The Aussie Battlers: Life with a disability in regional, rural, and remote NSW

DANSW Scoping Research Report

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Introduction

People with disability (PWD) who live in regional, rural, or remote (RRR) areas are doing it tough. As Gething[1] describes, they are double disadvantaged, because they both live with a disability and are burdened with geographical issues such as thin markets, social isolation, inaccessible built environments, and poorer employment opportunities. Following the social model of disability, we hold the view that it is not a person's disability that is disabling per se, but society's response that is disabling[2]. This means that our social responses – in the form of our social service systems and polices – are a large part of the double disadvantage that is disabling PWD who live in RRR areas.

Service systems often fall short in providing adequate care and support for PWD who live in RRR areas. Many of the policies and practices underpinning these systems are well-intended. However, the implementation, running and interaction of service systems in RRR is disjointed and fragmented, often leaving PWD without adequate care. There are often impenetrable bureaucratic processes, and confusing pathways to access services, which makes navigating service systems challenging. In turn, it creates conditions where PWD frequently report that they feel like they are 'going to war' with service systems to receive services and support that should be a right, rather than fight. For many, such an experience is reported as more stressful than having a disability itself. These battles are often fueled by an acute scarcity of resources in disability, health, and community services sectors.

The context in which we find ourselves today is partly due to reforms of the disability care system in Australia. Some five years after the NDIS rollout was completed, we are now observing the impacts that such a significant transformation has had on the disability community and sector.

This report is not intended to focus criticism on the NDIS. Rather, it discusses the implementation of the NDIS in RRR as way of sketching out the broader context in which we find ourselves today. We see the introduction of the NDIS as a watershed moment in Australia's history that signified the country's commitment to the Convention on the Rights of Persons with Disabilities (CRPD), which enshrined that PWD have the right to actively participate in their communities.

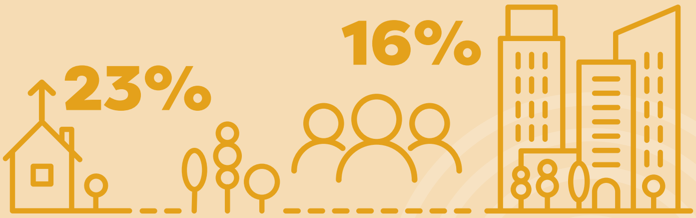
As an advocacy support service, Disability Advocacy NSW (DA) services over two thirds of NSW, making us the largest disability advocacy service in Australia. With most of our offices in RRR areas of NSW, we see firsthand how inadequacies within service systems can disadvantage PWD who live within these communities.

What becomes apparent through these research findings, is that although PWD can access forms of support and services through our social service systems, their lived experience of interacting with systems is rarely felt as person-centred or operating from a framework of human rights, and fairness. In fact, overwhelmingly, interacting with service systems was often reported as an experience of going to war – a constant and exhausting battle – in order to receive support and care.

This report aims to shine a light on these experiences, by giving voice to PWD and their families who live in RRR in NSW. It draws on research comprising of consultations with advocates, surveys and interviews with PWD and carers conducted in 2021, as well as data collected by DA over a five-year period (2017-2021).

To read more about the research process, ethical considerations, and limitations, please access the full report at XXXX

Life with a disability in regional, rural, and remote NSW



Disability rates are higher in RRR areas compared to major cities.

Thin markets

It is widely acknowledged that there are fewer services in RRR areas. In NSW, the availability of allied health services decreases with rurality, disadvantaging PWD because they have limited access to health services[4]. Yet, disability rates are higher in RRR areas, with 23% of people reporting a disability compared to 16% reported in major cities[8]. Adding to this, are issues with retaining and recruiting health professionals and service providers in rural and regional areas due to lack of support and limited career development[9, 10]. Consequently, this leads to a small pool of allied health workers and service providers in RRR areas, which can make it especially challenging to find good quality professionals who have the appropriate training and expertise needed for specific disabilities. With few options in RRR areas, there are often issues with geographical distance and the need to travel, cost, and waitlists.

