Experience of NDIS participants with Psychosocial Disabilities 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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Within the Mental Health Recovery lab embedded within CDRP, we have conducted a series of nationwide studies exploring lived experiences of the NDIS. Here we highlight our most recent learnings specific to those living and/or working within rural and remote regions of Australia.

We draw upon 3 pieces of work:

1. **National Mental Health Commission funded project (2022): Breaking down Barriers: Co-designed recommendations to reduce stakeholder identified NDIS access barriers for people with psychosocial disability**. Full report can be downloaded here

2. **Hamilton, D.E., Hancock, N., Scanlan, J.N., Banfield, M. (2020). The National Disability Insurance Scheme (NDIS) and people with severe and persistent mental illness / psychosocial disability: A review, analysis and synthesis of published literature. Australian & New Zealand Journal of Psychiatry. DOI: 10.1177/0004867420967747** (noting that lead author Hamilton is a lived experience research PhD candidate and an NDIS participant)

3. **Hamilton, D., Hancock, N., & Scanlan, J.N. (2023). Barriers to choice and control within the NDIS: Experiences of people living with psychosocial disability. Disability and Society. DOI: 10.1080/09687599.2023.2263629 (**noting that lead author Hamilton is a lived experience research PhD candidate and an NDIS participant)

A) National Mental Health Commission funded project (2022): Breaking down Barriers: Co-designed recommendations to reduce stakeholder identified NDIS access barriers for people with psychosocial disability.

This project included:

- Phase 1. A scoping review of literature to identify previously reported barriers to applying to the NDIS for people with psychosocial disability – used to inform phase 2 survey.
- Phase 2. A national survey to identify current, stakeholder informed and prioritised barriers.
- Phase 3. Co-design of practical, lived experience informed recommendations to address NDIS access barriers with stakeholders.

Full report can be downloaded here

PHASE 1: Reviewing the literature: Barriers to Applying for the NDIS

One theme and two sub-themes from this review are related to rural and remote communities as follows: Theme 1 Social inequities acting as barriers to applying: subtheme #1: geography – the more rural and remote the greater the barriers; and subtheme #2 : lack of culturally appropriate services and supports (as reflected in greater NDIS access barriers for Aboriginal and Torres Strait Islander people and culturally diverse communities).
A full peer-reviewed manuscript of this review is available here

PHASE 2. Stakeholder identified NDIA access barriers for people with psychosocial disability

Barriers were informed by 386 stakeholders. These included workers attempting to support people to apply for access to the NDIS (W); people who identify as having a psychosocial disability and are attempting top apply to access the NDIS (P) and family members trying to support people with psychosocial disability to access the NDIS (F). Participants came from across all states and territories and 13.5% (n=52) of these identified as living or working in rural, regional or remote areas.

The findings that are pertinent to rural and remote communities are pasted below (with report page numbers provided):

2. Hard to get supports to help to apply - formal (services) and informal (family and friends)

a. Hard to find or access supports (exacerbated if living in rural, regional or remote areas)
Page 36

Both people themselves and workers repeatedly highlighted how hard it can be for some with mental illness to access formal mental health supports or services that they need to help them to navigate the process required to apply for the NDIS. Barriers to accessing this support were greatest for **those who were not already connected with mental health services and supports**. Barriers included a **lack of mental health services available –** particularly, but not only for people living in rural, regional and remote areas.

For others, while services did exist, there were again, **long waiting lists** to being accepted by the service and thus being able to access support.

> Sample quotes (note. W = worker assisting applications for NDIS; P = person and or family trying to apply for NDIS access):
>
> *"I also can't find any advocacy groups near me who are willing to assist" [P093]*
>
> *"Limited resources to assist in NDIS applications… our waitlist alone is 6 months long" [W081]*
>
> "*And services that could help, put you on a waiting list that can take weeks and months" [F048]*
>
> *"Not supported enough with the process" [W196]*
>
> *"I don't know where to look for support" [P085]*
>
> *"lack of appropriate supports in remote locations" [W057]*
>
> *"limited support to understand process" [F036]*
>
> *"Not everyone has a Support Coordinator … who will be able to gather medical evidence and know the pathways to joining the NDIS" [W070]*
>
> *"Many people with psychosocial disability do not have access to or are not eligible for services to assist with application process" [W015]*
>
> *"not enough direct worker support purely for NDIS access" [W034]*
>
> *"lack of support to complete applications" [W053]*
>
> *"Not enough services funded to complete NDIS applications" [W061]*
>
> *"nobody to support them through the process" [W119]*
>
> *"Limited support network to support to complete the application" [W167]*
>
> *"No organisations that will help with application process" [W196]*

