

NDIS participant experience in rural, regional, and remote Australia

Submission to the Inquiry led by the
JOINT STANDING COMMITTEE ON THE
NATIONAL DISABILITY INSURANCE
SCHEME

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The Centre for Disability Research and Policy (CDRP) at the University of Sydney, presents its submission to the Inquiry on NDIS participant experience in rural, regional, and remote Australia.

We thank the Joint Standing Community on the NDIS for the opportunity to contribute information to the inquiry.

This submission from CDRP is based on the research supported by our Centre. CDRP Researchers contributing to this submission have between 10 and 20 years of experience working in rural, regional, and remote areas in Australia, exploring issues experienced by people living with a disability in these regions and developing solutions, through new practices models and policy recommendations, to improve the life of people living with a disability in rural and remote areas.

Following our values of upholding the motto “Nothing about us without us”, we held an online consultation who was attended by people with disability, carers, disability sector peak bodies representatives, non-governmental organisations, health care professionals, allied health professionals, non-for-profit service providers and other professionals of the disability sector. Experience shared by participants during the online consultations informed this submission. Anonymous quotes from participants illustrate every section of this submission and are identified as Online Participants – OP#1,2,3 etc..

Some of the issues highlighted in this submission are not specific to rural, remote, and regional areas but are exacerbated by the remoteness of some regions. The further out from a capital city a region is, the more serious the issues become e.g. access to services, access to information, access to specialists, digital accessibility.

The submission is structured according to the Terms of reference of this inquiry.



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A) EXPERIENCE OF APPLICANTS AND PARTICIPANTS AT ALL STAGES OF THE NDIS, INCLUDING APPLICATION, PLAN DESIGN AND IMPLEMENTATION, AND PLAN REVIEWS

- Our research on NDIS planning in rural and remote areas emphasised the importance of the development of personal connection and trust throughout the process.
- Our research includes examples where planners worked primarily over the phone and were seen to lack firsthand understanding of the person's individual experience of disability in their local context and were less effective in addressing needs.
- Our research participants argue that decisions cannot be adequately made over the phone without seeing and understanding the individuals' situations firsthand.
- We found that visiting people in their homes to discuss their needs is more effective than phone conversations. This, however, is less readily available and accessible in rural and remote areas.
- Telepractice encompasses more than just the telephone. It is the way we use technology to connect with others based on individual needs, capabilities, and preferences.
- Our research on telepractice indicates that it is important not to make assumptions about the best vehicle for telepractice delivery.
- The critical first step is to work out what form of telepractice may work for each individual person and their supporters as part of the suite of options for person-centred planning approaches.
- Often, planning via telephone may not give planners insight into the person's individual circumstances, and alternative visual methods, such as using video conferencing or sending photos or videos via mobile, maybe more useful.

The online consultation, led by CDRP in preparation for this submission, with people with disability, members of peak bodies representing people with disability, and professionals of the disability sector living in Rural, Remote, Rural Australia has revealed that:

- **Access to information is difficult:** how do people access information in remote areas “How do they find out about the scheme” despite the scarcity of NDIS planning team and assessment teams, unstable internet connection, and poor digital literacy.

NDIA office often not being staffed appropriately means that “*you can't walk into the office and ask simple questions*” (OP1)

“*We know that communication is an issue. So, whether this be because someone speaks a different language or because people can't - simply can't access the information out there due to lack of technology, not being able to have a phone to talk to someone about it.*” (OP2)

“*A lot of people living in areas where there isn't even phone reception. So, yeah, if you need something - ask a question, yeah, either by email, and that takes time*” (OP3)

“*They (clients) don't have LACs (NDIS Local Area Coordinators) in their town, so they need to be supported to go to their access meetings and that's once they have the evidence*” (OP4)



- **Access to diagnosis is difficult**, because of the scarcity of qualified health professionals to deliver assessments for diagnosis in rural and remote areas; because of the time and costs needed to travel to visit health professionals often closer to major towns or capital cities, because of the long waitlist to obtain an appointment with qualified health professionals.

“ something we see in the city as well, but a bigger issue in rural areas is access to diagnosis and specialist staff ... allied health across the regions are generally generalist allied health staff so they may not have perhaps expertise in paediatrics or as we spoke about earlier, particularly, in a particular diagnosis to be able to provide the evidence that's required to get access” (OP5)

“expert assessments. So, they either have extreme wait times. They aren't there in the region, or the cost is just exhaustive.” (OP2)

- **The complexity of the assessment required to access NDIS for some conditions is a barrier**; because of the high level of qualifications needed from the health professional delivering the assessments, therefore increasing the difficulty to find such professional in remote areas; because of the considerable time needed for such assessment, therefore the need to travel several times to the health specialists because of the high cost of such assessments.

