



**Lived  
Experience**  
AUSTRALIA

23<sup>rd</sup> February 2024

# NDIS Participant Experience in Rural, Regional and Remote Australia

Submitted to:

The Committee Secretary

[Ndis.joint@aph.gov.au](mailto:Ndis.joint@aph.gov.au)

For:

The Joint Standing Committee on the National Disability Insurance Scheme

**Address Details:**

Committee Secretariat  
Joint Standing Committee on the National Disability Insurance Scheme  
PO Box 6100  
Parliament House  
Canberra ACT 2600  
(02) 6277 5829

Lived Experience Australia Ltd  
Contact: Sharon Lawn  
Executive Director  
[slawn@livedexperienceaustralia.com.au](mailto:slawn@livedexperienceaustralia.com.au)  
PO Box 98, Brighton SA 5048  
Phone 1300 620 042  
ABN: 44 613 210 889

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## Introduction

Lived Experience Australia Ltd (LEA) is a national representative organisation for Australian mental health consumers and carers, families and kin, formed in 2002. Our 'friends' include more than 7000 people with lived experience of mental health concerns, including suicide and suicidality, across Australia.

**Our 'friends' network includes many people living in regional, rural and remote locations across Australia. It also includes many people who are currently receiving NDIS support and their families, carers and kin, and many who are navigating eligibility or have unmet needs related to their psychosocial support needs.**

All members of our Board and staff have mental health lived experience as either a consumer, family carer or both. This includes lived experiences with the NDIS and with the needs and experiences of mental health, NDIS and support availability, access and provision in rural, regional and remote Australia.

Lived Experience is core to our advocacy, recognising that the impacts of policy and practice are felt not only by individuals, but also by families and whole communities. Our core business is to advocate for effective policies and systemic change to improve mental health care, services and support across the whole Australian health and social care system, including within State and Territory jurisdictions.

As part of preparing this submission, we reached out to our 'friends' network through a brief online survey to seek their views and experiences. Fifteen people with direct experience of NDIS in rural, regional and remote Australia were pleased to provide their perspectives.

We welcome the opportunity to provide our feedback to this crucially important issue for people with psychosocial disability and their families, carers and kin in the Australian community.

## Purpose of this Consultation

A Joint Standing Committee on the National Disability Insurance Scheme has been established to inquire into and report on the NDIS participant experience in rural, regional and remote Australia.

### **The Terms of Reference include:**

As part of the committee's role to inquire into the implementation, performance and governance of the National Disability Insurance Scheme (NDIS), the committee inquiry makes particular reference to:

- a) The experience of applicants and participants at all stages of the NDIS, including application, plan design and implementation, and plan reviews;
- b) The availability, responsiveness, consistency, and effectiveness of the National Disability Insurance Agency in serving rural, regional and remote participants;
- c) Participants' choice and control over NDIS services and supports including the availability, accessibility, cost and durability of those services;
- d) The particular experience of Aboriginal and Torres Strait Islander participants, participants from culturally and linguistically diverse backgrounds, and participants from low socio-economic backgrounds, with the NDIS; and
- e) Any other related matters.

## Our response to the Terms of Reference

In summary, our brief survey was open for two weeks. We asked people general demographic information about their circumstances (state/territory, rurality, LE perspective as a consumer or carer). We then asked people one broad question:

*“What is your experience of applying for, or receiving NDIS (or supporting a family member or friend with this process) in rural, regional or remote Australia? We are particularly interested to hear about:*

- *experiences of the NDIS application, plan design and implementation and plan reviews;*
- *views on availability, responsiveness, consistency and effectiveness of NDIS for people living in rural, regional or remote areas;*
- *experiences of availability, accessibility, cost and durability of NDIS services.”*

Of the 15 people who responded, 7 were located in rural, 2 in remote and 6 in regional Australia. They were located variously across all Australian States and Territories. Seven people identified with lived experience as a consumer/NDIS recipient, and six as a family/carer supporting someone applying for or accessing NDIS; two of the people who responded had or were currently working in roles connected with NDIS (engagement officer, recovery coach). People could choose to identify themselves or for their contributions to remain anonymous.

