National Regional, Rural, Remote and Very Remote Community Legal Network

The Hon. Libby Croker MP, Chair
Joint Standing Committee on the National Disability Insurance Scheme
PO Box 6100
Parliament House
Canberra ACT 2600
15 May 2024
By email: ndis.joint@aph.gov.au

Dear Ms Croker

Response from the National Regional, Rural, Remote and Very Remote Network ('4Rs Network') to question on notice regarding the proposed new Disability Rights Act by Senator Steele-John at the Committee's hearing in Darwin on Tuesday 16 April 2024

Thankyou on behalf of the 4Rs Network for the opportunity to appear before the Committee in Darwin on 16 April 2024 to speak to and answer questions in relation to the Network's written submission dated 8 March 2024 (submission 82 published by the Committee).

This is to respond to the two questions on notice by Senate Steele-John which are stated below, with our response.

1. Wait times for access to assessments or specialists in relation to NDIS applications

Question 1:

Would you be able to provide the committee with any data or case studies that you are aware of or possess in relation to the wait times that people experience to access assessments or specialists in relation to NDIS applications? I want to get a clear idea of what people are facing at the moment in relation to accessing those services that are necessary to be able to make a successful application or engage in a successful review.

1. From experiences among services focusing on the NDIS in the 4Rs Network, the issue of wait times for access to assessments and specialists in relation to NDIS applications and establishing the first plan, is pervasive.

2. Wait times are generally substantially longer and intersect with other barriers including, but not limited to, understanding of the NDIS, the administrative and logistical burdens of the access process, distance, and cost. [1]

3. NDIS Participant Service Guarantee Timeframes are helpful in indicating timeframes from certain NDIS decision points (see example below),[2] but these do not indicate the wait times for the person with disability in relation to access and establishing the first plan or how this varies between urban and 4Rs areas.

4. Experiences indicate that waiting times have blown out since the NDIA has implemented PACE. For example, it is not unusual for there to be a wait of 2-3 months for a planning meeting, once access has been granted.

[1] Also see the following research: John Gilroy et.al. 'Disability workforce and the NDIS planning process in regional, rural and remote regions of Australia: Scoping review (2023) 31 *Australian Journal of Rural Health*', 839–854 open access: .https://doi.org/10.1111/ajr.13020 Damian Mellifont et. al, (2023) Barriers to applying to the NDIS for Australians with psychosocial disability: A scoping review. (2023) 58 *Australian Journal of Social Issues* 262–278 open access: https://doi.org/10.1002/ajs4.245

[2] NDIS, NDIS Quarterly Report to disability ministers, December 2023, p. 105 online at: https://data.ndis.gov.au/reports-and-analyses/quarterly-report-supplements with national and jurisdictional trends against these measures in Supplement E National Statistics and Supplement R 'Access decisions and first plans'

Examples of NDIS Participant Service Guarantee Timeframes

Table D.31 Participant Service Guarantee Timeframes (% guarantees met) for the quarter ending 31 December 2023 [39] [40] [41] [42] [43] [44] [45]

PSG	Service Guarantee	NSW	VIC	QLD	WA	SA	TAS	ACT	NT	NAT
1. Explain a previous decision, after a request for explanation is received	28 days	98%	98%	98%	93%	94%	100%	100%	100%	**97%**
2. Make an access decision, or request for more information, after an access request has been received	21 days	100%	99%	99%	100%	100%	100%	99%	100%	**100%**
3. Allow sufficient time for prospective participants to provide information, after NDIA has requested further information	90 days	100%	100%	100%	100%	100%	100%	100%	100%	**100%**
4. Make an access decision, after more information has been provided.	14 days	91%	90%	91%	87%	92%	80%	93%	97%	**91%**
5. Commence facilitating the preparation of a plan, after an access decision has been made	21 days	97%	94%	95%	96%	94%	2%	99%	79%	**95%**
6. Approve a participant's plan, after an access decision has been made (excludes those ECA that have received initial supports)	56 days	96%	93%	93%	92%	93%	77%	97%	72%	**93%**
7. Approve a plan for ECA participants, after an access decision has been made	90 days	99%	98%	94%	95%	98%	100%	100%	91%	**97%**
9. If the participant accepts the offer, hold										