> *"No support/funding for them to go through the application..."[W206]*
>
> *"Inability to access services that support an application" [W207]*
>
> *"Many people with mental health issues cope by themselves because they don't qualify, or can't afford help, or can't find any help especially in regional and remote areas and so can't get the evidence they need - catch 22" [W161]*

3. Hard to obtain evidence required by the NDIA
Page 41-42

a. Hard to access experts to obtain evidence of impairment and psychosocial disability (exacerbated if living in rural, regional or remote areas)

The difficulty accessing an expert who was able and prepared to do an assessment and provide the expert evidence of the person's psychosocial disability was a frequently reported barrier. Experts included clinicians, GP's and psychiatrists. Some respondents describe the **lack of any available experts** – **particularly for those living in rural and regional areas**. Others described **long-waiting lists** and thus the extended time it took for people to get an appointment, particularly for people not currently connected with or using expert or clinical mental health services and**, again, for those living in rural and regional areas.** Finally, many people described potential **experts being unwilling to provide evidence** for various reasons including the lack of adequate government funding for the time required.

Why are some experts unwilling to help? One reason provided for expert or specialist lack of willingness to do the assessment and report was the **lack of adequate funding through Medicare to cover the extended appointment time**/s that would be needed. Some said that they **lacked an understanding of their client's needs and or the NDIA requirements**. Others said that witnessing or hearing of **others being rejected even with evidence provided** deterred some experts from being prepared to assist.

In addition to these barriers to accessing expert evidence, **people who were too mentally distressed to leave their homes and people in prison services** both faced additional barriers to accessing experts to obtain evidence of their psychosocial disability.

Sample quotes:

> *"I don't currently have a psychiatrist or psychologist I trust and who understands me" [P095]*
>
> *"Difficulty getting doctors etc to support the application" [F043]*
>
> *"Mental health professionals can also be reluctant to help with applications when they have seen or heard of other applications being rejected" [W129]*
>
> *"Person unable to leave unit, therefore can't access treatment or proof that they need NDIS help" [F014]*
>
> *"The government also needs to pay additional attention to rural areas that experience limited specialist services and inconsistent GP availability" [W009]*
>
> *"Psychiatrists saying that it is not their job to support the application and that it should be done by and Occupation therapist" [F043]*
>
> *"limited access to medical supports/reports to provide evidence of condition/diagnosis" [W190]*

“Specialists refuse to fill out forms” [P053]

“Finding specialists to complete assessments not easy” [W202]

“Most do not have access to a regular GP who can fill out the NDIS forms correctly and understand their client’s needs” [W212]

“In the current Covid climate it is near impossible to see cost-effective psychiatrists/ psychologists without waiting a protracted period” [W172]

“treating doctor refuses to provide evidence or does not respond to request for evidence” [W113]

“GPs that deny their responsibility to assist with the supporting evidence” [W155]

“The main things stopping them from applying is lack of support from their psychiatrist and the fact that their psychiatrist does not understand what the NDIS is or how best to support my friend” [F030]

“my Psychiatrist treats me as if they don't have the time to complete an application” [P024]

“People with psychosocial disability in prison are significantly less likely to have access to medical services/information/reports needed to meet strict eligibility criteria” [W015]

“Conflicts with Medicare requirements (some MH professionals say they can only continue to claim Medicare benefits if the client is improving, and therefore will not say the client's functional impairments are permanent)” [W132]

“getting a client a psychologist which regionally can have a waiting list of months” [W055]

“GPs that deny their responsibility to assist with the supporting evidence. They state they do not get "paid" (Medicare rebate) for the time it takes to complete paperwork” [W155]

“Also, the GP and Psych's that support be don't really understand it so how can they help when the NDIA doesn't really support them” [P046]

“There is also a large gap in finding practitioners who are willing to support with bulk billing NDIS access reports. This needs to be a Medicare-funded item.” [W126]

“needing medical psychological assessments. Waiting time for specialist appointment” [W199]

“The evidence needed is often hard to obtain” [W200]

7. The negative reputation of NDIA staff and culture

b. Staff are not respectful and lack empathy
Page: 56

Respondents reported that people had directly experienced **disrespectful and non-empathetic interactions with staff** and for some this had led to or contributed to them withdrawing from the process of applying. Others had heard about these negative interactions with NDIA staff from the **recounts of others** and this contributed to them not applying for the Scheme. Some said that staff sometimes **treated personal information in disrespectful ways** and breached people’s privacy.