“It is problematic to use functional capacity assessments for this purpose to access the NDIS because they are such a comprehensive assessment. You know, they take a minimum of 10 hours to undertake, and complexity will add considerable hours to that. ... Functional capacity assessments do require specific qualifications of occupational therapists and they do provide quite comprehensive information down to support hours required to undertake tasks, all sorts of things. So, they are very valuable but they are not accessible to people who are trying to get into the system. It is obviously far too expensive.” (OP7)

- **Providing the necessary documents for the NDIS application is difficult**, because of the travel needed to the nearest office to get physical copies of documents, because of difficulty to access a good internet connection because of lack of digital literacy to access online request forms, and digital versions of documents, because of the cost involved in requesting some documents.

“many of our consumers do not have a birth certificate or a passport so their application is being held up time and time again until they can access that. They can't afford it most of the time so we have to try to find free ones, things like that. It has put a huge strain on community support” (OP8)

“I have a current consumer who is a refugee from Sudan. She can't provide a birth certificate. What she can provide is a copy of the document from when she entered the country as a 10-year-old child ... we did manage to get that access meeting done, which is fantastic, but that was on 18 January and now we're still looking at ID issues. Her access is still sitting there, and has not been submitted because we can't get POI for her. ” (OP4)

“a lot of my clients might have an intellectual disability so they are going to the partners and saying, “I would like to inquire about going on the NDIS” and they say, “You go off and find the evidence and bring it back and we will help you.” These people don't have the capacity, if they don't have the support, they can't find the evidence” (OP4)



- The process of applying to NDIS through a specific local provider is a barrier.
- **All the above issues are exacerbated by the higher prevalence in rural and remote areas of low socio-economic status**, increasing the difficulty to afford travel and access to technology to simply access the scheme.

“We often have populations who are in the lower socio-economic bands. So, the additional impost of getting access or the costs of travel, then they just keep their loved ones at home and just continue to look after them rather than being able to actually access the scheme in the first place.” (OP9)

The consultation led by CDRP highlighted the needs for:

- **More funding to allow travel costs** by either the participants to travel to health professionals or the health professionals to travel to participants to attend assessment appointments.
- **Developing more programs like the Remote Community Connectors Program** whereby local people will go into the community to provide information about the NDIS to educate the best they can.
- **More education in the communities living in rural and remote area** to develop roles similar to the remote community connectors, so they can go in communities to inform people about the NDIS, who is eligible and how to access it. Travel cost funding for these roles should be considered so they can travel to several remote communities within their regions.

“Some need to travel six hours into the communities to be able to provide information to people so that they can jump onto the NDIA” (OP1)

- **Sustainable funding of programs like the Remote Community Connectors Program** to ensure sustainability of the workforce delivering this program

“When the funding is about to run out and funding renewal or extension is late, the person in the RCC ROLE leaves the job and you get a brand-new person that you would need to train up” (OP1)

- **NDIA to partner-up with community-controlled organisations**, organisations that are well known in the region, trusted by people of the community and who know the community really well, in terms of culture, geography, service available, and needs. These organisations are a trusted point of contact for people in the community and this removes the barrier of having to interact with a government-controlled organisation. Aboriginal Community Controlled Organisations are the main gateway to ensure that Aboriginal and Torres Strait Islander people with disability are not disadvantaged in the NDIS planning and implementation phases. Members of these organisations are locally implanted and used to travel to remote areas of their own region of influence, know people living in those regions and who might need access to the scheme. They can facilitate access for participants who might not have otherwise information or support to access the scheme.



“I manage the community connected program up in the Kimberley region and we have actually heard a few success stories with assisting people accessing the NDIS. The way we deliver it is through two streams where we have community connectors. Local people employed in the respective remote community. We are talking about remote communities that are hours away from the bigger towns. So they work on the ground and assist people with pointing them in the right direction. It might be to NDIA if they already have a plan or to what we call an evidence access officer. Essentially what they do is to hold their hand for the application focus and help with paperwork, gathering the information, and organising the correspondence and meetings with NDIA. That's been something that works really well.” (OP3)

- Accepting **different ways for participants to confirm their identity** like the CRN number or Medicare card number.

“Having a birth certificate should not be a barrier to getting the support that you need.” (OP8)

What do rural and remote Australian with disability need during the disability planning process?

Professor John Gilroy, Decolonisation and Disability theme leader for CDRP, lead a large four-year study exploring ways to improve the NDIS planning process for people with disability living in regional, rural, and remote regions of West NSW and Central Australia.

Our team interviewed people with disability, carers and workers in Central Australia and Western NSW to learn about their experience of the NDIS planning process. We heard from Aboriginal and non-Aboriginal people in regional, rural, and remote areas.

Nearly 90 people were interviewed, including people with disability on the NDIS and workers involved in the planning process. Nearly half of the participants were from local Aboriginal communities.

The main finding of the study is that the NDIS is improving the lives and wellbeing of thousands of people with disability living in regional and remote regions of Australia. However, the NDIS planning process of traumatic and scary for these people. Professor Gilroy said “the fear of losing your NDIS, or even a fraction of the current budget and items, is equivalent to workforce insecurity. The fear and trauma are justified as any negative changes impacts on their lives and independence”.