5. Regarding data or case studies that we are aware of about wait times for access to assessments or specialists in relation to NDIS applications:

5.1 Regarding data, it may be useful for the Committee to request available data and analysis from DSS regarding the National Disability Advocacy Program, especially:

- time periods from the first support session related to a person wishing to make NDIS access up to achievement of NDIS access, and
- grouped and compared by client location.

5.2 Whether this is (or could be) reflected in the design of indicators for internal monitoring and external (public) reporting.

5.3 Some other data sources / indicators are:

Deloitte *Evaluation of the Decision Support Pilot – Final Report Department of Social Services* June 2023[3]

> "**3.2.1.3 External barriers to the achievement of NDIS outcomes**
> It is important to note that the Pilot's ability to support clients with their NDIS process goals was limited by the following external factors:
>
> • **Client financial barriers to obtaining evidence to inform an NDIA Access Request**. Clinical evidence to inform a NDIS Access Request requires out-of-pocket payment to an occupational therapist to perform a functional assessment. Some clients also required reports from other medical specialists, such as psychiatrists and neurologists.
>
> • **Timely access to clinicians to provide the necessary evidence and reports to inform a NDIS Access Request**. This was a particular barrier in remote areas. For some clients, waitlists for medical specialists were several months…." [4]

National Workforce Census by National Disability Services, which as indicated in the August 2022 article '*New report shows critical need for allied health workers, as wait lists grow across the country*', permits analysis of geographic patterns including more severe shortages in

[3] Deloitte *Evaluation of the Decision Support Pilot – Final Report Department of Social Services* June 2023, online at https://www.dss.gov.au/decision-support-pilot-evaluation-report
[4] Ibid, p. 32

remote areas.[5] Survey findings from the 2024 Workforce Census are due to be released on 5 June 2024.[6]

Media reports, such:

- Natasha May, 'How can I help myself to help him?': the rural NDIS waiting game, *The Guardian*, 6 May 2022,[7] and

- Morgan Lolitta 'RACGP - Why fixing 'two-tiered' NDIS is a priority' *GP News*, 7 March 2024[8] reporting on submissions by the Royal Australian College of General Practice

6. Regarding case studies, these are pervasive relating to problematic wait times for assessments and specialists for NDIS access applications for people with disability in regional, rural, remote, and very remote areas. It is also clear that active facilitation in 4Rs areas, including in remote and very remote areas is essential. [9]

7. In relation to NDIS access this includes requirements for the access application and if unsuccessful, review and appeal. The NDIS often asks for specific issues to be addressed in assessments and this can cause repeated and lengthy delays in trying to obtain the further assessments in response.

8. NDIS process often present the person seeking NDIS access with more and more requests. This can result in dilemmas to the effect that it is up to them whether they wish to obtain the further assessments in support of their application, the implication being that it will be unsuccessful otherwise. This is particularly difficult at the AAT stage, where the NDIA raises issues and casts doubts which may not be shared by the AAT at hearing. This often places applicants under additional pressure due to the time factors and delays involving further assessments.

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[5] National Disability Services, 9 August 2022, the article is online at: https://www.nds.org.au/news/new-report-shows-critical-need-for-allied-health-workers-as-wait-lists-grow-across-the-country

[6] https://www.nds.org.au/resources/all-resources/nds-workforce-census-key-findings-report

[7] Outlining the experiences of Mr James Button and his mother Fiona Steele, in Maningrida. https://www.theguardian.com/australia-news/2022/jun/18/how-can-i-help-myself-to-help-him-the-rural-ndis-waiting-game?