Sample Quotes:

“Staff need to have empathy and people skills. I cannot speak for other NDIA offices only the one I deal with” [W075]

“Lack of empathy towards people with psychological disorders” [W154]

> *"I have seen countless breaches of privacy, and inappropriate and disrespectful conversations, and it concerns me to think that I would be seen in that light" [P024]*
>
> *"paternalistic attitudes to deal with – no real understanding of the problems in relation to trying to have a social life for person with p.schiz. as well as other aspects of her illness" [F025]*
>
> *"Please find a way to make it better, easier for them to be seen as a person, a human being; not just an NDIS number to file away and provide them the help and funding and services that they need to 'live the life'; the life that many of us can take for granted at times" [W149]*
>
> *"Staff at NDIA (in my rural town experience) can be condescending towards people and can become easily frustrated with clients. This is so annoying to see and hear. Staff need to have empathy and people skills. I cannot speak for other NDIA offices only the one I deal with" [W075]*
>
> *"I do not trust that my information would be handled sensitively or with due respect" [P024]*
>
> *"Fear of disclosure of information" [W087]*
>
> *"I also know that the way that staff at the NDIS in particular (to a lesser extent, partner organisations) treat and view mental illness" [P024]*
>
> *"having to share their story repeatedly to bureaucrats who have no empathy" [F013]*
>
> *"NDIS appears so impersonal to my Participants" [W149]*
>
> *"Last year on a 3 week visit to me, my son agreed to go to the NDIS office at [regional location] because he realises that he needs help and support. THIS WAS OUR EXPERIENCE: Behind the counter were two women [staff] sitting down chatting. There was no one else in the office. My son and I stood in the line to speak to an NDIS Representative. One of the women asked what we wanted. Son, [who is 47yrs] was overwhelmed even with the question. After a time when I could see he was struggling, I stepped forward and said 'My son is here to see about an application for the NDIS'. Both women almost in one raised voice said: 'Oh no it's not that easy you probably won't be eligible'. Said in raised voices, my son immediately panicked, turned to me and started yelling at me saying 'I told you this is no good' – and turned his back to walk out of the office which he did, then furious with me. The women's shocked faces told me their reaction to my son's outburst….they sat with their mouths open. I then said to them, 'My son has been entitled to receive NDIS for 4 years or more...it has taken me that long to get him into an office to apply'. Neither woman said a word." [F049]*

10. It is not worth the effort – NDIS won't meet my needs anyway
Page: 65

There were many respondents who said the people were not applying for the NDIS because they didn't believe that if they were eligible, an NDIS plan would meet their needs. There were two overarching reasons given for this: a) My plan would not include the things that I need, and b) I would not be able to use my plan because services do not exist or there is not enough money to cover service costs. Both are described below with sample quotes.

b. I would not be able to use my plan because services do not exist or there is not enough money to cover service costs

A number of respondents, **particularly those from rural and regional areas**, said that people believed that even if they did get the things that they needed and wanted in their plans, that there would be **barriers to them being able to actually use or 'activate' the plan**. These barriers were: 1.

that there are **not services available to provide aspects of the plan** (‘thin markets’), and 2. that even if there were services, that the **funding within their plan would be insufficient** to meet the service costs.

Sample Quotes:

> *“lack of appropriate supports in remote locations” [W091]*
>
> *“The lack of services in regional areas is a deterrent, why bother applying for services that don't exist” [W071]*
>
> *“Besides when they give barely any support or funding, is it even worth it? It's such a big fight to get it, and I probably won't even get the help I need” [P043]*
>
> *“a lack of services even if a package could be applied for” [W091]*
>
> *“Biggest barrier in rural areas... the lack of services and professionals should a package be made. Essentially it makes the NDIS redundant the majority of the time” [W091]*
>
> *“The government also needs to pay additional attention to rural areas that experience limited specialist services and inconsistent GP availability” [W009]*
>
> *“It is left to market forces to function” [W096]*
>
> *“Thin Markets is one of the main reasons and the lack of services to rural and remote communities” [W052]*
>
> *“Lack of mental health trained NDIS supports in regional and remote areas” [W208]*

PHASE 3. Solutions proposed by stakeholders to address NDIS access barriers for people with psychosocial disability

Details of the process and more detail regarding these stakeholder proposed solutions are provided within the report. All of these are relevant to people living in rural, regional and remote areas.

THE RECOMMENDATIONS

Seven recommendations were identified, reviewed and refined by stakeholders. These recommendations are practical, lived-experience informed actions to address NDIS access barriers faced by people living with psychosocial disability.

1. Build, maintain and disseminate accurate, up-to-date, easily accessible information - Update, enhance and build upon best currently available information. Invest in and maintain the update of a single national source of information. Enhance the dissemination of this information including easy read downloadable one-pagers that can be printed and paper-based fliers to maximise accessibility.

