



*Deaf Australia's submission to the review into
NDIS participant experience in rural, regional
and remote Australia.*

February 2024

About Deaf Australia

Deaf Australia acknowledges the Traditional Owners and Custodians of the lands on which we work and pay our respects to Indigenous Elders past and present. Sovereignty has never been ceded. It always was and always will be, Aboriginal land.

We recognise the past atrocities against Aboriginal and Torres Strait Islander peoples of this land and that Australia was founded on the genocide and dispossession of First Nations people. We acknowledge that colonial structures and policies remain in place today and recognise the ongoing struggles of First Nations people in dismantling those structures; and especially that of Deaf, Deafblind and hard of hearing First Nations peoples.

Deaf Australia was founded in 1986 as a not-for-profit organisation that represents all Deaf, Deafblind, and hard of hearing people, and others who are fluent and knowledgeable about Auslan. The focus has and continues to be on developing access to information and accessible communication. We work with Australian governments and collaborate with key stakeholders to make sure that Australia complies with the United Nations Convention on the Rights of Persons with Disabilities. The UN Convention and the National Disability Strategy guides our work; we aspire to achieve equity for Deaf people across all areas of life.

Deaf Australia advises that this document may be publicly distributed, including by placing a copy on our website.

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Introduction

Deaf Australia is pleased to make a submission to the NDIS review in regional, rural and remote communities. Deaf Australia operates in advocacy to ensure alignment in all areas of life to the Convention on the Rights of Persons with Disabilities (CRPD) as mandated by the United Nations (UN). Deaf Australia advocates for the right of Deaf, Deafblind and hard of hearing people who use Auslan to participate fully in their communities and to achieve a full social, economic, and civic life, as per Article 9: *Accessibility*, 21: *Freedom of expression and opinion*, and 29: *Participation in political and public life*.

Deaf Australia hosted an online roundtable to ask the following questions as highlighted in bold in the following document. A diversity of people participated in the roundtable and their perspectives are included in this submission. Deaf Australia would like to convey their gratitude to those who participated; this submission would not have been as rich and detailed without their input. One of the most highlighted common experiences of the participants were the quality of their interactions with the Local Area Planners (LACs). Deaf Australia invites the reader to read the following for further insight into participants' experiences with LACs as well as their broader experience with the NDIS.

Please note that the name 'deaf' applies to all deaf and hard of hearing people who use Auslan as their primary language in this submission.

a. the experience of applicants and participants at all stages of the NDIS, including application, plan design and implementation, and plan reviews;

The NDIS rollout across the country was slow and extremely varied; the regional, rural and remote areas were respectively the last to access the scheme. The delay in the rollout from the city to the regional, rural and remote areas were, at each stage, significant. When the scheme did finally arrive, it was assumed that by then the problematic aspects would have been smoothed out. This was not the case as the following challenges identified:

1. The application process: this was unwieldy and not user-friendly. Information on how to apply was confusing and would contradict itself. It was not visual and easy to find; how to search for information to explain each stage of the application process, such as the differences between consumables and daily activities, was near impossible. What information was required from the client was also unclear; one client mentioned having their plan rejected because audiology-related information and other paperwork were not provided. One family reported they did not even know that an application was made on their behalf and were surprised to receive information from the NDIS stating their funds were due to expire - they hadn't been used up yet. This is concerning that this application process happened without the family's knowledge.
2. Meeting the LACs: unless the clients themselves had experience of being a LAC and knew how the process worked, meeting the LAC was more likely to be miss than hit. IF a client was lucky enough to be able to meet the LAC in person, it was an unhappy

and negative experience. LACs are by far the majority lacking sensitivity, knowledge, experience and skills working with deaf clients. They also lack experience, skill and understanding of the workings of the NDIS and therefore unable to accurately convey information or answer questions in full. They will, for example, insist that the deaf client provide their own interpreters when this is highly inappropriate and not the responsibility of the client; or book interpreters without asking the deaf client for their list of preferred interpreters. When inappropriate interpreters were booked, the LAC's attitude was this interpreter was all that was available and bad luck if the client didn't want the booked interpreter. Where an interpreter was not available, the LAC would ask either if the client could bring a family member to interpret¹ or if the client had sufficient English to communicate in written English. Part of the NDIS' philosophy includes choice and control; however, in RRR areas there is often the only one LAC for the entire region and if a client is unhappy with their services, they are unable to switch to an alternative LAC who can better match the clients' needs.