A key finding from this research is the lack of training for workers in the disability services sector on the NDIS planning process in regional and remote regions. In response, the research team has designed online training modules for workers in the disability services sector on the NDIS Planning process for people with disability living in regional and remote regions. This training has Aboriginal culture built into it philosophies. The website is <https://heart-led.org.au/>

While the NDIA has come a long way in providing accessible information on its website for people with disability, accessing this information and making meaning from it may still be difficult for some people living in regional, rural, and remote Australia. Formal, family and individual advocacy played a significant role in being able to access and provide information as part of the NDIS planning process. Innovation is needed in how that information is used to explain it to people in a way that they can understand.



Based on what people told us, we found ten unique perspectives and needs in the planning process:

1. I need information about the planning process in a way that I can understand.
2. I need to know what I can ask for, and what is reasonable and necessary.
3. I need to feel heard about things that matter most to me, like my culture, my language, my local community.
4. I need to feel safe to speak up for myself and my family or have someone beside me who can.
5. I need you to know about all the complexity in my and my family's life.
6. I need to have time to develop trust.
7. I need you to know about my disability before I meet you and understand that it is lifelong.
8. I need you to understand the impact of planning on my social and emotional wellbeing.
9. I need you to see what life is like for me, where I live.
10. I need you to know what services are available to me in my local area.



B) AVAILABILITY, RESPONSIVENESS, CONSISTENCY, AND EFFECTIVENESS OF THE NATIONAL DISABILITY INSURANCE AGENCY IN SERVING RURAL, REGIONAL, AND REMOTE PARTICIPANTS

- Research regarding service provision in Australia has found that there are fewer allied health workers per capita in rural and remote areas compared with urban areas (National Rural Health Alliance, NRHA)
- The features of rural and remote areas impact on the capacity to develop the market of providers who can deliver supports in rural and remote areas.
- Expertise in areas including assessment and diagnosis of autism and other neurodevelopmental conditions is limited or absent in many rural areas, meaning that accessing the scheme in the first place is difficult or impossible.
- Telepractice is a service model as yet unrealized in its potential to expand the provider market for rural and remote NDIS participants.
- Although the pandemic provided impetus to use telepractice in a widespread way, significant barriers to the use of telepractice remain, specifically gaps in digital inclusion and the digital divide, a known difficulty in rural, regional and remote areas.

The Online consultation with participants, carers and professionals of the industry sector living in rural and remote areas has revealed:

- **A lack of NDIS workforce on the ground in rural and remote areas**, causing difficulties to access information about the scheme when it cannot be accessed remotely (online or via phone), causing difficulties in completing applications to enter the scheme, difficulties to access NDIS planning or review

“This ... lady lives in Wagga, so she is very lucky because we have an LAC in Wagga. The majority of our clients don't. They don't have LACs in their town so they need to be supported to go to their access meetings and that's once they have the evidence.” (OP4)

“There is also very limited face-to-face engagement if any, and that goes from accessing NDIS staff in their office but also the planning meetings and planning reviews so it's all generally done over the phone and if you call the number, you might end up with someone that doesn't have that good overview of the local context” (OP3)

- **Lack of staffing of NDIA offices located in regional and rural areas.** This means that people who can travel to a physical office may not be able to see someone after traveling sometimes several hours. These people are at high risk of not pursuing access to the scheme.

“the NDIS offices- I think we've got two up here in the Kimberley. It is about the same size as Germany, area wise. Even those offices are not really well staffed. You never really know who you can call up or who can help out.” (OP3)

- **A lack of trust from the rural community towards the NDIS services.**

“Many Aboriginal people are very fearful of Government services full stop. The risk of child protection taking their children away is really huge so there are a whole bunch of parents who simply do not want to have anything to do with the NDIS because they don't see the distinction between state-based child protection services and Commonwealth. They all are Government and they all could take my children away.” (OP6)



- **Lack of NDIS staff availability increases the carers' burden**

"The complexity and length of time for access to services is also an issue. So, for carers, often carers assist the person they care for with access to the NDIS. So, when it takes two years just to navigate the service, it's a very - very downhearted issue and experience for them. When they don't have any help to guide specialists in how to write the right report or how to write the report the way that the NDIS wants it to be written, some guidance in terms of what the NDIS wants to see on a report would be a really good initiative to have" (OP10)

"When you have things like no LACs in regions, for example, in the wheat belt, that has very limited access to LACs, that just adds more pressure to the carer to try and navigate access to the services. (OP10)

The Online consultation led by CDRP has highlighted the need for:

- **More NDIA workforce on the ground** such as NDIS planners, LACs, remote community connectors or navigators, for people who cannot access information and application processes online because of cultural or technological barriers (lack of internet connections, phone signal or digital literacy)
- **More face-to-face interaction**, allowing for more complex information to be communicated, more complex issues to be solved.

"I think it would be good to have someone you can go and talk to or have more NDIA staff on the ground for those people that are in limbo to get more definitive answers. I think a lot of the people that we engage with, they also prefer that face-to-face engagement and it's not always appropriate to be on the phone. A lot of people living in areas where there isn't even phone reception." (OP3)

- More **specific training for planners around specific disabilities**, so that they can direct people towards certain services with the appropriate knowledge of what that person might need.

