred to rely on unregistered providers. Some expressed concerns that unregistered providers may be subject to less accountability and oversight, potentially resulting in poor quality of care, lack of professionalism, or unethical behaviour from providers. However, respondents also expressed concerns about the potential implications of mandatory provider registration, fearing that it would leave them with even fewer options.

"The only way for us to find providers that are suitable and available providers is by employing non-registered ones."

"My NDIS plan is self-managed and I only use unregistered providers. I do all my therapy on Telehealth. There aren't enough providers here. I've had to wait more than 2 years for some services."

"I use only unregistered providers, because there are almost no registered providers in this area. And the registered providers that are here have a terrible reputation... The unregistered providers I use have been brilliant, and are a lot cheaper... I'm really, really worried about the NDIS Review recommendations for mandatory provider registration. I talked to my providers, and they all said that they won't ever register, which would leave me with no support."

5.2.4. Concerns about ethical practices:

Concerns were raised by several respondents about unethical practices among some service providers, both registered and unregistered, emphasising the need for greater accountability and oversight within the NDIS framework.

"All my current providers are registered and provide good quality services and care, but I have heard that there are some providers that are not ethical in their delivery of services and this concerns me for my future choices."

"I feel also that the level of service and the quality of services that some local providers provide to participants is not only charged at exorbitant rates but the quality of service is very poor as majority of the workers simply have limited experience working with people with a disability and are given minimal training... I feel there is a trend or belief that because we live where we live, services go under the radar, therefore can and do charge what they want because who is here to make these providers accountable? ... Provider routing I feel is a major issue."

"The service providers need to be looked at as they charge ridiculous amounts per hour. This is wrong."

"It's dangerous. Untrained, uncontrolled, unqualified workers."

6. Concluding comments

AFDO would thank the Committee once again for the opportunity to provide feedback on the experiences of NDIS participants living in rural, regional, and remote areas of Australia.

As this submission aims to have demonstrated, these individuals face significant challenges, and their responses shed light on a troubling landscape marked by inequity in access, services, funding and a pervasive sense of powerlessness, in stark contrast to the emphasis placed on choice and control.

Addressing these challenges will require a multifaceted approach that includes revisiting funding models to account for increased costs associated with accessing services, improving the responsiveness and accountability of both NDIA staff and service providers, exploring innovative solutions to expand the availability of quality supports and developing comprehensive workforce strategies that are designed for specific regions and funded to address the participants needs in these areas.

AFDO intends to expand further on these potential solutions in our forthcoming response to the Final Report and looks forward to sharing this work with the Committee upon its completion.

Submission Contact:

Rebecca Rudd
Coordinator – Policy & Submissions
M: 0493 123 269
E: rebecca.rudd@afdo.org.au