3. LAC attitudes: There is a demonstrable lack of respect towards the clients on the LACs' part. During the roundtable for information gathering to write this submission, deaf people would share experiences of rudeness and bullying from the LACs. This is demonstrated by the following, for example:

"After my 3rd different LAC /3rd plan meeting went badly, I realised I needed an advocate to support me. I tried to find one and that was difficult – finding someone who could support me and have my back and the 3rd LAC was a bully. Organisations with advocates either were not taking on anymore clients or had waitlists or couldn't meet my need. And I just had a need for someone to be there with me and have my back and notice when maybe I missed information. I tried [again] the SC with me for the 4th meeting and that did not work out either. When I tried to clarify information with [the] LAC, she said, 'Check with your SC' rather than deal directly with me. She even scolded me for missing information – despite me saying I couldn't hear with my aids and cannot lip-read everything."

4. Plan Design: due to the LACs' lack of knowledge, experience and skill, what can be requested and included is inconsistent. It is arguable as to whether LACs bring their own personal bias into the plan design. For example, one LAC refused to allow the client to design their goals and insisted on writing up the goals for the client and could not articulate why this would be the case. Another LAC told a client that they could only have 3 goals because "...it's difficult for Indigenous people to determine what goals they would like to establish for their future..." which is a form of discrimination, racism and ableism, particularly prevalent in the RRR areas. Even if OT reports recommend the use of specific supports, it appeared to clients that it was up to the LAC to decide whether to include them in the plan design.

¹ It is NEVER appropriate to request a family member to interpret for a deaf client. Governmental departments across Australia make this very clear in their language policies so it is very concerning the LACs make a habit of making this request. They will also state in the plans without the client's input or approval that the clients have family members to assist with interpreting; again, this is never appropriate.

“I needed higher level hearing aids and applied for these to which one LAC was very rude and unhelpful and raised her voice to me stating: “Just because someone needs a particular wheelchair doesn't mean we will fund it.” The implied message: what you have is enough for you, ignoring the fact that the hearing aids [that] I have I can't hear with or use...”

5. Taking Advantage: it was felt that LACs take advantage of clients lacking knowledge of what a good quality plan looks like. Many clients attend planning meetings not knowing what to ask for and how much funding is available. It took one client, for example, four years before an advocate told them how poor their plan was. There was no way to know that, nor was there a way to find out and use terminology that best matches the criteria for a good quality plan. LACs do not take the clients' wishes into consideration when designing a plan and it is only when hearing treating professionals provide reports that these wishes are included. The LACs do not provide navigation of the bewildering forest that is the NDIS. When clients need to know what is possible and what is available, they rely on the LAC to provide this information. Even then this information is biased; counselling and speech therapy was offered to a family with a deaf child, for example, rather than offering all opportunities.
6. Interpreting: the provision of interpreting is problematic right from the application process to LAC meeting to plan design to funding. There is a diplomatic dance at each stage; there is a lot of negotiation involved to get interpreters for whatever purpose. We have already covered the tennis game of whacking the responsibility of booking interpreters for planning meetings to the client. If interpreters cancel bookings for planning meetings for whatever reasons, it is near impossible to find another interpreter. There are very few interpreters living in RRR areas and they're usually employed within the education system, for example. The funding of interpreters within the plan is unnecessarily difficult to achieve. Interpreters won't travel to the regions unless their travel costs are covered, including accommodation. Where funding is provided this runs out very quickly because it's so much more expensive in the regions. Where interpreters are requested as part of the planning process, support workers are offered as an alternative; often an unwanted alternative.
7. COVID19 and rollover funding: COVID19 impacted how one could access interpreters. Then, the NDIS required significant evidence to demonstrate why that funding couldn't be used and why a similar amount should continue to be provided post COVID. COVID19 has also impacted how plans are reviewed, meaning it is more common than not to ask if clients are happy to have their plans rolled over for another 2 years, for example. This can mean that the client never meets the LAC at all.

b. the availability, responsiveness, consistency, and effectiveness of the National Disability Insurance Agency in serving rural, regional and remote participants;

There is a lot of frustration with the quality of NDIA services to the regions. This submission has covered the quality of LAC staffing already, with the seeming inability to treat clients with common courtesy and respect. Unless the services themselves have deaf staff also working there, many LACs are not deaf friendly or aware. To gain answers to questions can take the form of either way: by having to drive to the LACs' offices to get answers quickly or having to wait 6 months for a yes/no answer to a question. Unfortunately, these negative experiences are not restricted to these, as the following challenges will testify:

1. High turnover of LACs: the experience of deaf clients of having to start all over again with educating the LAC, regarding communication, interpreting and cultural sensitivity.