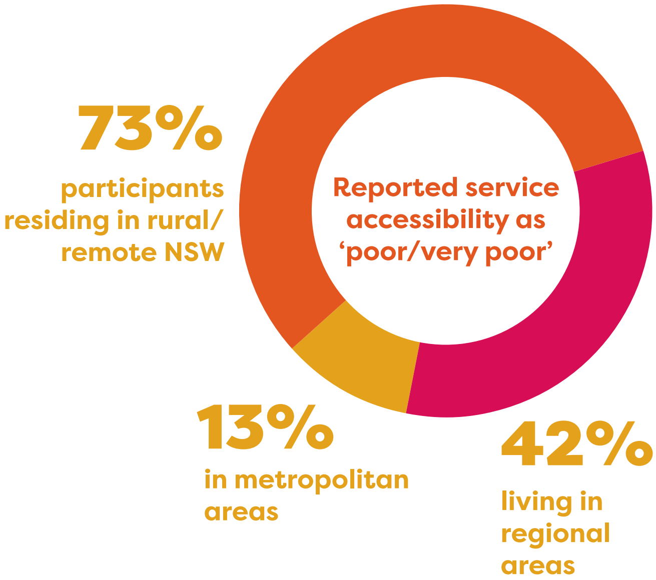
The implementation of the NDIS's quasi-market model was intended to stimulate a caring economy that would provide PWD with more choice and control. However, this model has not adequately addressed the shortages of supports and services in RRR areas. In fact, in some cases, it has further entrenched disadvantage. Not only has this led to lack of diversity of services in many RRR areas, but it has also meant that many service providers can face precarious financial situations.

Limited services

There are often not enough good-quality providers in RRR areas with space to take on more clients.

This was demonstrated among surveyed participants indicating accessibility significantly decreased as distance from metropolitan areas increased. In total, 73% of participants residing in rural/remote NSW reported service accessibility as 'Poor/Very Poor', compared to 42% living in regional areas, and 13% in metropolitan areas. Additionally, satisfaction with services available was 68% lower in RRR locations compared to metropolitan areas.

> **'Inconsistent access to supports is not inclusive enough… I am isolated, and no one is around to hear us'.**



Case study 1: Heather

Heather is a single mum who lives in Bathurst with her young adult daughter, whom she cares for. Both are NDIS participants. She refers to the NDIS as the 'National Disgrace Incompetent System'.

Heather has a psychiatric condition and was an inpatient at various psychiatric hospitals after experiencing significant stress while attempting to manage insufficient NDIS supports for her daughter.

Due to a lack of supports in her area, Heather and her daughter need to travel to Sydney – approximately 200kms one way - for medical appointments.

In Heather's experience, the Bathurst community often adopts a 'that will do' attitude in relation to supports. Seemingly this is because there just aren't a lot of services or options available.

Heather says she 'would take the old system over NDIS any day'. She explains it was much easier to access support. She could ring and say, 'I need help', then she would do 'easy paperwork and then you got help. Now, no one can assist people until they get access to an NDIS plan and getting a plan is near impossible'.

In her own (written) words she describes, **'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).'**

DA Interviewee from 2021 scoping research

With few services to choose from, the respondents reported that many service providers had lengthy waitlists with closed books, creating delays and barriers in accessing treatment. This could lead to what one participant, Heather (case study 1), described as a 'that will do' attitude, where people accept subpar services because they have few other options to choose from.

Travel and transport

Having few services available in RRR areas leaves little options but for PWD and their families to travel lengthy distances in order to access services and supports. Vicki, a carer for her son who has a disability, spoke about how she frequently travelled six hours with her son to see a psychiatrist in Sydney, as there was no one 'decent' available in her area. She advised that it took 12 months to access local treatment as good-quality providers had no space to take on additional clients.