One person provided extensive feedback and has given permission for this to be included in its entirety within this submission (**Please see this attached at the end of this submission**)

### **a) The experience of applicants and participants at all stages of the NDIS, including application, plan design and implementation, and plan reviews**

We heard many comments about challenges at all stages of NDIS for people in rural areas.

One person described the many difficulties in navigating the various steps and stages of the NDIS process, given the nuances inherent in small communities where there are thin markets or no markets of providers available to adequately serve the need even when a plan is approved. This person had good knowledge of the system, but it still didn't seem to help them navigate the process effectively or get the right help to do so. As they said, they ended up doing much of it themselves. This is mirrored by Rhiannon (see their story at the end of this submission) who has described in significant detail the many hurdles experienced with the application process, and the sheer persistence and self-agency required.

The comments below also point to the vagaries of rural communities where issues of privacy and confidentiality are different to urban/metropolitan centres where there is more choice of NDIS workers and services. We know from previous evidence and also a current trial that we are involving in with rural communities, peer support and primary care that receiving support from individuals who also live in the same small local community can be problematic, given the many other community relationships and connections that are more likely to be embedded within small communities.

*I am the wife of and mother of NDIS participants. Prior to this, I was a community engagement officer for a LAC provider in my region. I was amazed at how difficult it was to access supports through the NDIS when my husband, and then later son, became NDIS participants. My husband joined the NDIS in 2018 and we are still 'establishing' supports for*

*him and are not entirely happy with them. We've ended up in court with an unregistered provider to get an intervention order after he came to our home and threatened me after we notified him we'd be no longer employing him due to inappropriate conduct. Support co-ordination does not help me. I end up doing all of the work anyway.*

Another person's comments point to problems with the quality of planners and delegates serving rural communities, and clear gaps in their understanding of the differing needs and circumstances for people living in rural communities. Several people have told us that there is little or no account of these differences, that the bureaucratic processes and people at the other end of the call sitting in urban offices are applying assumptions based on urban environments with their far greater level of available services and access which simply do not match rural environments.

*Appalling treatment by NDIS planners and delegates, lack of valid responses, ignorance to evidence provided. And as a provider and mother with lived experience the appalling treatment from the commission and the ECEi approach is a complete mess.*

The comments from the person below demonstrate just how much awareness, capability and knowledge of the NDIS system, and sheer persistence and capacity to drive the process themselves, in the absence of other services to support the application process, a person living in rural areas may need to navigate that NDIS application process. Their comments also suggest a high level of informal support and learning occurring among people in rural areas which would otherwise be available to applicants through formal paid services if they were located in urban/metropolitan areas. This issue is something that family carers, regardless of their location, experience as part of 'picking up the tab' when systems fail. We suggest that this is an even greater problem in rural areas.

*I have a vast amount of experience in applying for NDIS for myself and other community members in the Wheatbelt (regional WA). In addition, I have significant experience on the availability and quality of NDIS services and supports in the regions, both for myself and other community members. This includes on a personal, community and professional level as a community engagement officer in the regions. I was unsuccessful for my first NDIS access request so, for the second application, I completed the professional NDIS training with Richmond Wellbeing, and then facilitated and completed my own NDIS access request, accessing all my documents and past treatments through FOI, as well as letters with the essential terminology stated to assist in the success of the application. I have completed support sessions with other consumers applying for NDIS, where I have provided information on the needs of specific documents and wording in the NDIS application. I have also provided other community members with information on specific NDIS terminology, services available in the regions as well as funding information for consumer and family needs in the area of disability and mental health challenges.*

We also heard about the difficulties people in rural areas experience when having their NDIS application accepted but then struggling to action the plan and spend the monies allocated due to lack of available services to deliver the required support.

People also raised concerns about the structural inequity in how transport and travel is accounted for in the pricing rules for NDIS which do not fully account for people living in rural and remote communities. Some people may live well beyond the allocated 1 hour provided for travel; longer distances between NDIS services and NDIS recipients are commonly much more than this. For some, this leads to getting no service, settling for online options (which may be patchy, unreliable,

or simply aren't available to some), or creative measures by providers to account for the discrepancy in what can be billed. Tyranny of distance impacts across every aspect that is simply assumed for metropolitan NDIS services.

