Disability Advocacy

Thin markets, thin hopes:
The NDIS in regional, rural, and remote NSW



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Introduction: Desperate times, desperate measures

The NDIS is plagued by thin markets and dubious service providers in regional, rural and remote (RRR) areas. The scheme often struggles because there is a lack or absence of service providers in small country townships. This means that many people with disabilities (PWD) living in RRR areas cannot access crucially needed supports and services. Understandably, PWD and their families living in these conditions struggle living day-to-day unable to access basic care. Desperate for services and support, they can become easy targets for questionable service providers that lack the expertise, knowledge and professionalism needed to work with PWD.

Unscrupulous services providers can take advantage of a lack of competition, where small communities have limited options to take their business elsewhere. Worryingly, it can make NDIS participants reluctant to report complaints about service providers as they do not want to jeopardise access to the limited amount of supports and services available to them in their area. This can fuel a lack of accountability and transparency where some of the most vulnerable members of the disability community are taken advantage of.

With the current review of the NDIS and AAT reform underway, now is a prime opportunity to discuss what parts of the scheme are not working and what needs to change for PWD living in RRR areas. This article is part 4 of our 5-part Aussie Battlers series that highlights the systemic disadvantage experienced by PWD living in RRR areas. This is based on firsthand experiences as reflected in our research findings gathered from interviews with PWD, along with a survey of PWD and consultations with DA NSW staff.



Case study

An unregistered NDIS service provider in the NSW's north provided disability services and was accused of fraudulent activity. The provider promoted themselves as an Aboriginal disability service that offered a host of services including assistance with day-to-day personal care (e.g., personal hygiene, meal preparation, domestic duties), social and community participation, supported employment, day programs, transport and respite. Several concerns have been reported to DA NSW by advocates, disability workers and clients.

One issue is that the service provider limited their client's access to other services. This agency employed a worker that provided assistance to PWD to access the NDIS. Through this process, the worker took clients to medical and specialist appointments. The worker listed their phone number on the NDIS access applications[1], which meant that they could field phone calls and act as a gatekeeper of services, restricting the client's choice and awareness of other service providers that were available to them.

Another issue is that the service provider was routinely overcharging clients. They double, and at times, triple billed clients, exhausting their clients funding. In one instance, the service provider had a client, Aaron, who was working under their employment support program as a retail assistant. The service provider received a government subsidy from which they remunerated Aaron minimally, as part of a Disability Employment Services (DES) program. At the same time, the service provider illegally billed his NDIS plan for employment support[2]. Not only did they go against the agreement made with the DES program, but they charged Aaron for employment support that was not provided to him. This consumed all of Aaron's NDIS funding. He had no service agreement with them, and he had no knowledge of them billing his NDIS funding. As Aaron describes, it felt like 'the whole world had been ripped out from under him'.

It has also been reported that the service provider had several home respite services that operated 24 hours, 7 days a week. Clients lived there full-time, not on a temporary respite basis. Again, the service provider overcharged its clients, billing their core support funding. They also limited access to other service providers.

Lastly, several instances were reported where the service provider applied for guardianship of its clients – often against the clients' wishes. If granted this, they would have held responsibility and control over these clients' finances and decision-making.

This service is no longer operational. However, its founder has started another disability business in the region.

Unfortunately, examples like this case study do not exist in isolation. In communities where there are a lack of services, a provider posing as a friendly ally that can offer a range of services and support can seem like a godsend. It is seemingly convenient, catering to multiple care needs. But, as shown in the case study above, it can allow providers to exercise an unwarranted degree of influence and control over people's lives, particularly when participants may not fully comprehend how the scheme works.



How did we get here?

Since the introduction of the NDIS, we've seen a shift from governments providing 'block funding' directly to service providers to personalised funding or individualised budgets [1]. The idea was that individualised budgets would empower individuals with disability to play more of an active role in goal setting and enable them to pick and choose the services and supports that best suit their needs. The assumption was that individualised funding would stimulate a quasi-market of service providers and boost choice, driving competition and innovation through demand and supply [2]. This has worked well for many people, particularly when people can exercise choice and control from an array of services and supports when there is an abundant market of service providers.

