

NDIS Participant experience in rural, regional, and remote Australia

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Contents

- Overview** 4
 - Introduction and key issues **4**
- Executive summary** 4
 - Recommendations:** **4**
- About Limbs 4 Life** 5
 - Amputee population and limb loss impacts 5
 - The impact of acquiring an amputation / disability 6
- Consultation process** 6
 - Question 1 – Please tell us about your experience of the application process into the NDIS? 7
 - Question 2 – Please tell us about your experience of your plan design and roll-out (*how well or how poorly your plan is working?*). 8
 - Question 3: Please tell us about your experience of the Plan Review process? 9
 - Question: 4 As a person living in rural, remote or regional Australia, how effective has the agency been in meeting your needs? 9
 - Question 5. Has the agency been responsive in dealing with any questions or concerns that you have had? 10
 - Question 6. The Agency is working in a helpful manner? 11
 - Question 7. As a participant, are you able to exercise choice and control over your services and supports and the people who provide you with those supports? 11
 - Question 8: Do you think that the services you receive provide value for money? 12

Overview

Introduction and key issues

The Joint Standing Committee on the National Disability Insurance Scheme launched an inquiry into the NDIS participant experience in rural, regional and remote Australia, in October 2024.

The purpose of the inquiry is to gain feedback from participants in rural, regional and remote communities and their experiences in relation to the application process, plan implementation, design and review. In addition, the Committee would like to gauge greater insights with reference to participants choice and control over services and supports, along with the experience of the process of the Aboriginal and Torres Strait Islander participants, participants from culturally and linguistically diverse backgrounds, and participants from low socio-economic backgrounds.

Executive summary

It is without a doubt that the NDIS has had a positive impact on the lives of many Australian's with disability. Access to services which were previously unattainable and assistive technology out of financial reach is being acquired by many that need it. However, the feedback from our consultation highlights that there is limited choice and control over access to providers in rural, regional and remote communities; that travelling long distances to appointments can not only be onerous, but costly and budgets don't always reflect those additional expenses, not to mention the costs associated by providers who are delivering services with sometimes expensive travel budgets attached.

Recommendations:

The following recommendations are based on the feedback from the consultation and outlined below in hope to ensure a more viable, efficient and effective service for all.

1. Open and efficient lines of communication with the Agency for participants is a must to ensure that the processes for both the participant and the provider work effectively to prevent delays and wait times.
2. Participants were vague regarding their responses in relation to products and services being value for money. If participants are not upskilled with RRP costs associated with their quotes, then they are unable to effectively trade in a competitive and open market.
3. A basic list price should be available for non-qualified services such as gardening, home maintenance and cleaning services. These seem to be extremely high with costs escalating in remote locations. Standard rate per hour for these services should be fixed price, thus preventing price gouging of any kind.
4. It appears that there is a lack of transparency with regard to quotes being provided to participants and they are often not line item detailed. All quotes irrespective of whom is responsible for approving them, should be shared with the participant, even if they are not self-managing.
5. It is also evident that some participants can grasp the concepts, forms and requirements of the system more so than others. For those participants who are struggling to understand how the NDIS

system works, education should be provided to upskill and support confidence building and self-advocacy knowledge.

6. Plan reviews and plan roll-overs should be advised in advance, therefore allowing time for the participant to consider their needs. Plans should never just be 'rolled over' without the participant having any knowledge of the process because a quota needs to be met, that is unacceptable.
7. Construct a detailed pathway or guidance system that participants can use and refer to for managing their own plans, supports and services.

About Limbs 4 Life

Limbs 4 Life has been operating in the disability sector for nearly 20 years and is the peak body for people with limb-loss. The organisation works to empower amputees through knowledge and support. Limbs 4 Life builds community connections among stakeholders, ensuring that people and their families do not go through amputation alone; Limbs 4 Life works to ensure that people pre or post amputation have access to our national best practice peer support program, along with the provision of resources and current information to assist them to transition back to independent living.

Limbs 4 Life's mission is to provide information and support to amputees and their families while promoting an inclusive community. Our philosophy is to empower amputees with knowledge and support to make a real difference, because no one should go through limb loss alone.

Limbs 4 Life provides services to thousands of amputees and their care givers, who rely on its programs and support for assistance prior to or after a limb amputation. Limbs 4 Life is supported by over 200 trained Peer Support Volunteers and is governed by a board and operated by staff with a majority representation from those with the lived experience of amputation or close contact with someone who does.

Since its formation, Limbs 4 Life has greatly extended the supports available to amputees, their families, primary care givers and healthcare staff. Limbs 4 Life's services include provision of:

- Best practice Peer Support Programs
- Evidence-based health literacy resources and wellbeing information
- Independent support and advocacy to assist people to navigate healthcare and disability systems and pathways
- Access to social and economic inclusion activities.