**b) The availability, responsiveness, consistency, and effectiveness of the National Disability Insurance Agency in serving rural, regional and remote participants**

Our 'friends' have told us about the problem of there being less availability and access to quality training and supervision for staff in services providing NDIS support in rural areas, either because of distance, technology issues, senior staff numbers and variety also being limited, and so forth. This includes the many people employed for their lived experience providing NDIS support, employed in high numbers within Community Managed Organisations with NDIS contracts, who are less able to access the Cert IV in Mental Health Peer Work and less likely to receive the Commonwealth supported access to this qualification that their urban counterparts.

A clear message we have heard is that city-based decision-makers have little or no understanding of the nature of rural communities, rural life and culture within rural communities.

We have also heard that health professionals providing core supports may be predominantly fly-in / fly-out workers not fully committed to living and working in rural communities, and therefore not as aware of the needs and nature of living in these communities.

People told us that face-to-face conversations rarely take place between coordinators, LACs, supervisors for support workers, and other staff involved in the planning, assessment processes, review of plans, or delivery of NDIS. This risks substandard understanding of the person's needs and preferences, and progress, leading to plans that are poorly matched to the person's actual preferred support. This disempowers people and works against the core principles of choice and control that NDIS is founded on.

**c) Participants' choice and control over NDIS services and supports including the availability, accessibility, cost and durability of those services**

The limited range of NDIS services available in rural areas has many impacts, as already stated. The ability to change provider, and indeed for providers to grow and develop based on open and transparent feedback if there are problems with the service provided, is significantly hampered. No-one living in rural communities wants to lose services. All infrastructure and services in rural communities are a vital resource, not just NDIS services. Therefore, there is greater potential for overcharging across many basic goods and services. There is also a greater risk of poorer service to go unchecked simply because any service is better than no service.

There is also the costs incurred that are unaccounted for for NDIS recipients and/or their family carers driving great distances to adjacent regional centres and metropolitan areas to source some services, simply because those services don't exist in their local area or because they feel unsafe to use them due to privacy concerns or other reasons.

There are also fewer options for changing workers for whatever reason, or for receiving quality coverage by alternative staff if workers have to take leave from their role,

We are also aware of the challenges with short-term funding contracts to NDIS providers such as Community Managed Organisations, many who have their central administration and main

workforces in metropolitan capital cities. The nature of these services, even in urban areas, is that the low paid support workforce is often tenuous with people moving between roles and jobs. This creates significant challenges for employers to recruit, train and retain their workforces. And this situation is exacerbated for rural areas where service contracts may be less attractive to providers because its all just too hard to deliver consistent services.

**d) The particular experience of Aboriginal and Torres Strait Islander participants, participants from culturally and linguistically diverse backgrounds, and participants from low socio-economic backgrounds, with the NDIS**

We know that rural areas have disproportionately higher representation of people who experiences greater socio-economic disadvantage due to differences in employment opportunities, food costs, transport costs, access to education opportunities, and so forth.

We know that rural areas are increasingly places where people from culturally and linguistically diverse backgrounds are choosing or being encouraged/required to locate. Rural Australia has a long history of welcoming people from many parts of the world to work, farm, and live. However, the issue of thin markets means that rural NDIS services may be even less likely to be staffed by people who have sufficient language skills or cultural competence to meet the needs of working in culturally appropriate ways with these groups.

We also wish to raise that we are aware of some experiences of prejudice and racism towards Aboriginal and Torres Strait Islander participants and participants from culturally and linguistically diverse backgrounds in some rural communities, predominantly as part of cultural factors that may be historical in the fabric of those communities.

**e) Any other related matters**

For NDIS participants in rural communities, their family and carers may be located further away (interstate or several hundred kilometres away). Therefore, they may have fewer informal supporters to assist them to navigate the NDIS application process, advocate for their needs and preferences, support plan management, monitor quality of services and support if there are problems with service providers, and so forth. In particular, there may be less support available to routinely monitor plan implementation, where this is an important part of family carers' role, and to respond to 'dodgy' provider practices. Self-managed plans may have significant family/carer input or indeed be a role that family/carers provide. Greater distances in rural areas make these processes more challenging.