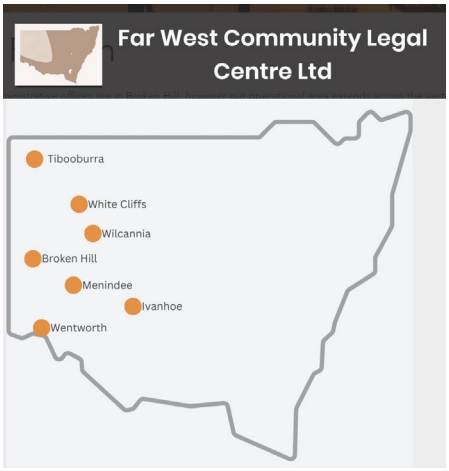
[8] RACGP - Why fixing 'two-tiered' NDIS is a priority

[9] As demonstrated by the Kimberley Access Program: Caitlyn S White et al., 'Equity in Access: A Mixed Methods Exploration of the National Disability Insurance Scheme Access Program for the Kimberley Region, Western Australia' (2021) 18 (17) *International Journal of Environmental Research and Public Health*, 890 open access: https://www.mdpi.com/1660-4601/18/17/8907

9. Below is the Far West CLC case study from the 4Rs Network submission followed by further case studies.

Case Studies

Far West NSW – waiting time and travel for assessment



A1.1 Far West Community Legal Centre Ltd

P 39 4Rs Network submission (submission 82)
Our main administrative offices are in Broken Hill, however our operational area extends across the vast west of NSW, from Tibooburra in the north to Wentworth in the south and Wilcannia and Ivanhoe in the east. We conduct regular outreach activities to provide support to communities of the far west. This map shows the main population centres we serve.
(https://www.farwestclc.org.au) In our region, there are a lack of specialists, even in Broken Hill and to get diagnoses, people will have to travel extraordinary distances - e.g. to Mildura or even Adelaide. For individuals and families on a low income, this is very challenging. We are aware of some parents who have tried to get their child assessed for autism but have had to travel long distances for multiple appointments and are still left with lengthy wait times. Even if they are able to access funds to finance travel, it doesn't cover all out-of-pocket expenses or meet full costs of accommodation etc.

Wait times and costs in South Australia

With regards to wait times in South Australia, for access requests, anecdotally, Autism SA has a waitlist of up to 12 months of assessment and the cost is approx.$1800. The wait time for a free assessment through the Women's and Children's Hospital specialist team is about 3 years. Additionally, it is not just wait time or availability of practitioners to undertake the assessments but the cost of the assessments that are barriers to access.

Wait times for assessment by positive behaviour support practitioner in South Australia

As indicated during evidence on 16 April 2024 by Cheryll Rosalles, Disability Advocacy Service, South Australia (Hansard p. 13), the waiting time is about 12 to 18 months for an assessment positive behaviour support practitioner in South Australia across the state, including in metropolitan due to a shortage of qualified and well-regarded practitioners.

Access and the AAT delay due to assessment requests by NDIA – case study

- Person has applied for access to the NDIS for a physical disability and psychosocial disability. The NDIA is not satisfied that they meet the requirements for substantially reduced functional capacity or that they have exhausted all medical treatment options. The matter is now at the AAT.

    - It takes 6 weeks to attend a first conference. The respondent's position is discussed at that first conference and the applicant agrees to provide further materials. Amongst other things, further letters from their treating specialists are provided (six weeks for applicant to provide and three weeks for respondent to consider).

    - A second case conference is held where the respondent is not satisfied that the applicant meets access criteria, and they suggest that targeted questions are answered by treating specialists. The applicant agrees to ask their specialist to answer these questions, but first the applicant must request a quote from the specialist as the NDIA have to approve the quote, as they have agreed to pay for the further questions to be answered (pending approval of a quote). It takes six weeks to provide the answers to the targeted questions and three weeks for the respondent to update their position.

    - A third case conference is held, and the respondent suggest issuing summons for past treatment history. The applicant agrees, and this process takes approx. 15 weeks. Two out of the three medical practices summonsed respond. It takes a further three weeks for the respondent to provide an updated position.