However, many people in RRR areas have not experienced the empowerment that comes with choice and control due to thin markets. A core issue in many RRR areas is that populations are spread across large geographical distances meaning that there is often a relatively small client base in comparison to metropolitan centres [3]. This makes it difficult to attract good quality NDIS service providers because it is not economically sustainable to provide services in RRR areas [4]. Alongside this, many community-based support services have become increasingly harder to access, as many pre-existing services and supports have either been discontinued, transitioned to the NDIS fee-for-service model and/or they have been absorbed in larger service providers. This has often resulted in a lack of diversity, and a thinning of markets in RRR areas [5]. Consequently, PWD in RRR areas have few, or worse yet, no good quality services and supports to choose from.

The NDIS and thin markets in RRR areas

Within thin markets there are minimal services that cover vast geographical distances. This increases demand on the limited number of services that are available in RRR areas, contributing to lengthy waitlists or closed books. As one participant described:

Lack of services in regional and rural areas means that there is not a lot of options. It also means that there are long wait lists for services
(Regional 2021 survey participant)

Subsequently, this creates a need to travel further to find available services and supports. We've discussed at length in the Aussie Battlers, that PWD living in RRR areas frequently need to travel vast distances to access reasonable and necessary services and supports because of thin markets. It is common for PWD to travel hundreds of kilometres for several hours to access services.

The issue here is that travelling can be extremely burdensome for PWD in RRR areas. Firstly, they often need to contend with poor infrastructure (e.g., unreliable public transport, inaccessible environments). Secondly, PWD who have mobility issues (e.g., wheelchair users), frequently experience challenges with inaccessible public transport, and may require support workers to assist them with their transport needs [6]. Lastly, there is the financial burden of travel costs. Many PWD on low incomes in RRR areas simply cannot afford travel costs. As one participant remarked:

The cost involved with travel is unaffordable, therefore the availability of services is rare.
(Regional 2021 survey participant)



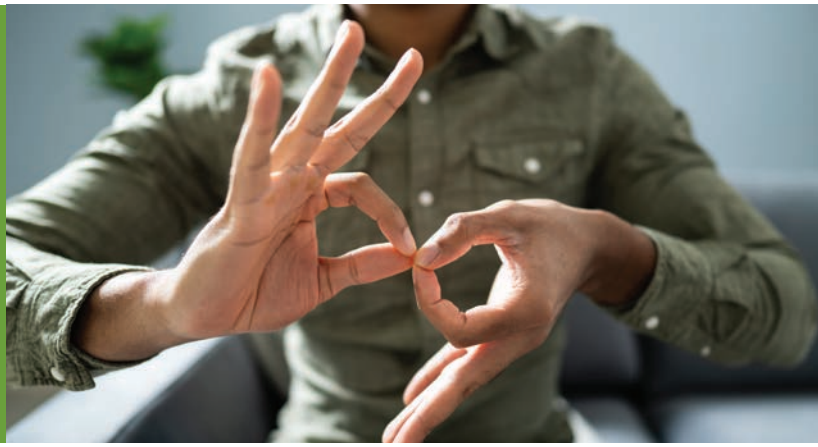
For those that are fortunate to access the NDIS, there may be funding to cover some travel costs, but this is limited[3]. It is often not economically viable for service providers to travel considerable hours to RRR areas to visit one or two clients. For NDIS participants, the travel costs that providers charge can consume a large portion of their NDIS budget. As one anonymous survey respondent described:

I have to find support people willing to travel to my home and paraprofessionals will only visit when they can cluster other appointments in the area which means once or sometimes twice a year. All other disability services or mainstream service, I have to arrange support and transport to, which ends up costing a lot of money from my limited NDIS funds.
(Regional 2021 survey participant)

Similarly, another described:

NDIS providers tend to charge the maximum allowable. Some also charge transport and time to and from and as this has not been funded in my plan it has resulted in a limited choice of providers for me
(Outer regional 2022 survey participant)

Many PWD cannot receive the level of support that they require because of the travel that is needed in RRR areas, even though they have access to the scheme. Additionally, accessing disability professionals such as allied health practitioners, clinicians and support workers is challenging in RRR areas. They are often in short supply due to difficulties with attracting and retaining workers to these areas because there is limited career advancement and support [7]. This results in a shortage of skilled and experienced disability professionals in RRR areas.