"There are loads and loads of people across Australia, from all walks of life, whether they are teachers or therapists, all kinds of people, who are helping people access the system, but it is actually not their job to do it. So I suppose my biggest concern is there is actually not a proper process and not necessarily people in that process that are skilled in the nature of the person's particular type of disability. So if someone, for example, is an amputee, is there someone who's got expertise around that supporting them to do so" (OP6)



C) PARTICIPANTS' CHOICE AND CONTROL OVER NDIS SERVICES AND SUPPORTS INCLUDING THE AVAILABILITY, ACCESSIBILITY, COST, AND DURABILITY OF THOSE SERVICES

The online consultation, led by CDRP in preparation for this submission, with people with disability, members of peak bodies representing people with disability, and disability sector professionals living in rural, regional and remote Australia has revealed that:

- **The shortage of disability workers and health professional in rural areas prevent participants from accessing the services they need, want, and are funded for through NDIS.**

"We've been finding that with the worker shortages in rural and remote WA this has been a real impact on people being able to use the services in their plan. So even if they have services allocated to them, thin markets mean they can't actually use that, or if they do it comes at a high cost because of costs of travel." (OP2)

- **The shortage of workforce in rural areas forces people with disability to move to metropolitan areas.**

"For example, we came across an essential worker who was having to move back to metropolitan region because she didn't have access to services for her daughter." (OP2)

"One service provider had a very unique quote that stuck with me, "People either move to access services or they die"" (OP2)

- **Travel costs for the professionals to attend to clients in rural areas are not appropriately costed** and funded by clients' NDIS plan, preventing clients from accessing services otherwise funded by their plans. This issue has arisen with the adoption by NDIS Modified Monash Model for costing allied health services. The modified Monash Model was not intended as a measure of the time it takes for an allied health professional to travel to other areas. The maximum amount of travel time allowed by the model is 60 minutes (for areas designated as MM4-5 – regional and remote areas) where it can take as much as 5 hours of "real-time" travel.

"When the NDIS first came into play there was no Modified Monash Model for allied health services. We would go to places that are four hours drive and see numerous people, split the cost between those people and it would cover our accommodation and travels and all sorts of things like that and it worked out reasonably well" (OP7)

"Rural and remote areas we note that the planners don't put sufficient funds in there to allow allied health professionals to go and see these people" (OP7)

"(In) very remote areas...the consumer in that situation had to save their money for some time and really scrimp on their capacity building fund so we could get to see them" (OP7)

- **Travel costs for participants to attend services prevent them from being able to access services** as often as necessary, despite a funded NDIS Plan



“So, for example, Kalgoorlie, we found that access to specialist services were limited-to-none. Because people would have high costs to access services when services came to the region. At times the cost of the travel would be tacked on top of the appointment costs. And at the other end of the scale, people with access to planes were flying their children to Perth every two months or whatever it was for an OT appointment” (OP11)

- The **lack of service access in rural areas increases the burden on the carers**, leading to carers not being able to fulfill their carer’s responsibilities. It also means that if the main carer is a support worker, the participant may be at high risk of losing their support worker through burnout.

“No services equals increased caring responsibilities and increased carer burnout. When you have things like no LACs in regions,... that just adds more pressure to the carer to try and navigate access to the services”(OP2)

- **Thin service market areas in rural and regions** mean that Health services have to provide services that should be the responsibilities of specialized disability services.

“From a health perspective ... we provide a lot of services that really should be provided by the disability sector. So, for example, community nursing, regardless of whether it is a health or disability need is predominantly provided by health due to such a thin market out there” (OP5)

“(our local) multi-purpose service is the local hospital but also has residential aged care beds and other health services there as well. We do have NDIS participants who have historically accessed that facility and are living in a residential aged care bed there and are an NDIS participant. We have had to go through the process of becoming a provider so we can continue to house those people.” (OP5)

“In the regions, we very much see the line between disability and health is very, very grey” (OP5)

- There is an **issue with service providers signing up clients but not delivering services**, especially services providing support coordination and plan management. This is a more frequent issue in rural, regional and remote areas where it is difficult for participants to find services and there is a lack of market competition between service providers. Participants have access to a limited choice due to the thin market in rural areas and therefore are more likely to stay with a provider despite lack of service.

“Some operators sign up participants to the service without them being a registered service and after that not much happens. Especially in support coordination space where there’s people signing them into plan manager and then nothing really happens. We have examples of people that they’ve had a plan for about five years. All they’ve really drawn on is support coordination of plan management ... there are even examples of independent workers, they basically promise the world, sign people up to get a signature and never deliver...” (OP3)

- Absence of specialist disability accommodation (SDA) in some rural and remote areas. This is due to the cost of building in remote areas, especially when it comes to [purpose-designed disability accommodation. Most SDA providers cannot afford the development of housing in remote areas or would have to offer these at prices well above NDIS pricing guide to recover their investment. As a result, non-registered For-profit providers will fill the gap, by buying existing properties and offering them as SDA. Often these properties will be purchased by a



provider of other disability services, suppressing the separation between housing and service delivery, and therefore restricting severely participant's choice in service provisions.