2. Co-develop and co-deliver systemic training and establish workforce support champions – Co-develop and deliver continually available training for health and community service providers. GPs, public, community and private mental health, disability and social services require ongoing access to training about the psychosocial stream of the NDIS. Workforce support champions will provide expert support and guidance to complement this training so that workers can provide accurate and helpful support, advice and evidence to people who are considering or are applying for the NDIS.

3. Establish navigator positions – independent and psychosocial specific - Create a clear, independent NDIS Psychosocial specific Navigator role to assist individuals, family members and service providers throughout the NDIS application process.

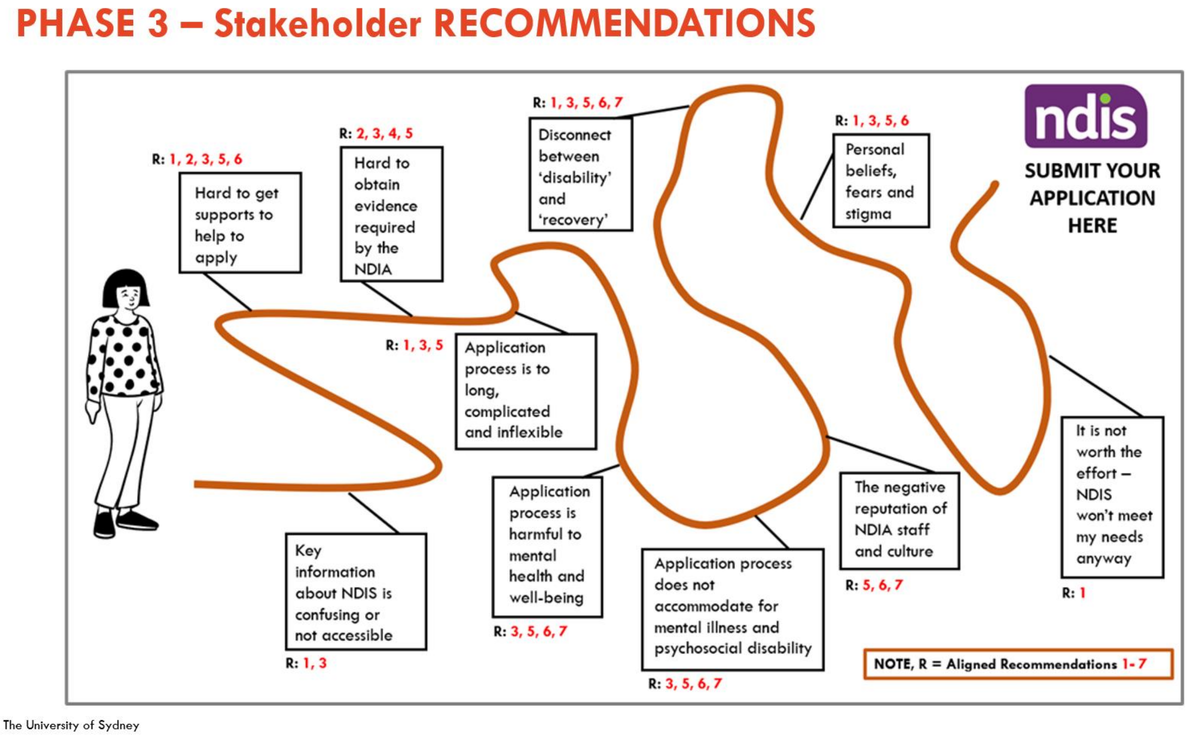
4. Cover out-of-pocket expenses - Create funding streams or models of reimbursement to ensure that people have equitable access to the experts required to provide evidence of psychosocial disability without incurring out-of-pocket expenses.

5. Commission and fund an independent evaluation of the application process specifically for people with psychosocial disability - Independent evaluation of the impacts of: a) recent legislative changes; b) the future implementation of the Recovery Framework; and c) adoption and future implementation of the recommendations within this report, on the experiences of the NDIS application process for people living with psychosocial disability.

6. Co-develop and co-deliver recovery and psychosocial disability training for a. NDIA staff, b) NDIA partner staff (Local Area Coordinators - LACs), and c) NDIS service provider staff (community managed/controlled organisations) - All staff within these 3 distinct workforces need to have access to recovery-oriented, trauma-informed psychosocial disability training and education that is co-developed and co-delivered with people with psychosocial disability.

7. Commission and fund an independent review of NDIA culture and workforce issues - Review the impact of implementing the NDIS Psychosocial Recovery-Oriented Framework agenda on NDIA staffing practice and cultural issues.