The Haves and Have Nots: The NDIS, an oasis in the desert

For people unable to access the scheme, the prospect of accessing crucially needed supports and services is dim. As one of the NDIS's architects, Professor Bruce Bonyhady described, the scheme has become an 'oasis in the desert' that is deeply 'inequitable' for those unable to access the scheme.

The NDIS relies on other mainstream service systems, such as health and community-based support, to ensure that PWD can receive adequate care and support. The scheme's success hinges on access to mainstream supports and services because they must interact to ensure smooth and easy access to supports and services for PWD. It was intended to work within an existing ecosystem of service systems that ideally functions cohesively to provide wraparound support for different levels of need [8]. Yet, the experience of PWD accessing disability care and support is that there is minimal or no support available outside of the NDIS:

'If you do not have a NDIS Plan you now CANNOT access any disability services anymore, while before you could access help straight away, (now it takes forever to get a plan before you can maybe access any help)'.
(Regional 2021 interview participant)

For many PWD living in RRR areas, the NDIS can seem like the only avenue to access crucially needed supports and services. Many community-based and mainstream services are inaccessible or no longer exist in RRR. After the NDIS was rolled out many services needed to transition to a fee-for-service model. As a result, it has become commonplace for service providers to refuse to accept clients that do not have NDIS access because they have no funding to provide services and supports.

Without access to the NDIS, PWD in RRR areas must rely on the slim pickings of mainstream and community-based programs, also referred to as 'tier 2' services. An example of this is the health system (e.g., Medicare) and bulk-billing practices. **There is a scarcity of available general practitioners (GPs) in many RRR areas**, and many GPs require a gap payment. For PWD on low incomes, the expense is so prohibitive that it prevents them from accessing health services. Combined with other issues associated with travelling, it can be near impossible to access mainstream and community-based programs in RRR areas. As one participant lamented:

I have had to cancel so many urgent medical appointments and treatments due to no transport
(Outer regional 2022 survey participant)

Sadly, the lack of tier 2 services in RRR areas limits the possibility of gaining entry to the NDIS. Many PWD rely on tier 2 services as way providing evidence to demonstrate that they are eligible for the NDIS. As we've discussed in our **Aussie Battlers report**, there are administrative burdens of organising documents and evidence as part of the application process that can be unduly complex to navigate [9]. But living in a RRR area where there are thin markets can add another layer of complexities to accessing the NDIS:

The availability and affordability of [e.g. OT] assessments and therapy is at average cost, i.e. unaffordable for most people unless they have NDIS funding, and most OTs in this region are booked to capacity for months. Some allied health providers who cover disability services and aged care, e.g. podiatrists, exercise physiologists, are booked out for 6 months. No physiotherapists, OTs, or exercise physiologists in the region have much knowledge of or experience working with less common physical disabilities
(Inner regional 2022 survey participant).

A lack of availability and affordability leads to difficulties with sourcing reports from specialists and clinicians in RRR areas, which are needed to demonstrate eligibility for the NDIS. As reflected in the quote above, there are issues of cost and limited expertise in RRR areas. In addition, getting to and from medical and specialist appointments to obtain reports to apply for the NDIS can be a significant hurdle for PWD (as discussed above). Furthermore, sourcing information and support to help navigate this process is also difficult in RRR areas. Living in RRR areas where there are limited tier 2 services can make it near impossible to fulfil the evidentiary requirements to demonstrate eligibility for the NDIS. It means some of our most vulnerable members in the disability community are stuck without adequate supports and services.



Eroded Quality and Safety

There is a risk that service providers can take advantage of PWD who are desperate for services and supports. When there is urgency and disadvantage, PWD do not have the luxury of choice and control. Faced with limited options, many will accept subpar and questionable services. Coupled with a lack of accountability and oversight, at its worst, it can potentially give rise to exploitation and abuse.