"There is no SDA housing here. We had met with multiple SDA providers to try and encourage people to come to the region. When they look at the cost of building in a very remote area, it's just not attractive... often non registered for-profit providers will go into a town and they will buy up housing and so it then makes it more difficult to say we need a supply of housing if people are housed. They are often being housed in properties that have been purchased by a provider, so you don't have separation of landlord and support ... There is that ethical dilemma... individual for-profit providers are building their own property portfolio wealth ... there has to be a role from the NDIA or from State Government to be looking at this provision of housing". (OP12)

The CDRP-led online consultation has highlighted the need for:

- More **block-funding to support community services**, as opposed to individual services.
- More clarity about Health care system responsibility and disability services providers' responsibility

"There seems to be a little bit of inconsistency and misunderstanding from the NDIA around what a multi-purpose service is. (OP13)

"To be really clear through the new intergovernmental agreements whose responsibility is whose" (OP13)

- **Recognition of an ecosystem of support** with coordination between the Health System, including services delivered by the Local Health District, NDIS, and disability service providers.

"There is also that idea of this ecosystem of support, right, this idea that it is not just in the NDIS or out, there are these other support services that will around to support people" (OP13)

- **Better remuneration for disability workforce in rural and regional areas** to promote recruitment and retention

"In that regional and remote area, I guess, we see not only with the thin markets but there is competition for staff - good staff in those areas when you are competing with aged care, who have a better award than we do, or you are competing with Government that pay better than we do, we don't have a fighting chance" (OP13)

- **More efficient or simplified worker screening processes** for joining disability workforce as a support worker. This is particularly pertinent in areas where there is no local Services NSW office, causing delays in getting up-to-date ID documents and delays in screening processes. Participants in our consultation suggested that the screening process needs to be more accessible in rural and regional areas and more streamlined while keeping participants safe. Participants suggested that it could be made national, and the types of safety checks could be recognised such as Working with Children checks or Aged Care worker screening.

"Worker screening is a huge issue in regional and remote areas in the different States and Territories. So, you can't deliver - you can't be a support worker at the moment without having a worker screening if you are in a risk-assessed role. If you can't prove your identity and can't follow the online processes" (OP13)



*“NDIS NSW has not been able to process the worker screening in individual towns” (OP5)
“If you don't have a department of main roads and transport where you live you have got to find another mechanism to get a new licence and whether that's going to your police station, whether that's going to post office” (OP13)*

- **More scrutiny on the quality of the disability services provided**, even if the service providers is not NDIS registered. An online participant drew our attention to support coordination and plan management services not delivering appropriate services to clients and suggested that specifically support coordination and plan management services should be systematically registered as NDIS providers.

“they need to be governed harder or there needs to be more of a governing framework for unregistered - especially those support coordinators because it is such a crucial role to assist the participant to link in with services that are appropriate... they need to be scrutinised and maybe picked up by the NDIA when they are noticed, “Why is this plan - this person's had a plan for years but hasn't accessed any services apart from the plan management and the support coordination” (OP3)

“support coordination, being such a specific NDIS role, I think should be registered and with that comes accountability” (OP3)

“We reported incidents to the Quality and Safeguards Commission but haven't had anything followed up on. There's a fair few reporting instances that we have put through, but nothing seems to happen” (OP3)

“The region where I've worked which has had some pretty unscrupulous providers come into the market... I, too, you go to the Quality and Safeguard Commission, and nothing happens in this space” (OP9)

- **Participants to be better informed about the potential risks in providers' choice** and how to report inappropriate service provision. Information could be generated by the Quality and Safeguards Commission and delivered by appropriately trained NDIS planners.

“We need well-informed participants who understand what the difference is between using Joe Bloggs from down the street versus using somebody who has some additional either qualifications or registration” Like any kind of information in our sector, it's got to be multi-method. Yes, we need written information ... but I think the NDIS planners have a role in this too” (OP9)

Therapy Assistant workforce to support service delivery in thin market area

Our research has identified that developing the Therapy Assistant workforce is a promising strategy for delivering regular and culturally responsive therapy services to people with disability in rural and remote communities.

You will find more information in the published Therapy Assistant Workforce Research Report <https://www.autismspectrum.org.au/uploads/documents/Therapy/Therapy-Assistant-Evaluation-Report.pdf>



- Therapy Assistants can provide local therapeutic and program-related support under the supervision of Allied Health Professionals, including occupational therapists, speech pathologists, physiotherapists and behaviour support practitioners.
- One of the primary benefits of employing locally based Therapy Assistants in rural and remote areas is that they have an intimate knowledge of their local community's needs and can be provided with knowledge, skills and support that are essential to ensure that quality supports are delivered to achieve client centred goals.
- This model can support the timely delivery of intensive services to participants in remote areas and has the potential to build capacity in the local community to support more individuals with a disability.
- Our research has found that telepractice has played a considerable role in the delivery of an outreach Therapy Assistant model. We asked stakeholders about their use of telepractice within their everyday work. Telepractice was used consistently as a primary mode of service delivery and to maintain the connection between therapists, therapy assistants and participants/families between outreach visits.
- Where COVID impacted the ability of therapists to go on outreach visits, telepractice was seen as a way to bridge the gap in services due to lockdowns and establish and keep the service going.
- Telepractice uptake, however, is dependent on the participant and their family's comfort and confidence in using online programs. Therefore, telepractice supports need to be individualised and considered for their contextual fit.