But travelling lengthy distances is not a viable option for some PWD due to health concerns, mobility issues, behavioural issues, and/or the need for support to attend appointments. In RRR areas, this is also impacted by infrequent and inaccessible public transport as well as infrastructure with inaccessible built environments (footpaths and inaccessible buildings are significant issues in RRR areas). This may mean that people simply miss out on supports and services, or in some instances they are forced to make the difficult decision to relocate to regional/metropolitan centres to access supports and services.

Financial disadvantage

Financial disadvantage is a significant issue for PWD living in RRR areas. Advocacy trends at DA reveal that over the last five years, most of our clients requiring support with finance-related matters reside in RRR communities. Moreover, support requests for finance-related matters were 52% higher in RRR areas. We attribute this, in part, to lower employment and educational opportunities, which lowers potential to get a job and generate income. There are multiple factors at play here for PWD living in RRR areas that can place them at increased risk of poverty; firstly having a disability alone places people in an above-risk of poverty, especially for those who have a more severe core activity limitation[13]. Secondly, living in a RRR area increases the risk of financial disadvantage as there are fewer educational and employment opportunities[13, 14]. These factors, if not addressed, can keep people stuck in poverty.

Missing out on supports and benefits: The cycle of poverty

People who are struggling financially and have a disability commonly report that the application processes for service systems (e.g., the NDIS, DSP) are overwhelming and many do not have family or friends who can assist them with navigating complex bureaucratic systems[15].

Financial constraints can prevent access to material resources needed to access and upload information to and from service systems' websites/emails. For PWD receiving social welfare payments, they often have little surplus money to pay for the internet after attending to basic necessities. The costs of living, plus data usage, and owning a digital device may be out of reach for welfare recipients[17]. Furthermore, living in RRR areas add to these costs as broadband networks are often not readily available, creating a reliance on mobile phones or satellite connections where the cost of data is comparatively more expensive than broadband[18].

Additionally, there is a burden of costs associated with gathering documentation that can impede access to service systems. An example of this that we often see in our advocacy work is PWD on Newstart or Jobseeker allowance, which unlike the DSP, does not factor in the additional living costs associated with having a disability. The low rate of these payments makes it difficult for PWD to afford the fees of medical and/or specialist appointments and travel costs, which can hinder their efforts to apply for the DSP because of the financial burden to provide the required evidence and/or being assessed, diagnosed and stabilised[15].

Case study 2: Grant

Grant is a DSP recipient who lives in a RRR area. He was unable to access the NDIS because of the costs associated with the need to travel to medical appointments. He explained that being on the DSP meant that he 'didn't have the money to drive down and back to [a regional centre] every couple of weeks'. This was compounded by his condition, which prevents him from driving, and having a child with high care needs. This meant that his partner and child would need to travel with him. He noted that while there is financial assistance for fuel – up to 70% of the cost – it did not take into account **parking, or food** that would need to be purchased for him, his partner, and child.

These costs created a substantial barrier for Grant that meant he was unable to attend the medical appointments with the specialist. Not only did this mean that he went without treatment for his condition, but he was also unable to obtain evidence to access the NDIS.

DA Interviewee from 2021 scoping research

'To be disabled is expensive': The cost of disability in RRR areas

The level of financial disadvantage for PWD in RRR areas is likely to be underestimated as the cost of having a disability is one factor, while having a disability in RRR areas is another. Several surveyed participants spoke about the unaffordability of receiving adequate support and treatment. Moreover, RRR participants commonly reported there are additional costs when living further away from city centres.

> **"I don't think people living in cities quite get it, we pay extra for postage, fuel, and so much more. How is my payment supposed to stretch further than someone who lives closer to a city?".**

The low rate of payments, coupled with difficulties surrounding access, prevents participation and social inclusion as it severely limits PWD's capacity to engage in activities outside of attending to basic needs (e.g., food, health, housing). These financial difficulties are worsened when service systems refuse to fund or inadequately fund support services, which can leave PWD with few options but to go without supports and/or services, or miss out on basic necessities.