Limbs 4 Life advocates for amputees by initiating or taking part in research, providing recommendations to government, responding to submissions, and educating the community about amputation and limb loss.

Amputee population and limb loss impacts

Of the 160,395 people who have undergone amputation in Australia, 42,007 are living with major limb loss and are potential prosthetic users, however not all are NDIS participants. In fact, as of December 2022, amputees made up 1% of Australia's NDIS participant population (n=4,060/573,340;

<https://data.ndis.gov.au/data-downloads#participant>).

The main causes of amputation include diabetes, cancer, vascular disease, infection, birth deficiencies and traumatic related injuries.

Notably, Australia has an appalling record when it comes to diabetic-related amputations with the rate of such limb loss increasing by 30 per cent in the past decade and resulting in our country having the second highest rate of such amputations in the developed world.

Of grave concern is the fact that major limb amputations are 38 times more likely in Indigenous Australians aged 25- 49 years than in the general population.

Scientific literature reports that over the past few decades the amputee community has identified problems with the function and comfort of their prosthetic products, as well as challenges with patient prosthetic communication (Hagberg and Brånemark 2001, Pezzin, Dillingham et al. 2004), and that these issues compromise amputee choice and control, limit independence and contribute to prosthetic abandonment for 1 in 5 amputees (Laskovy, Long et al. 2023).

The impact of acquiring an amputation / disability

It is worth noting that people who undergo amputation (limb loss) are required to face a number of complexities including:

Coping with and processing the impact of limb loss can require psycho-social support;

- The impact of limb loss on their day to day lives, including selfcare, employment and income, social and recreational activities and relationships;
- Trying to understand a sometimes complex healthcare system (which healthcare provider delivers which service);
- Working to physically regain mobility and balance;
- Learning and working to physically regain functionality; and,
- Navigating and engaging with funding streams such as the National Disability Insurance Scheme.

Understandably, the myriad and complexities of this amount of information can increase anxiety and a person's mental health.

Consultation process

The purpose of The NDIS Review is to seek feedback from NDIS Participants to determine their experience in rural, regional and remote Australia with reference to:

- 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;
- c. participants' choice and control over NDIS services and supports including the availability, accessibility, cost and durability of those services;

- d. the particular experience of Aboriginal and Torres Strait Islander participants, participants from culturally and linguistically diverse backgrounds, and participants from low socio-economic backgrounds, with the NDIS; and
- e. any other related matters.

Participants were asked to respond to questions anonymously using an open comment box format. 10 percent of respondents identified as Aboriginal or Torres Islander people; while a further 64 percent reporting English being their first language.

The survey was shared nationally via social media, our website and across Limb 4 Life publications. The survey was deidentified and personal details were not collected. Using a thematic approach, survey responses were consolidated to form feedback and provide this report by way of a submission to the NDIS Review. Limbs 4 Life also facilitate a closed/private Facebook group which engages amputees and their family members. This group boasts 2.5K members nationally. We utilised this platform to seek feedback to the questions above as some community members prefer this platform for communication purposes. A total of 74 individuals took part in the survey.

Question 1 – Please tell us about your experience of the application process into the NDIS?

47.5 percent of respondents stated that they found the application process easy and that the transition was a smooth process. 2.5 percent of respondents were not NDIS eligible as they were + 65 years of age and funded by the various limb schemes in their respective state/territory, and/or Commonwealth funding services such as My Aged Care.

The remaining 50 percent reported a range of issues and complications including:

The length of time and drawn out application process due to the tyranny of distance and assistance/support needed to complete the Access Request Form, along with the accompanying report requirements which made the process difficult and onerous. Some stated that NDIS staff failed to have a clear understanding of limb loss (a person missing a full or partial arm or leg) as a disability and respondents expressed the need to fight for things. Some respondents indicated that they had a lack of understanding about what was required.

A number of respondents reported having difficulty finding and accessing allied healthcare providers to write and complete reports along with undertaking personal assessments due to their location, ie, being away from a major city.

“The transition from Disability SA to the NDIS did not go smoothly.”

“We were sent in different directions because the NDIS 1800 staff didn’t know who could be our Plan Managers because we were so remote.”

“Long process time, NDIS staff not recognising or understanding rural areas and the limited services available.”

Question 2 – Please tell us about your experience of your plan design and roll-out (how well or how poorly your plan is working?).

There were very mixed responses to this question. For some, their experience was good, and plans were designed to be reflective of need based on daily living requirements and their disability. Most people who indicated this response also outlined the fact that they played an active role in the development of their plan; made notes prior to their planning meeting; that funding was sufficient and clearly outlined in the documentation provided, and that it met their needs. This group also indicated that they had a good/positive experience with the planner and/or Local Area Coordinator (LAC), and that there were no barriers in place.