Telepractice to support service delivery in thin market area

Our research has found that telepractice can be used reliably to assess and diagnose language, literacy and cognitive difficulties using consumer-grade equipment in homes or in community hubs such as schools.

Johnsson, G., Bulkeley, K. (2022). Delivering behaviour support to children and adolescents with autism via telepractice: a narrative review. *Research and Practice in Intellectual and Developmental Disabilities*, 9(2), 164-181. <https://www.tandfonline.com/doi/full/10.1080/23297018.2021.1896975>

- Our research has found that autism diagnostic assessments are feasible and valid in young children using online modes.
- Telepractice provision of services, therefore, can be considered as an option as part of a suite of services.
- However, online services are more restricted in regional, rural, and remote areas and among less socially advantaged groups. Patchy, unreliable, or non-existent internet coverage provides specific challenges when trying to access high-speed internet such as is needed when using video conferencing.
- Digital literacy and access to e-Health services are lower in remote communities and those with lower education and low socioeconomic status.
- The uptake of telepractice prior to the pandemic was slow with technological, regulatory, cultural, financial and workforce barriers recognised. Although the pandemic provided the impetus to use telepractice in a widespread way, significant barriers to the use of telepractice remain, including patient and clinician preferences for face-to-face interaction where possible.
- Given the known challenges of telepractice in rural areas, including the digital divide and lack of adequate technology, consideration should be given to supporting working across services to provide participants with adequate spaces and equipment for accessing service via



telepractice, for example, a family attends a local community health centre or preschool to access quiet space and equipment and receives services delivered by a highly experienced clinician via telepractice.

- Our research with early childhood practitioners in Australia and Canada identified the value of telepractice as part of the suite of options for supporting children with developmental delay, difference and disability.
- Practitioners required training and support to develop their skills to provide early childhood supports using a variety of telepractice modes (phone, text, videoconferencing, apps, online programs etc.) in order to adapt their practice to optimize the outcomes for children and their families.
- We have developed a practice guide, Ready Tele Go ([Disability workforce – Faculty of Medicine and Health \(sydney.edu.au\)](https://www.sydney.edu.au/medicine-and-health/disability-workforce)) which has been widely taken up across the sector, including a French translation of this resource by colleagues in Ontario.
- Our literature review supports the value of telepractice as a service delivery option that is suitable and accessible for people with disability in rural and remote areas:
Johnsson, G., Bulkeley, K. (2022). Delivering behaviour support to children and adolescents with autism via telepractice: a narrative review. *Research and Practice in Intellectual and Developmental Disabilities*, 9(2), 164-181.
<https://www.tandfonline.com/doi/full/10.1080/23297018.2021.1896975>

Dental care provision in rural and remote areas

As an outcome of the recent Senate Enquiry Into Dental Services, the committee recommended that the National Disability Insurance Agency clarifies that dental and oral health supports that are directly required because of a person's disability can be funded under the National Disability Insurance Scheme (NDIS), and provides specific training and guidance for NDIS decision makers. The kinds of supports that could be funded include:

- oral splints that assist with speaking or swallowing.
- modified toothbrushes and flossing devices; and
- any other reasonable and necessary oral health care consumables.

The Child Dental Benefits Schedule (CDBS) covers part or all of the cost of some basic dental services for eligible patients. The Department of Veterans' Affairs (DVA) also provides a wide range of dental treatment. However, there are few qualified dental practitioners to provide these services.

Patient assisted travel schemes (PATS) provide patients (and eligible escorts) with financial assistance towards the costs involved in travelling to, and staying near, non-GP specialist medical services while the patients are undergoing treatment. However, PATS does not cover travel for general dental services.

There is a need for training local health practitioners in early identification of health conditions including dental (lift the lip for obvious problems) and appropriate timely referrals.

This training could be supported by the introduction of more rural placements for medical/nursing/allied/dental students under the direct/indirect supervision of relevant specialists.



D) 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

The online consultation, led by CDRP in preparation for this submission, with people with disability, members of peak bodies representing people with disability, and disability sector professionals living in rural, remote and regional Australia has revealed that:

- **Aboriginal parents may be fearful of government systems, including NDIS.** They do not see the distinction between NDIS planners, NDIA and other government services, especially child protection services associated with the forced removal of children from families.

“We work a lot with the Aboriginal Medical Service in Kalgoorlie and one of the biggest things they find, particularly access for children, is that many Aboriginal people are very fearful of Government services full stop. The risk of child protection taking their children away is really huge so there are a whole bunch of parents who simply do not want to have anything to do with the NDIS because they don't see the distinction between state-based child protection services and Commonwealth. They all are Government and they all could take my children away. That is a big access risk for families who don't understand Government and what their roles are.” (OP6)

- **Some services are not being provided in a culturally safe way.**

“early childhood intervention programs... the service area is tiny. They are run by mainstream service and so not always culturally appropriate for Aboriginal kids and their families” (OP14)

- Support Workers and service providers are not funded for training time and could see this as an extra burden.