When one service system fails a PWD, the individual will often need to fall back on other limited service systems for support. When both (or more) service systems fail to support a PWD, it is the individual that is ultimately entrenched in enduring systemic disadvantage.

Burden of evidence

Obtaining ‘acceptable’ evidence is a frequent problem reported by both participants and advocates. The issue is not isolated to gathering evidence, but a lack of clarity around what constitutes credible evidence. Navigating these processes, often across multiple service systems, requires people to produce substantial documentation and verification, which is time-consuming, financially burdensome, and human resource intensive.

Providing evidence: A hurdle to accessing support

In both the NDIS and DSP systems, applicants must compile evidence from their health and medical practitioners, treating specialists, service providers and government agencies to build a case that demonstrate that they meet eligibility criteria[19]. Both survey and interview participants reported difficulties with obtaining evidence due to a lack of clarity around the requirements.

> **It is like ‘the secret service’... you have to know and write the correct codes to gain access to help and only [government] staff know this ‘special language’ and they don’t share it with anyone else.**
>
> Heather, regional participant.

Requirements are vague and unclear, making it difficult for treating specialists to provide evidence that is accepted. A part of this issue is that doctors and or treating specialist are not provided with adequate training or support to write reports for access requests[20].

As a result, many access requests are rejected based on issues surrounding evidence. We can see this in the drastic decrease of approved application rates for the DSP since the introduction of the impairment tables for the DSP in 2012. It reduced from 60% in 2011 to 30% in 2021[21]. Arguably, this relates to issues with providing evidence that meets the criteria in the impairment tables. For the NDIS, numbers of individuals who are deemed ineligible for the NDIS are not reported. However, AAT statistics are telling, with a 400% increase of appeals in the past year. It is likely that many of these matters have issues surrounding evidence. This is reflected in our advocacy trends, where 61% of DA's cases in RRR areas were identified as having difficulty obtaining adequate evidence to support NDIS evidence requirements due to limited accessibility of service providers.

As Grant's statement (below) argues, the expertise and credentials of PWD's treating specialists are often not given due credit to assess their own patients:

I think they [the agency] need to pay a bit more attention to a person's existing treating specialist, you know, a person didn't get a specialist for being a bullshit artist. They are a specialist through bloody hard work and through education. So I think instead of playing down another specialist's education, calling them stupid because of something they don't agree with, they need to start paying attention to that. My pain specialist, for example, as I said, he had this issue before with the NDIA. And he's fed up with it. And, I would imagine he's not the only one. So they need to stop ignoring people who are qualified and experienced.

DA Interviewee from 2021 scoping research

People who pursue matters - particularly those who are willing to take matters to the AAT - are generally the best resourced to follow up their complaints, given the costs and labour needed to interact with the appeals and reviews process[19]. There is also the issue of providing evidence beyond the application process when an individual's circumstances changes and they require different levels of support or services and must produce evidence to demonstrate this. Similarly, this can also be an issue for PWD who require the same level of support from year to year and must produce evidence to make a case to receive the same level of supports/services.

61%

of cases in RRR areas had difficulty meeting evidence requirements due to limited accessibility of service providers.

2.4 x

...longer for participants in RRR communities to resolve matters, due to limited services.

The costs and burdens of obtaining evidence in RRR areas

Without experience or guidance to complete reports, time-poor specialists and doctors often find that their assessments and reports are deemed unsatisfactory. As a result, they find that they must reword and revise their reports. This can place a financial burden on participants and a strain on health professionals. In the quote below, Montana reflects on a discussion she had with a 'high up there' housing provider representative about obtaining evidence:

You (service system provider) want me to fill this medical form, that's fine, I'm happy to do it. But you know, my doctor charges me $90, you know for that appointment. So, you want me to pay $90 for that appointment? Mind you, you've already rejected the first form, and no one will tell me what information it is that you actually need.