    - At the fourth case conference Respondent then requests an independent OT do a functional capacity assessment and an independent psychiatrist do an assessment. It takes six weeks to schedule, four weeks for each of the reports, and three weeks for the respondent to provide an update to their position.

    - 14 months to that point before the AAT.

Other examples of delays involved assessments (not relating to NDIS access)

Reviews at the AAT (three case examples)

- A participant at the AAT, with a matter ongoing for 18 months. The NDIA has requested a continence assessment (at the last conciliation conference). The wait for that assessment is 12 weeks with a report to be ready 3-4 weeks after the assessment.

- A participant at the AAT, with a matter ongoing for 6 months now, it took 8 weeks to schedule a behaviour support practitioner with the interim BSP ready 6 weeks later.

- Instances of participants who are at the AAT, who have been working consistently with an Occupational Therapist (OT), who have been requested to get an updated functional capacity assessment (FCA) and the OT has refused to complete the new FCA as they were too busy to take on such detailed work. We then needed to find different OT's to complete the FCA. The disadvantage was that the new OT did not have the same background knowledge as the OT who had been working with the participant.

2. Wording for rights inclusion of people in 4Rs areas in the proposed new Disability Rights Act

Question 2:

For the 4Rs alliance, in your submission, at recommendation 3, you talk about the need for the rights of folks in 4Rs communities to be explicitly mentioned within a disability rights act. I'd be really interested to know what kind of specific language or clauses within that proposed act you would like to see.

Regarding Senator Steele-John's question about the specific wording or clauses that the 4Rs Network would like to see in the proposed new Disability Rights Act, we greatly appreciate this question which follows on from Recommendation 3 in the Network's submission namely:

> **Recommendation 3: new Disability Rights Act and 4Rs location**
> The rights of people with disability in regional, rural, remote and very remote areas should be made visible in the proposed federal Disability Rights Act.

2.1 Background

Section 2 of the Network's submission 'Human Rights and Systems Failures for People with Disability in the 4Rs' (included at Attachment 1):

- outlines failures relating to the human rights of people with disability in 4Rs areas, and
- highlights the opportunity presented by the proposed new Disability Rights Act. This is an opportunity to make the rights of people with disability in 4Rs areas visible.

2.2 Wording regarding people with disability in 4Rs areas

The following wording is proposed for inclusion in the proposed new Disability Rights Act having regard to fundamental principles of equality and non-discrimination.

The drafting should reflect the problems to be overcome and the rights to be ensured. This means drafting intended to help:

- Address and overcome practices of non-inclusion and discrimination experienced by many people with disability in 4Rs areas.
- Ensure the rights of people with disability in 4Rs areas.
- Ensure people with disability in 4Rs areas are not subjected to adverse discrimination, including based on their 4Rs location.

2.2.1 Preferences about terminology

Preferred terminology is 'regional, rural, remote or very remote area' (all specified). For example:

- 'people with disability in regional, rural, remote or very remote areas'

This is:

- Preferable to 'place of residence' alone which would be economical but would not serve the purpose of making geographic areas visible, or the specific purpose of making regional, rural, remote and very remote areas visible.

- Preferable to 'rural' alone which would also be economical but would not make remote, very remote and regional areas visible.

- Preferable to 'regional, rural and remote' which would not make very remote areas visible.

'Regional, rural, remote, very remote'

- Reflects the range of the locations to be made visible and helps reflect that there can be substantial differences between each of the four, including between remote and very remote areas.

The word 'in', is:

- Preferable to 'resides in' because 'in' is broader than 'resides in' or 'whose place of residence is in.'

2.2.2 Preamble

If there is a Preamble in the new Act:

- Include visible reference to people with disability in regional, rural, remote, and very remote areas, and

- Ensure the drafting achieves the intended backdrop for the rights contained in the Act to apply equally to people with disability in regional, rural, remote and very remote areas.