- **Within NDIA, staff need to understand the cultures they are working with.** Such as attitudes of being fearful towards government, portraying themselves to planning meeting, needing to build relationships with people in the community.

- **There is a significant gap in service access between Aboriginal and non-aboriginal children.**

“One of the major Closing the Gap milestones should be 55% of kids going through national early development goals... Currently we are going down from WA's 31.3% and nationally 34.3%. There is a huge gap there of between Aboriginal kids and non-Aboriginal kids” (OP14)

“No one can get into the NDIS because there is waiting lists, waiting lists, waiting lists as well as expensive, that is exacerbated in remote - just no one to assess” (OP14)

The consultation led by CDRP highlights the needs for:

- **More cultural awareness and cultural safety across the whole sector, including NDIA department, NDIS workforce, support workers and service providers**

“(need for) cultural safety, even within the department itself, within NDIA itself, staff actually understanding the cultures that they are working with” (OP1)



- **Cultural awareness Training for NDIS workforce and service providers.** Some services are already offering cultural awareness training, but caution should be taken with a nation-wide unified cultural awareness training that would not take in account cultural specificity of the different areas.

“there are a lot of different cultures here as well. So, it's tricky to just do the one training to make sure that you are practising in a culturally safe way” (OP3)

- **NDIA to invest in cultural training for its workforce.** Participants have suggested that training for a specific worker could be funded through the client' NDIS plan. However, cultural awareness and cultural safety are such essential components to work in rural and remote areas, that there is a place for the NDIA to fund the training of the workforce, acknowledging it takes time and funding.
- **Facilitating reflective practice and informal cultural training** by engaging with Aboriginal colleagues or engaging with local Aboriginal elders for guidance when possible.

“We have an elder Aboriginal lady who works with us in our Broome office...So every time a new employee starts with us they sit and they meet and they can ask questions and they get some information from our Aboriginal liaison worker but it means that they have a relationship and if they're supporting somebody and they have a question, they actually have a link with someone that they know, that they feel comfortable with, that they can sit and meet. So it builds the culture of your organisation and I think it's more than just training ... it is something that we want to replicate because we can see the benefit of that for the quality of our service, confidence for our workers” (OP12)

- Funding through NDIS plans, cultural navigators, as support workers for a participant, to be the point of contact and link the participant with service providers ensuring cultural safety.
- More funding for **long-term establishment of community-based navigator programs** such as the Remote Early Childhood Supports (RECS) program developed in the Kimberley, or Remote Community Connectors (RCC), both NDIA block-funded. Remote Early Childhood Services (RECS), developed by the Kimberley Aboriginal Medical Services (KAMS) and its consortium members, help children aged under 7 access early supports and services. This is currently a pilot program in Western Australia. Remote Community Connectors (RCC) provide culturally appropriate and locally based support in remote areas, with a focus on improving First Nations peoples' awareness and understanding of the NDIS. Participants to our online consultation spoke highly of both services and expressed the need for these services to be rolled out nationally and be sustainably funded to improve First Nation people's experience of NDIS and the life of First Nation people living with a disability.

“I just wanted to highlight (the RECS) program that is happening because it is fantastic - not a solution I guess, but a help to Aboriginal kids. It is frustrating though because it is only in the Kimberley and it is not as well funded and short-funding cycle ... we would love to see it across WA and across many places.” (OP14)



Recruitment and Retention of Aboriginal Health, Ageing, and Disability Workforce

The National Aboriginal Community Controlled Organisation's (NACCHO) NDIS capacity building program shows that Aboriginal and/or Torres Strait Islander people only access health and disability services if the agencies have an Aboriginal and Torres Strait Islander workforce.

NACCHO reported that around two-thirds of Aboriginal and/or Torres Strait Islander people access Aboriginal community-controlled health services and programs because the workers are related to their clients/patients.

(National Aboriginal Community Controlled Health Organisation, 2016 - <https://nacchocommunique.com/wp-content/uploads/2016/12/20178.pdf>)

This is supported by our own recently ARC-funded research in remote and metropolitan regions, led by indigenous scholar Professor John Gilroy (Gilroy et al., 2016; Veli-Gold et al., 2023).

An Aboriginal workforce is essential for community self-determination, community governance, and the design and delivery of culturally safe services. An Aboriginal community-controlled health sector including a substantial Aboriginal workforce has a significant positive influence on Aboriginal families' health and well-being.

Often, Aboriginal workers known or local to Aboriginal communities who access the health, ageing, and disability supports play a vital role in guiding their non-Aboriginal colleagues in ways to adapt their interactions, advice, and interventions to ensure that they are culturally appropriate and safe for Aboriginal patients and clients.

There is a serious gap in the availability of Aboriginal workers in the disability sector and the unmet need for supports by Aboriginal people with disability. An ARC funded workforce project led by Professor Gilroy found that Aboriginal people like working in the disability workforce if the environment is culturally friendly, balances well with family and community needs, and workplace conditions are suitable. In addition, Aboriginal people like working with their own Mob as it reflects cultural lifestyles by giving back to community.