"They tell me, oh, this person knows Auslan, and they can communicate with you. And I think, oh, okay. So, then we have a zoom call, and the person only has, like, say, very basic Auslan skills. And they've only done a class for the last 6 weeks, and the meeting is...while they write things down, and there's not really much communication within the meeting."

2. Response time: families with deaf children are left on the phone for more than an hour to get a response to a question and even then, this phone call goes unanswered. When plan reviews are coming up, families and deaf clients either do not know they have a plan review coming up and the plan is automatically rolled over, or the request for a meeting is ignored. This quote encapsulates the experience of many relating to all the above.

"I have found getting answers to various questions to be a nightmare. A lot of information contradicts each other. I had a situation where I was coming up for a plan review and someone emailed me to ask if I needed the meeting. The request [for the meeting] was ignored, and the plan rolled over. Often emails are not answered but depends on the person. I would say the responses are not satisfactory. Also, there is a lack of professionalism and a lack of understanding as to the information need and how information is provided."

3. Communication: asking for preferred interpreters to be booked for meetings is taken as the client being demanding and difficult, when that is not at all the case. Preferred interpreters are highly compatible with the client's communication needs; they are trusted to know how to relay communication between the client and LAC.² LACs do not respect the request to text or email deaf clients – for example, in one situation a LAC left messages on a landline phone despite requests to email and the client needed a family member to transcribe the messages. This is inequitable and lacking in respect for the client's communication requirements.

² For further information into why preferred interpreters are preferred, see here: https://deafaustralia.org.au/wp-content/uploads/2022/09/POSITION-STATEMENT_PREFERRED-Interpreters_2022.pdf

4. Complaints process: The complaint process is difficult. Going through the safeguarding commission was challenging yet to be able to get the LAC or other staff within the NDIS to respond, one needs to go through them to get the desired outcome. The complaints process is unfortunately a strategy to get LACs to stop leaving messages on the phone, for example.

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

1. Provision of services: the specialisation of services mean that one needs to pay a lot of money for a professional to travel out from the city to the regions. Even then the quality is not always up to scratch. There are examples of where funds run out without having seen a professional; for example, FIFO (fly in fly out) interpreters to FNQ (Far North Queensland) are an inappropriate service of meeting the need for interpreting. FIFO interpreters are not familiar with the communication requirements there and need additional support from people with lived experience who are not paid to provide the supports to the interpreter. Interpreters are still paid regardless of whether they do the job in the timeframe or not and cancellation policies mean that FNQ communities run out of funds very quickly without having seen an interpreter. Some services require that a person joins the service as a client first before providing a service; if you're not a client they won't help, even if you're in crisis. Some services will ask for information more than is felt necessary, for example: *"What's your NDIS plan? How much money do you have? And can you provide us with a copy of your plan?"*
2. High demand, extremely low supply: even when services are available there is a significant waiting list for up to a year in some cases.
3. Online service provision: travel costs are often prohibitive, so online services are offered. This is frustrating given that internet connectivity in the regions is so poor. The services will still insist on the provision of online services, despite this not-insignificant barrier. There were ridiculous examples of the inappropriateness of online services brought up during the roundtable for this submission; video relay interpreting was offered for a client doing farm work, for example. Also: how can an occupational therapist adequately assess a client's environment based on an online viewing?
4. Travel costs: this is a significantly inequitable issue. The NDIS does not cover travel costs for services, yet this is factored in somehow and the costs really blow out. This leads to funding running out very quickly. Clients are expected to work out how to get to the city to access the services they desperately need, and yet their travel costs are not covered. Clients need to take time off from paid work to travel to the city; they need ensure they have the interpreters they need for these services – there is a significant mental load in the organising of accessing services because of the refusal to travel from the service provider.

5. Provision of unwanted services: there have been examples where there was a provision of services not wanted by the client. One client, for example, requested for funding to cover the costs of 1:1 support, such as a swimming instructor to work only with the client, not in a group setting. The LAC ignored this request and incorporated into the plan for a support worker, which was unreasonable given this was more expensive compared to 1:1 support from people with expertise in their field of work.

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;

This submission has covered LACs' attitudes towards deaf clients and by implication, the need to improve this aspect of the NDIS. The challenges of deaf clients, clients with a First Nations background and/or with a LGBTIQ+ background adds a layer of complexity which the NDIS seem not quite able to meet appropriately.

1. Assumptions: LACs make assumptions about deaf clients' communication and language skills. This is a significant barrier to including the deaf client in fully participating in THEIR plan design. For example, a person who grew up with spoken language as their mode of communication may meet someone within the NDIS who assume that this means they don't need an interpreter. A person who uses speech is assumed to be effective lipreaders³.