The impacts of long-distance travel on the health and wellbeing of support workers is not currently considered.

For very remote communities, in particular, there is increased burden on the community and on families, carers and kin where thin markets and no markets are the norm.

Online support options rely on people having good access, good literacy and good connectivity, which is not the case for many in rural Australia.

Natural disasters disproportionately disrupt rural communities, including NDIS services. NDIS participants can go for long periods without their usual supports in place whilst services re-establish after natural disasters like floods or bushfires.

## Contact

We thank the Joint Standing Committee for the opportunity to put our views forward. We wish you well with the next steps and would be pleased to contribute our lived experience perspectives to any future discussions about this important topic.

Your sincerely

*Sharon Lawn*

Professor Sharon Lawn  
Lived Experience Australia Ltd  
Executive Director  
Email: [slawn@livedexperienceaustralia.com.au](mailto:slawn@livedexperienceaustralia.com.au)  
Mobile: 0459 098 772



**NDIS in the regional towns of Western Australia. Rhiannon Hudson's story of going through NDIS access declines after several brain surgeries since 2006.**



**Rhiannon's brave battle**

# I just want to hold my babies

I'd grown so attached to the twins I couldn't bear to be away from them

Rhiannon Hudson, 29, Atwell, WA

It's a strange feeling to me, but when I see the NDIS logo, I feel a mix of hope and despair. I just want to hold my babies.

When I was pregnant with my twins, I was told that I was at high risk of complications. I had to have several brain surgeries since 2006, and now I have a permanent disability. I want to be able to hold my babies, but the NDIS won't fund it.

I had to stay strong for my boys.

I don't want them to forget me, I told Peter.

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My first application for a NDIS request was back in 2020, to which I was declined. Coming from a long history of brain surgeries due to an ongoing brain tumour, which is the root cause of an acquired brain tumour, I made the assumption that with the letters from specialist stating all treatment utilised since 2006, an ABI diagnosis and several admissions into a public hospital would be sufficient. There were no services at this time to support myself in the wheatbelt to put together the Ndis application. The outcome of this application was a decline, which stated specifically "Rhiannon Hudson's application for NDIS has been declined due to not all treatment options been used and exhausted". This was absolutely gut wrenching, when I had been through three brain surgeries since 2006, many hospital admissions and significant impairments, and that this just wasn't enough to access services.

My thoughts at the time, how disabled to I actually need to be? How many more brain surgeries do I need? How much more of my brain do I have to get cut out to be classified as disabled in this state? who can actually help me apply for the Ndis? All these questions running through my head resulted in a deterioration in my health and giving up on applying for the NDIS.

A couple of years later, I was starting to really battle to afford supports to function at a medium level. As I had 10 years' experience as a Social Worker at the time, a Consumer Advocate in many different fields I decided to take it upon myself to complete training through Richmond Wellbeing remotely on "how to support consumers to apply for the NDIS. "

After the training was completed, I wrote down numerous notes on specific tricks on what the NDIS required for a successful NDIS application. I then contacted the Social Worker at Northam hospital, which I felt a bit funny about. I felt funny because I am a Social Worker (myself) and had been for many years.

I ended up talking to the Social Worker about what I needed for a successful NDIS application, to which I had learnt from the training. The Social Worker was amazing, she was honest and upfront about the challenges regional consumers with a disability are having with regards to applying for NDIS. She was also honest in saying that their service did not have capacity to complete an NDIS application themselves, however would do their absolute best to assist myself. I explained to her exactly what wording I needed, and she agreed to allow me to write the application with her support due to my knowledge and training completion. She then assisted me to have OT and speech to complete the assessments required in the supported evidence part of the application.