Below is a presentation slide in which stakeholder recommendations (Phase 3 – numbers 1-7 in red) are aligned to stakeholder identified barriers (Phase 2 – black text in boxes)



PHASE 3 – Stakeholder RECOMMENDATIONS

R: 1, 2, 3, 5, 6
Hard to get supports to help to apply

R: 2, 3, 4, 5
Hard to obtain evidence required by the NDIA

R: 1, 3, 5, 6, 7
Disconnect between 'disability' and 'recovery'

R: 1, 3, 5, 6
Personal beliefs, fears and stigma

ndis
SUBMIT YOUR APPLICATION HERE

R: 1, 3, 5
Application process is to long, complicated and inflexible

It is not worth the effort – NDIS won't meet my needs anyway
R: 1

Key information about NDIS is confusing or not accessible
R: 1, 3

Application process is harmful to mental health and well-being
R: 3, 5, 6, 7

Application process does not accommodate for mental illness and psychosocial disability
R: 3, 5, 6, 7

The negative reputation of NDIA staff and culture
R: 5, 6, 7

NOTE, R = Aligned Recommendations 1-7

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B) Hamilton, D.E., Hancock, N., Scanlan, J.N., Banfield, M. (2020). The National Disability Insurance Scheme (NDIS) and people with severe and persistent mental illness / psychosocial disability: A review, analysis and synthesis of published literature. Australian & New Zealand Journal of Psychiatry. DOI: 10.1177/0004867420967747

The full paper is available here and findings are pertinent to this review:
This scoping review synthesises the early NDIS literature (up to 2019), coded the literature into themes and then organised these themes into NDIS Strengths, Weaknesses, Opportunities and Threats

We draw your attention to the Table in the results: Table 1. Thematic analysis of literature (SWOT: strengths, weaknesses, opportunities and threats).

All findings are relevant to this inquiry, with identified strengths, weaknesses, opportunities and threats identified being as pertinent now as they were in 2020. Below we will highlight a few passages that speak directly to rural, regional and remote contexts:

Page 5: "There was a noteworthy absence of literature representing the lived experiences of those in rural/regional/remote settings, Aboriginal and Torres Strait Islander, LGBTQIA and linguistically diverse people, despite the unique and additional needs of these communities (Heneker et al., 2017; Kaplan and McGrath, 2018; Smith-Merry et al., 2018; Somerville et al., 2017)."

2 identified threats (page 7):

- That, without access to strong advocacy, the interests/needs of people with PSD will not be fully recognised under the NDIS. The risk increases for Aboriginal Australians, people in rural and regional communities and those with co-occurring complexities
- That lack of or limited availability of services and resources will limit NDIS participants' ability to exercise choice and control in actioning their plan. This is particularly the case for people living in rural and regional communities

Page 9: "Additionally, many publications spoke of a multitude of threats to the community-managed mental health system, including loss of qualified staff, casualisation, threats to financial viability, lack of access to services for rural and remote communities and loss of services for individuals not eligible for NDIS (Furst et al., 2018; Malbon et al., 2019; Rosenberg et al., 2019).

C) Hamilton, D., Hancock, N., & Scanlan, J.N. (2023). Barriers to choice and control within the NDIS: Experiences of people living with psychosocial disability. Disability and Society. DOI: 10.1080/09687599.2023.2263629

This full paper is available here

Twenty people on the NDIS were interviewed in-depth about their experiences of choice and control within the NDIS. This paper reports on the barriers experienced (a manuscript currently under review reports on the enablers). Of the 20 participants, six lived in regional areas and one in a rural area. Additionally, two people had recently moved, one from metropolitan to regional and one from regional to metropolitan.

As with the work above, all of the barriers identified within the thematic analysis are barriers (and often exacerbated barriers) for those living outside of major city centres.

The barriers identified and detailed with quotes within this publication include:

- ***Systemic and procedural factors impeding choice and control***
- ***Rigidity;***
- ***Complexity of information and procedures;***
- ***Opacity;***
- ***NDIS systemic disorganisation and Inconsistencies;***
- ***Powerlessness: 'They have the power';***
- ***Limited available options***

“Ben, from a non-English background, said ‘I don’t have a psychologist. And I have to find one. And it’s very hard to do. [They are] not [from] your local, your tribal… So that means for us… that the services are limited’. Blair moved to a regional setting: ‘There are not many services out there that really offer psychosocial support… particularly in my area’. “ (page 14)

- ***Lack of accommodations to support choice and control***
- ***The fluctuating nature of psychosocial disability***
- ***The impact of anxiety***
- ***Dissociation and other effects of past trauma***