Others stated that their plan did not in any way reflect the discussion that they had with their planner. Some shared the fact that they felt confused because their plans continued to roll over with minimal discussion held and that they struggled to even know how much was available to them. Others stated that their plans did not reflect their goals at all; that they received funding in areas that they did not need.

As a side note and evident in the responses, many participants reported that their plans did not have adequate funding for prosthetic or other assistive technology devices. It therefore would appear that no one bothered to explain to the participants that separate quotes would be required from their prosthetic or allied healthcare provider for items such as prosthetic devices or wheelchairs; complex assistive technology.

“Currently my plan is working well in the context that there are sufficient funds, however now that I live in a rural area (and a different state) finding providers is proving to be challenging.”

“My plan was not clearly explained, it’s working okay, but more information would have been helpful.”

“My plan is working well but only because I have a very good and experienced Support Coordinator. The LAC never returns calls, doesn’t know what to do and when to follow up. I have lost count of the errors in equipment scripts, inexperienced OT’s and companies trying to rip me off. It’s not like I can just go up the street to access what I need.”

“My first plan was very good and it does depend on who prepares it. I’ve had issues with people changing my plan without a review or speaking to me first.”

“The plan design did not align with my goals.”

Question 3: Please tell us about your experience of the Plan Review process?

Feedback for this question was similar to the feedback in question #2. People either had a very positive experience or quite negative experience, and this seemed to be attributed to the person developing or in charge of reviewing the participants plan.

People in rural, remote and regional areas that they felt the need to be very organised prior to the review process. They feared that if something was forgotten or left out then that would lead to future problems. Participants also indicated their concerns that if plans were incorrect and/or did not reflect their requirements as outlined during planning meetings. Some stated that they felt they had not been heard or listened to and the decision about what to include in a plan were questionable; while others stated it was a 'tick a box' exercise they were told "not to worry, if things were missing it would be 'fixed' later!"

There was a common theme of lack of clear communication and like previous responses a significant number suggested that the outcome of their plans depended on the person doing the review.

There were also examples of plans just being 'rolled over' without any consultation whatsoever.

"The Plan Review process can work very well, you just need to talk to the right person."

"My experience was very bad! The NDIS approved a revised plan without contacting me. I now need to request a further review."

"When having a plan review I think that you need to be organised and ready. An LAC will submit your new plan for approval even if key information is missing. Sometimes the process can be confusing."

"Not having any local services is not ideal. My plan has been rolled over and I am still struggling to find providers. On occasion my plan has finished before I can find a provider who is not too far away and I know that if I don't spend the funds that I won't get them again. Living in a rural community is very different from having access to services in the city."

Question: 4 As a person living in rural, remote or regional Australia, how effective has the agency been in meeting your needs?

There were a range of mixed responses to this question. 42 percent of respondents indicated a positive or effective service as delivered by the agency. However a further 58 percent stated the opposite, with key themes indicating a complete lack of contact or communication from the agency; difficulty getting responses and delays in approval wait times, along with feelings of overall frustration and confusion.

21 percent of respondents stated that they had to travelled to the metropolitan areas or interstate to access services and supports.

61 percent shared that updates like home and vehicle modifications were difficult to coordinate due to lack of service providers within, or near to their local community area.

"I travel in the outback and see others that are battling."

"Not very effective at all. Seeking assistance results in hearing all the 'right things' while nothing ever changes or gets done."

"I've never seen anyone from the agency, and I've never received a phone call from them either."

"I can't really complain. I lost both of my legs in 2019. The process to get my bathroom modified has been a really long haul and it still hasn't been done because of delays in approvals and further delays finding and engaging providers."

"The difficulty being in regional Australia is the ability to access providers like OT's. It's also hard getting equipment. Waiting on suppliers etc. I now have a spare set of electric wheelchair tyres because I know it could take months to get replacements."

"The help I need is sometimes booked out for up to 12 months. Waiting on providers and equipment has led to falls and fractures and more hospital stays. This makes trying to use my funding difficult. So not very effective."

"I am very limited by my choice of supports as there hardly any providers in my rural area. I give up really easily if things don't fall into place quickly."

"Things are generally good in the bush, you don't have many options."

"There are no direct services where I live. I have to travel interstate and those costs are not covered."

Question 5. Has the agency been responsive in dealing with any questions or concerns that you have had?

28 percent of respondents indicated that the agency was responsive in addressing concerns and questions in a timely manner.

However, a further 53 percent raised issues about the agency's responsiveness. A further 19 percent stated that they never bothered to make contact. Information wasn't forthcoming as to why contact had not been made; participants may not have experienced any reason or need to engage with the agency.