During this process, I did attempt to contact the services that are "funded to support consumers to apply for NDIS" to which I was unsuccessful. I then took it upon myself to continue the process, and wanted to put the hard work into it, as emotionally I did not feel I would cope with another decline stating "You have not exhausted all treatment options". I then contacted every single hospital I had been through and went through freedom of information to access all my records to evidence all the treatment options I had used and absolutely exhausted since 2006. I then went through my current GP and Psychologist and requested letters to state 1) what treatment I had completed 2) how long I had been accessing treatment 3) all treatment options had been used and exhausted 4) my disability impacted on all aspects of my functioning.

Thankfully, at the end of this process, I was successful. What an achievement that felt like. I am so thankful to the Social Worker and allied health team and Northam Hospital for providing this support. However, I would like to add without my professional knowledge, skills and expertise what chance did I have at getting onto the NDIS? What chance do thousands of people in the regions have at going through an exhausting and highly challenging process as I explained above? The process proved to me as a consumer we need a service in the regions that's prime role is to support consumers and families through this intensive process of applying for the NDIS.

Since getting on the NDIS, I found the first assessment by NDIS, "the planning meeting" to be very inappropriate for what people with disabilities in the regions need. The first planning meeting is on zoom, to which is very challenging due to the lack of people interactivity. This also takes away the human non-verbal communication, especially as many people with disabilities require alternative communication measures over verbal communication online.

Once my planning meeting was over, I was then left in the dark to where I go next. The worker who completed the planning meeting referred me to APM to do the next assessment on putting together all my support. I was then advised by NDIA that they don't service Dowerin, and again that APM do.

I was becoming so exhausted having to go between both services, none of which were able to support me in Dowerin, despite only being 77 km away, which in the regions is not a massive distance. I then decided to stop this fight for services and put down a rental property I had in the metro to access a service remotely in Perth.

All of these experiences having further reinforced to me the complex challenges many consumers and families impacted by disabilities face in the regions. We are talking about vulnerable people, who are the highest risk of so many different issues. Yet we have a lack of support and services despite the regions having the highest rate of risk.

My biggest passion as an individual with a lived experience of a disability in the regions is increasing support for people with disabilities. This includes developing a service that's prime focus is on assisting people to apply for NDIS. Then supporting people on the NDIS to navigate their services in the remote towns, this includes increasing services and resources available to people with disabilities in the remote towns.

Pictures below after my cranial surgeries and West Australian article 2006 and after graduating in 2012.

‘REPREHENSIBLE’ ACTIONS

# PM bashes banks for cutting jobs

Shane Wright  
Economics Editor

Julia Gillard has labelled the actions of the big banks in cutting staff and lifting interest rates “reprehensible” but the Reserve Bank has backed their claims of rising costs.

As signs continue to emerge that business conditions are improving, Ms Gillard used Parliament to launch her most strident attack against the big four.

The ANZ, Westpac, Commonwealth and NAB have lifted their standard mortgage rates by between 0.06 percentage points and 0.1 percentage points despite the Reserve keeping the official cash rate steady.

ANZ this week announced plans to slash 1000 jobs nationally by September, with unions estimating 2000 finance jobs have been axed since the start of the year.

Ms Gillard said that despite the burgeoning middle classes of Asia offering enormous opportunities to Australian banks, their most recent actions were disgusting. “The combination of putting your interest rates up, then announcing job losses and then seeking to blame it on someone else, both of those decisions on someone else, is reprehensible,” she said.

The Government claims the banks had no legitimate reason to increase their mortgage rates

outside the Reserve’s own decisions. But Reserve assistant governor Guy Debelle told a conference in Sydney there was no doubt borrowing costs for the banks had increased sharply.

“This global repricing of bank debt has clearly affected the Australian banks’ wholesale funding costs,” he said.

However, he also said there had been no real change to the Reserve’s own policy settings because of what the major banks had done.

Borrowers got some good news with the nation’s biggest credit union, CUA, announcing it would keep its standard variable rate at 6.72 per cent.



Tough years: Rhiannon Coggin has triumphed over great loss. Picture: Lee Griffith

## Graduate makes the grade against the odds

Volanda Zaw

To say the past five years have been tough for Rhiannon Coggin, 22, would be an understatement.