Other than the work done in our recent research, there is limited mention of Aboriginal and/or Torres Strait Islander people in the disability workforce research; similarly, there is no mention of the disability workforce in Aboriginal and/or Torres Strait Islander workforce research. The recent Review of the NDIS (Department of the Prime Minister and Cabinet, 2023) recommended that the Government must "attract, retain, and train a workforce that is responsive to participant needs and delivers quality supports" to ensure that NDIS is sustainable for people with disability (Department of the Prime Minister and Cabinet, 2023).

In addition, the Review recommends the NDIA must work with Aboriginal and/or Torres Strait Islander peoples to address the seriousness of the workforce challenges.

Despite a plethora of research into Aboriginal employment and recruitment, the extent and nature of the retention of frontline Aboriginal people in health, ageing, and disability workforces are currently unknown. There is a need to identify the factors that inhibit (push) and promote (pull) staff retention or departure of this workforce from the sectors.



Heart-Led NDIS Planning

Research led by Prof. John Gilroy, Drs Kim Bulkeley and Genevieve Johnsson, under the ARC (Australian Research Council)-funded project “A Better Life under NDIS”, has found a lack of training and sensitivity for workers across several areas associated with the regional, rural, and remote context. These include knowledge and understanding of geography, service availability, and culturally safe and responsive practices for Aboriginal people with disability. When coupled with insensitive attitudes, quality and values of workers, people with disabilities reported a negative impact on their social and emotional well-being.

CDRP co-designed a series of training modules with people with disability, local Aboriginal community-controlled organisations, allied health workers, the NDIA, and disability service providers. The training modules incorporate the Head, Heart, Hand holistic principles that capture the importance of THINKING, FEELING, and DOING. This approach recognises that disability support planning requires consideration of thoughts and feelings, as well as the practical application of these. By focusing on all three areas, the Heart Head Hand approach aims to create a well-rounded and comprehensive planning experience that prepares people for success in their personal and professional lives.

Information on this research and access to training modules are available on the following website, designed by the research team:

<https://heart-led.org.au/>

The website, as well as including leading research papers and resources on the NDIS, also introduces materials to help build on the cultural safety of the disability workforce for Aboriginal and Torres Strait Islander people with disability. Professor Gilroy said that “these materials were designed and developed by Aboriginal people with disability and carers”.

Cultural Safety of Telepractice

- Our research has highlighted that many NDIS participants in rural and remote Australia experience a digital divide that impacts the quality and accessibility of telepractice services and supports. The features of the digital divide relate to infrastructure issues such as poor internet coverage or poor bandwidth as well as access to devices and adequate experience for both providers and users in delivering telepractice services.
- Socioeconomic barriers to telepractice may be a more significant issue for some rural and remote NDIS participants as it is recognised that socioeconomic disadvantage is higher in these areas. Solutions such as portable dongles and loans of devices as part of service delivery or plans in rural areas is an important consideration.
- However, it is important to recognise the diversity of rural and remote communities, making a clear assessment of the needs of individual NDIS participants to determine their requirements and context.
- The need for cultural responsiveness in the delivery of telepractice services has been supported by our research in Australia and Canada. There is a need for flexible hybrid delivery options and exploration of the way services can be provided, with each individual NDIS participant, cognisant of the potential of telepractice, rather than the poor experiences from a rushed shift to online service delivery during COVID.



Research into NDIS planning process in regional, rural, and remote regions of Australia

People living in Australian geographically regional, rural, and remote areas have reported difficulties in accessing and engaging with the NDIS planning process since its inception in 2013. These challenges are different for Aboriginal and non-Aboriginal people due to cultural and social norms and obligations. Many people in these regions claim that there is limited research into the planning experiences of the workforce in regional, rural, and remote regions of Australia. As such, our team conducted two scoping reviews of the research on the NDIS planning process in regional, rural, and remote regions of Australia.

The first review explored what research exists about people's experience of the NDIS planning process in regional, rural, and remote regions of Australia. The second paper explored the level of scholarly investigation into workers' experiences of NDIS planning. The two reviews concluded that there is limited research into people's experience of the NDIS planning process in regional, rural, and remote regions of Australia. As such, policy decisions on the NDIS planning process in these areas are informed by scant research.

Gilroy J, Veli-Gold S, Wright W, Dew A, Jensen H, Bulkeley K, Lincoln M. (2023) Disability workforce and the NDIS planning process in regional, rural and remote regions of Australia: Scoping review. Aust J Rural Health. Jul 23. <https://onlinelibrary.wiley.com/doi/full/10.1111/ajr.13020>

Veli-Gold S, Gilroy J, Wright W, Bulkeley K, Jensen H, Dew A, Lincoln M. (2023) The experiences of people with disability and their families/carers navigating the NDIS planning process in regional, rural and remote regions of Australia: Scoping review. Aust J Rural Health. Jun 27. <https://onlinelibrary.wiley.com/doi/full/10.1111/ajr.13011>