Thin markets in RRR areas can allow service providers to monopolise some areas. Where there is no competition for clients, there is little need for service providers to innovate and improve service delivery. In these conditions, NDIS participants can become dependent on the one or two service providers that are available in their area as they are unable to pick and choose from other services. As one participant described:

It's a regional town so the support is adequate but not outstanding, people with disabilities just get what they get, and to the non-disabled it's enough
(rural 2022 survey respondent)

Adding to this are unregistered service providers who do not share the same level of quality assurance as registered service providers. These providers do not undergo the same time-consuming and expensive auditing and compliance processes as providers that are registered with the NDIS Quality and Safeguards Commission. This has some benefits as it enables more service providers to operate without the red tape that registered providers have. This can be empowering for small local business to operate in RRR areas, and it potentially gives NDIS participants more choice and control[4]. There is also more flexibility around cost. But there are also some inherent risks. While there is a NDIS Code of Conduct unregistered providers must adhere to, they have more flexibility around how they vet employees and manage complaints. This doesn't mean that registered providers are immune to poor-service delivery – being registered or unregistered does not relate to the quality or professionalism of supports – but there are inherent risks within the discrepancy in quality assurance and compliance.

Additionally, some PWD are fearful to report inappropriate conduct or poor service quality as they don't want to 'rock the boat'. In RRR communities where there are relatively small populations, anonymity can be difficult to maintain which deters people from reporting and lodging complaints. They fear the potential repercussions (such as losing access to the one service) that can come along with being identified. These conditions can also erode quality of services as there is little accountability, and in worstcase scenarios it can perpetuate exploitation and abuse. As one person explained:

I find if you put in a genuine complaint in a small town, it always gets back to you. That is when you are treated like dirt, so you never put in a complaint
(rural 2020 survey participant).

Additionally, another expressed fear of reprisal:

I've had enough punishment - don't want to unleash their wrath
(outer regional 2022 survey participant)

Despite several mechanisms in place to address misconduct and fraudulent activity, PWD in RRR areas continue to experience exploitation. While the NDIS Quality and Safeguards Commission is responsible for investigating complaints, this can be hampered if PWD are fearful to speak up. The Australian government is also attempting to address fraudulent activity among service providers and has set up a taskforce to investigate suspicious activity among service providers. Additionally, the Disability Royal Commission investigated abuse, exploitation, neglect and violence of PWD – part of which looked at NDIS service providers. These are positive steps to address these issues, but based on the trends we are seeing; more measures and safeguards are desperately needed that focus specifically on PWD in RRR communities and the unique challenges that they face associated with thin markets.

While service quality has been long standing in thin markets, the NDIS has contributed to some of the issues that we are seeing with service providers in RRR areas. In some instances, a lack of regulation and oversight that comes with a quasi-market model has contributed to the emergence of scrupulous service providers that exploit some of the most vulnerable members of RRR communities.





What can change?

1 NDIA's Quality and Safeguards Commission has increased oversight to monitor activity among unregistered providers - particularly in RRR areas.

This must be done in a way that does not stifle market growth and choice and control for participants. We recommend that the NDIA develops a specialist team to monitor unregistered providers, alongside an alert system that flags suspicious activity (e.g., when there is one contact person for numerous NDIS access requests, as seen in the case study provided).

Additionally, an on the ground state-based Quality and Safeguards Commission may allow for more close monitoring of NDIS service providers.

2 The NDIA invests in building capacity in RRR communities to identify and report exploitation, abuse, violence and neglect.

This can be done through increased advocacy support as well as providing clear accessible information on how PWD and/or their families can lodge complaints. This will better arm vulnerable communities with information and knowledge to identify and report misconduct.

3 States and territories and federal governments must work together to identify thin markets and ensure tier 2 services are readily accessible in RRR areas.

To ensure that PWD who live in RRR areas do not fall through service gaps, states and territories and the federal government must work together to identify thin markets, and develop measures to ensure that such areas are adequately funded to supply tier 2 services. This is particularly important for PWD who do not meet the access requirements to the NDIS.

4 Federal government invests in developing local labour forces and incentivises working in RRR communities.

We recommend that efforts are made to develop the labour force within RRR areas, rather than rely on workers who need to travel into RRR areas. Providing funding to individual plans alone is not enough to attract service providers. We recommend that the Federal Government invest in a national program that firstly aims to skill up communities so that labour can be sourced from within communities. And secondly, aims to incentivise specialists/professionals to live and work in RRR areas. This may aid in stimulating markets, thus providing more choice and control.

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End notes

1. Allegedly through clients signing a consent to act form.
2. The provision of a support worker to assist and supervise work activities.
3. See **NDIS Pricing Arrangements and Price Limits 2022-2023**
4. Unregistered providers are only available to self-managed and plan-managed NDIS participants.







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