DA Interviewee from 2021 scoping research

In DA's advocacy trends, the time taken to resolve a matter for a participant in a RRR community is 2.4 times longer than participants in metropolitan areas because of issues associated with difficulties obtaining evidence in areas where there are limited services. In this context, GPs and treating specialists who are often ill-equipped – time-poor and without appropriate instructions – are asked to provide the documentation needed. This is often compounded by the fact that access requirements for different types of disability support like the NDIS and the DSP are markedly different. So, a report that satisfied the NDIS criteria may not satisfy the DSP and vice versa.

Inaccessible information

Accessible information is a human right

People need accessible information to make informed decisions. Under the UNCRPD – of which Australia is signatory – accessible information is a human right[22]. In this, government agencies have an obligation to the 'equal enjoyment of human rights' for PWD, which includes the right to access materials in accessible formats and the right to support to assist facilitating access[23]. These provisions are the foundation for opportunities for PWD to participate in decision-making and to participate in healthcare. Likewise, Australia's disability service systems have objectives to foster participation, choice, and control. However, providing these opportunities to make decisions is meaningless without offering accessible information about what options are available[24]. As Rosen et al., (p.18) describes, making informed decisions relies on access to 'understandable, relevant, and high-quality information'[25].

Yet difficulties navigating the disability service systems due to inaccessible information is a common complaint [see previous research[15, 16, 19, 27, 28]]. Unsurprisingly, this was mirrored among the survey and interview respondents who frequently described that navigating the disability system as 'complicated', and 'confusing'. Several questioned 'how anyone with a disability could follow it.' Numerous participants expressed concern for people who may not have the functional capacity to comprehend inaccessible or overly bureaucratic information provided by government departments. Taylor described information as difficult to access and understand:

> **I don't think I would have gotten it [the NDIS] without Disability Advocacy's help, and it was also really hard to find out about Disability Advocacy because the NDIS, doesn't go, 'we've rejected you from the NDIS, here's Disability Advocacy'... They just go, 'here is a random link to some web page that you're absolutely not going to comprehend because it's written in frickin bourgeois parlance'.**

The presentation of information often assumes literacy skills, computer literacy, as well as access to stable internet, and electronic telecommunication devices[30]. Without appropriate support to access and understand information, PWD risk being able to voice their concerns and advocate for their rights.

Locating information

People find it difficult to source information if they do not know what they are looking for. Before trying to find information, it firstly helps to know what services are available, and what information is available for these services[31]. A lack of information to start with can potentially disadvantage PWD if they do not possess the resources to put in the time, energy, self-education to search, and comprehend information.

Without clear information about how to navigate or use systems, PWD risk facing delays in accessing much needed support. Karen, a carer for her son, explained that for 12 months she was unaware of payments for education support that her son was entitled to. She described Centrelink as 'not proactive' and that:

They [Centrelink] don't tell you what you're entitled to get. And I find that really frustrating, like especially because he's not going to be able to go to work and, and all that sort of stuff. And my husband and I both work - we always have. We've paid our taxes. And...the government hasn't supported us to the extent that we should and could have been supported. So why not give it like, shouldn't they tell you? Yeah, so I find that really frustrating.

DA Interviewee from 2021 scoping research

For PWD living in RRR areas, locating information can be even more challenging. The risk of social isolation that is heightened living in these areas can limit people's capacity to access information. This is because social isolation limits the potential to share information within social networks. Coupled with financial disadvantage, people can become housebound further limiting their social interactions where they might exchange information[16] .

Moving into a [rural] new community it was difficult to know what services were available and how to access them. It has taken 6 months to establish the support services I need. NDIS and Centrelink information that I was given was not correct (rural survey participant).

Like financial disadvantage, informational inequity can keep PWD entrapped within a cycle of marginalisation.