"I think people don't appreciate that I still do need access to a sign language interpreter because that will provide me with equal access to the communication. You know. Yes, I lip-read sometimes, but that's exhausting, and I must constantly explain that. You know that people say, oh, you've been to Uni. You're fine, you understand what's going on. But you know, my experience using the NDIA has not necessarily, you know, those skills have not necessarily helped me in terms of my access to the NDIA or being a participant."

2. Audism: There is a persistent and pervasive view of deaf people from a medical viewpoint, with the constant offering of medical intervention to 'fix' deafness. There is little to no thought given to developing community links and social elements that is "vital to a full life" according to one client.
3. Insensitivity to First Nations people's cultural links and backgrounds: there are huge gaps in understanding service needs and planning processes for First Nations communities – FIFO does not work. There is a strong need to establish great support and services on the ground in these communities that can work to access appropriate, culturally appropriate supports in appropriate languages. Services need to be designed in a way that allow communities to really achieve their goals. LACs

³ One can only perceive about 30% of English on the lips. That leaves 70% guesswork – hence the very high potential for communication breakdowns.

can be highly insensitive when they comment that people can just move because the plan follows the client, asking questions such as, why can't you move to an area where there is a larger deaf community?

4. Paucity of information for those who are aged 50 and over: there is significant confusion over who pays for what and when, especially when navigating aged care on top of navigating the NDIS.
5. Operating on city mode in the country: organisations need to be more aware that how the country operates is very different to how the city operates. Country behaviour, environment and pace is slower in the country.
6. Insensitivity to complexity: LACs can be highly insensitive when they comment that it's too hard to respect and accommodate the intersectionality of participants. They comment, making it a complaint, that they find it too hard to know how to respond to planning design and prioritise needs based on being First Nations and/or as LGBTIQ+. Participants reported that they just want to achieve their own goals - "Why can't they just provide me with the access/services I need to achieve my goals?... [Why should I] share my personal information and history? I just want to be able to achieve my goals. That's it."

e. anything else?

The NRS as a form of communication with the NDIS is not without its problems. Questions were asked as follows:

Do you use the NRS when you are contacting the NDIA? And if you do, what is that service like? Do you feel like, as suggested, that you're on hold for a long time, or is it quick to get through? Do you feel like you just give up and you end up sending an email or finding another quicker way to make contact?

There were significant issues with making contact through the relay service. One client mentioned:

"So, I rang, using the NRS service and I ran the 1 800 number for the NDIA, and I waited over an hour, probably an hour and a half for them to tell me that they would call me back. The Relay officer said, 'do you want to hold?' And I left my number, yet they never got back to me. Then I think it was through Convo that I also tried to call them, but they wouldn't accept a call from Convo. Via an interpreter. So that was an issue.

Then I had an interpreter that was booked for me. That was with me in person. I asked them to call, and they said, no, the interpreter is not registered as a person who has authority to speak on my behalf so they wouldn't speak to them. And the Interpreter explained, 'No, I'm interpreting for her. I'm not speaking on her behalf, so you know she's here with me. I'm just her voice.' You know, and they said, no, no, you must call through the NRS.

So, I called through the NRS again. To be told: 'I'm sorry we're not able to assist. You need to contact like it was another hotline that they wanted me to contact. Anyway, it was just a big disaster, really, and I gave up on that...'

Patchy and poor-quality internet services affect using the NRS effectively. Connection out in country is not equivalent to that of the city. When one uses the relay service the connection will often drop out. Using the chatbot on NDIA's website is limited to simple questions with minimal complexity.

Conclusion:

The experiences of those who live out in the regions are, perhaps avoidably so, more challenging than those from who live in metro areas. On the surface it seems that high demand paired with very low supply of services create significant problems, yet it is suggested that the attitudes of LACs in the regions exacerbate the problems. How to address service provision supply is a complex one – certainly funding plans more than adequately while at the same time ensuring the quality of services are demonstrably high is one recommendation. How to address the quality of LACs is also complex, yet how complex is it to expect that LACs demonstrate a level of sensitivity, respect and responsiveness to deaf clients, families and their deaf children, those who are First Nations and those who identify as LGBTIQ+? Deaf Australia is keen to see significant improvement in how LACs interact with deaf and hard of hearing clients within the NDIS; certainly, the attitude of treating deaf and hard of hearing clients is not something that should be taught. Courtesy, respect and open dialogue should always be essential skills in an LAC.