Diagnosed with a life-threatening brain tumour just before starting Year 12 at Leeming Senior High School, Ms Coggin had surgery over the holidays but returned to school on the first day of term. The risky operation to remove the 6cm tumour damaged her vocal nerves and inhibited her ability to swallow. Unable to speak for a year and fed through a nasal tube, she struggled through her high school work and secured a university place.

Following in her mother Debra’s footsteps, Ms Coggin chose to study social work at Curtin University. Two years into her degree, her mother was diagnosed with terminal cancer and died within six months.

Ms Coggin helped her father care for her four younger siblings, including her sister who was less than a year old when their mother died.

But she kept studying and will graduate next week, fulfilling a dream she shared with her mother.

“In the last few months of Mum’s life I was spending all my time with her at the hospice and sleeping there before waking up and going straight to university,” Ms Coggin said.

“There were times when I thought that I should defer my studies but Mum was very determined that I keep going.”

“She kept telling me how important it was to her. I think she would be really proud of me.”

Ms Coggin is a case manager for children in foster care.

“My line of work can be challenging but I often think about how Mum is with me in spirit,” she said.

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# News



Photo by Rhianon Coggins is looking forward to Year 12 as she recovers from a massive brain tumour. Photo by Gregor

## Rare brain tumour can't stop Rhianon

with a week she had contracted pneumonia and spent another seven days in the high-dependency unit.

The mother, Debra, credited Rhianon's recovery from the infection to dedicated staff but was worried for the young fighter.

"One night her heart was beating so fast and they just couldn't slow it down. It was 'read and go,'" Mrs. Coggins said.

The health team show the family from Glasgow, the mother said, Rhianon said the support of her twin brother and two younger siblings helped her through her time in hospital.

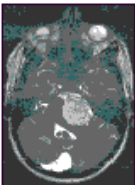
"It's all over dramatic too, they looked after me so well," she said.

Mrs. Coggins said that at a point, being told her daughter had a brain tumour was terrifying. "I thought about all the times Rhianon complained of a headache on her gym for some time. Thinking back, it was probably the tumour," she said.

Rhianon said her twin brother and two younger siblings helped her through her time in hospital.

"I started to lose my voice and I was reading a lot so they sent me for a scan just to check," she said.

The lab surgery on December 22 but her recovery did not go to plan.



This left A CT scan shows the tumour appearing as white areas.

## Whitbread prize for Spurling

London

Miss Spurling has won the Whitbread Book of the Year Award for her biography *Madness in the Mirror*.

The award was given to her by other authors to celebrate 2008.

The Oxford-educated author won the Whitbread Book of the Year Award for the best non-fiction book of the year, the second time she has won the award, having also won it for *Madness in the Mirror*.

Spurling thanked Miss G's grand children for granting her access to his archive.

"This book opened my eyes to what a brilliant man he was. It's amazing that the way a man's work, and yet a small life story."

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# \$8m work camp plan for illegal fishermen

## GEORNA TITILLON

The State Government plans to establish a work camp at a cost of about \$8 million to house fishermen caught poaching in WA waters.

Justice Minister John D'Orazio said yesterday a camp was needed to report to the expected influx of fishermen which Federal and State authorities estimate would reach one if the present rate of poaching in WA waters continued over the next year.

A work camp would also be built with one being proposed by the WA Government that would house the new poachers in jail.

It cost \$200,000 a week to house illegal fishermen in WA prisons but in fact being out at any one time would cost the State \$1 million a week and a new prison would cost \$150 million to \$200 million.

Mr D'Orazio said a work camp was a much cheaper option than a new prison and would allow poachers to be kept under close supervision.

"There are problems, certainly, but they're being managed for now but we don't want it to escalate."

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work camp because it was a Federal responsibility. However, the WA waters only covered when Federal authorities failed to capture illegal fishermen in coastal waters which are managed by national rather than WA's three coastal and inland waters.

The State would also seek to be compensated by the Commonwealth for the operational cost of containing illegal fishermen.

The new fleet, revealed in 7th April's budget, would include 100 new patrol boats for poachers estimated from two to five years and then to more up to \$150 million.

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