The constant battle

Disabling systems

The issues PWD face living in RRR can impact on their wellbeing and health outcomes[1, 5, 32, 33]. A lack of services[3, 4, 34, 35], financial disadvantage[14, 15], organising evidence and difficulties with finding information to navigate systems[16, 19, 25] as highlighted in this report can feel like a constant fight. Among the respondents there was a striking commonality where they spoke about the negative impact that these experiences had on their wellbeing. The experience of having a disability coupled with these issues were often described as the causes of significant distress, and exhaustion. Some even labelled it as 'traumatising'. Such experiences align with concerns of the social model of disability that argues that it is social responses (e.g., policy, service systems and service provision) that are often more disabling then having a disability itself[36-38]. In this, not having access to basic necessities, such health care and information, not only prevents PWD and their families from participating in daily life[39], but it also erodes away at people's wellbeing[1].

Case study 3: Bronnie

Bronnie is a single mum who cares for her 17 year old, who is living with a disability. They live in social housing, which she explains has a lot of repairs that are needed. In her words, 'it's falling to bits'. They live in a semi-rural area, but it is situated on the fringe of a metropolitan area so service access has not been an issue. Bronnie describes her interaction of dealing with government services, including housing, Centrelink and the NDIS as 'like going to war'.

She has been through the appeals process in relation to insufficient funding in her son's plan. She described herself as a 'squeaky wheel' who called the agency weekly, following up on a matter. She also went to her local MP. As she put it, 'you got to dig your heels in and fight because otherwise, you're not going to get what you need. And it shouldn't have to be like that but is like that'.

Similarly, she recalled her experience in dealing with Centrelink as 'long and drawn out', and 'challenging'. She explained that their first DSP application for her son was rejected due to delays on documentation. In total, she reported that it took approximately six months until her son's application was approved. This resulted in a backpay payment. However, because Bronnie received the family tax benefit, the back payment was classified as an overpayment ($1700). However, housing had overcharged her rent, so she had these funds returned, which she was able to use to pay the Centrelink debt.

Bronnie described her experience as exhausting and isolating, as a carer with no informal support network. She has had her own mental health issues, and during the covid lockdowns, the sense of isolation was heightened as she had limited contact with other carers, which was the only form of socialisation she had.

For both PWD and their families, attempting to participate in healthcare, is often stressful and all consuming, particularly when multiple service systems are involved. While this is common among PWD, this is particularly strong among people who care informally for someone with a disability[32, 40].

For both PWD and their families, service systems can place unreasonable demands on the limited resources that they have, be it, time, energy, finances etc. This is often compounded by negative interactions with service providers that 'gaslight', 'bully' and 'coerce' them into what they regard as unfair and unjust decisions made for them. Such experiences exemplify that it is not disability alone that leads to significant mental distress, but engaging in multiple negative interactions with service systems – often for basic necessitates – that deteriorates the wellbeing of PWD and their family member who care for them[36, 41].

While there are mechanisms in place for PWD and their families to make complaints, and challenge decisions made about them, these avenues inherently disadvantage some of the most vulnerable members of the disability community[42]. Many, PWD and their families request reviews and appeal decisions that they believe are unfair. This was reflected in this research with half of the interview respondents reporting that had taken matters to the tribunal or had lodged formal complaints. In doing so, many had experienced victories with overturned decisions. However, this is not without financial and emotional costs. Many reported that even though they had matters resolved in their favour, problems relating to unfair decisions persisted later down the track, with many needing to appeal decisions for a second or sometimes, even a third time. As one interview participant remarked, 'I'm just waiting for something to go wrong from week to week.'

Summary

This report has highlighted four core systemic issues experienced by PWD and their families in RRR as existing across multiple service systems. This cohort is arguably one of the most disadvantaged within our society. Living in RRR areas gives rise to unique conditions that can 'double disadvantage' PWD. Thin markets, financial disadvantages, evidentiary requirements and inaccessible information contribute to this 'double disadvantage'.

The double disadvantage that PWD living in RRR areas experience has been widely acknowledged. The issues raised in this paper suggest that more work is crucially needed in this area to achieve equal opportunities for PWD regardless of their location.

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