There was a consensus whereby 33 percent of respondents indicated that there was little or no point contacting the agency with concerns due to the fact that the wait times for responses were lengthy and by the time that some matters are dealt with, it was too late.

18 percent suggested that it was easier and preferred raising issues with their Plan Manager or LAC.

“When I have dealings with the agency it is like a game of chasey. They do not return calls when they say they will. Everything is a long time frame, the uncertainty while you wait is very stressful.”

“I haven’t bothered because it’s all been too hard.”

“When I have, they refer me back to my LAC’s which have not been useful and the support coordinators that don’t seem to know what to do so nothing gets done.”

“Yes, but the stress of constant following up is starting to annoy me.”

“I just use my Support Coordinator for any assistance and they have always been helpful.”

Question 6. The Agency is working in a helpful manner?

51 percent agreed that the agency was working in a helpful manner.

27 percent stated no, while 22 percent suggested sometimes, but not always, or yes and no, or failed to respond.

“If helpful means making your life easier than yes. I am very grateful to have the mobility equipment I have. It was very costly to get the right equipment and scripting. I have a prosthetic leg, but cannot wear it.”

“Yes, I am very satisfied with the current operation of the NDIS, although to be fair, my providers organise all of my needs and supports.”

“Too much bureaucracy still and red tape especially with oversight of OT’s. I understand the need for it, but the big things are really hard work.”

Question 7. As a participant, are you able to exercise choice and control over your services and supports and the people who provide you with those supports?

Again, 51 percent of respondents said that they were able to exercise choice and control over their services and supports.

The remaining 49 percent indicated that due to the tyranny of distance, choice of providers and services was extremely limited. Some stated that they had to travel 3.5 hours for a 10 minute appointment, while another shared that there was no choice. This respondent also stated that due to the lack of prosthetic providers in his area, he was concerned that if he complained he would be fearful that access to prosthetic services would be rejected.

There were also a group of respondents who stated that they felt that their plans were impacted because they had to invest a significant part of their funding covering additional costs for provider travel time because they did not reside in or close to a metropolitan area.

“Choices are very limited in rural areas; so control is limited; what is offered is often inflexible.”

“Yes, but only because I self manage my funds. I also use private providers for general services such a cleaning and lawn mowing – not agency services. They are cheaper than registered providers.”

“Mostly, my primary support which is my prosthesis is out of my control as it is driven by availability of funding to travel interstate and time off from work.”

“Due to living rurally we have limited access to clinicians. Therefore choice isn’t always on our side. We usually have to default to Melbourne for prosthetic services which is a 7.5 hour return trip. It’s exhausting.”

“I am an amputee so I can choose my provider. I do have a problem with the people doing the assessment who don’t know me in rural Queensland. When I lived in NSW I had access to everything, now it seems hard to get access to anything.”

Question 8: Do you think that the services you receive provide value for money?

This question received very mixed responses and robust comments.

32 percent indicated that services were value for money because they had a successful outcome and access to supports and devices which enabled quality of life based outcomes.

21 percent stated no, that services were not value for money.

12 percent indicated sometimes or maybe.

A further 36 percent shared their own personal experiences about what they believe is ‘value for money’ when using tax-payer funded supports.

Alarmingly, a number of respondents who agreed that the services were value for money, also commented that they believe that pricing was over and above regular pricing, citing that if suppliers / service providers know that a person is funded by NDIS then there is an immediate increase in costs.

There were also varied responses based on service providers who deliver homecare (unqualified) services for example: cleaning, gardening, lawnmowing etc, suggesting that the hourly rates are too high and, in some cases, outrageous; stating that it is a ‘flat out rip off!!’

Two respondents stated that the cost of some services and products were a ‘total waste of tax payer money.’

While some respondents indicated that they wouldn’t be able to function without the support of the NDIS and the products and services that they had been granted, they acknowledged that there were ‘too many extra fees’ and that items often ended up being duplicated unnecessarily.

“I arranged my own second hand wheelchair (very good condition), also about 8 years ago, the bathroom modification that I needed, both at my own expense. I am very concerned at the extreme high cost of the NDIS services.”

“I do, however I find that the costs are multiplied numerous times once the NDIS is mentioned.”

“Not often...I’ve had providers attempt to produce an item for me and not fit for my use. Prosthetics have been a long drawn out saga.”

“No, all too expensive – I feel totally ripped off!!!”

“Personally I don’t know about value for money because what do I have to compare it to? I have tried to Google, but I can’t find prices for my arm, anywhere.”

“Mostly, although some prosthetic people seem to think they can just charge any outrageous amount and it will be met.”