For example, the wording in the Preamble might be:

- 'Recognising the human rights of people with disability [among visibly listed inclusions, *include*:] 'including people with disability in regional, rural, remote and very remote areas',

2.2.3 Geographic definitions

Geographical definitions should reflect the ABS Remoteness Structure:

- Inner Regional
- Outer regional
- Rural
- Remote
- Very Remote[10]

This is consistent with Commonwealth legislative usage. For example:

> **Higher Education Support Amendment (2022 Measures No. 1) Act 2023 No. 3, 2023**
>
> Division 144—Special measures for location-preferred HELP debtors—health practitioners
>
> 144-1 Meaning of *location-preferred HELP debtor (health practitioner)*
>
> 114(1)(f)

[10] Applying the Australian Bureau of Statistics Remoteness Structure, Australian Statistical Geography Standard (ASGS) Edition 3, Reference period, July 2021 - June 2026 (updated by the ABS on 21/03/2023).

f) the work is carried out in an area specified by the Guidelines, by reference to the *ABS Remoteness Structure, as **a rural area, a remote area or a very remote area** for the purposes of this paragraph

Health Insurance Act 1973 (Cth)

Interpretation s.3

"eligible location" means:

(a) an area prescribed by the Bonded Medical Program rules as a regional, rural or remote area; or

(b) an area prescribed by the Bonded Medical Program rules as an area of workforce shortage.

" Rural Health Minister" means the Minister responsible for health in rural, regional or remote areas.

S.23DU – Remote areas

Remote areas

The Minister may, by legislative instrument, determine which areas within Australia are taken to be **remote** areas for the purposes of this Division.

Health Insurance Act 1973 Part VA—National Rural Health Commissioner

79AA Object of this Part

The object of this Part is to establish the National Rural Health Commissioner to assist in improving health outcomes in **rural, regional and remote areas**, particularly in relation to improving the quality and sustainability of, and access to, health services in those areas.

The wording of the object for s.79AA above (bold added), shows inclusion of 'rural, regional and remote areas' but it is proposed that for the new Disability Rights Act, 'very remote' areas should also be visibly included.

- In this example, the title of the Health Commissioner has been designated as 'Rural' with the relevant areas ('rural, regional and remote areas') stated to be included.

- As noted above, combining the four areas into one term is not desirable for visibility and inclusion. Consequently, full specification of 'regional, rural, remote and very remote' is preferred, not a grouping up as 'rural'.

2.2.4 Principles

If the new Act has a statement of Principles:

- Include visible reference to the ensuring the rights of people with disability in regional, rural, remote and very remote areas.

2.2.5 Other operative provisions

- Continue the theme of making the rights of people with disability in regional, rural, remote and very remote areas visible in the Act.

- This could also be achieved through a drafting technique, early on, which ensures that references to people with disability in the Act includes people with disability in regional, rural, remote or very remote areas.

    - However, if this technique is used it should not be limited to the 'Interpretation' / 'Dictionary' section, because that would not fully achieve the objective of visibility.

We hope this assists and are happy to discuss any further aspects.

Judy Harrison
Co-convenor 4Rs Network
Contacts supplied.

ATTACHMENT 1

2. HUMAN RIGHTS AND SYSTEMS FAILURES FOR PEOPLE WITH DISABILITY IN 4RS

2.1 Multiple systems are failing people with disability in 4Rs Australia including health, housing, social security, employment, access to legal assistance. All of these connect with social determinants of health[35] and impact individually and combined wellbeing.

2.2 There is still insufficient accountability to people with disability, and other vulnerable people, in the 4Rs and 4Rs location is often used as an excuse.

2.3 The proposed new federal Disability Rights Act may help with geographical discrimination against people with disability in the 4Rs, but the prospects would increase if the new Act highlighted that rights do not diminish with distance from capital cities and metro areas. The same applies to all federal, state and territory human rights, anti-discrimination / equal opportunity legislation which is typically silent on the issue of 4Rs geographic location. This silence fails to challenge myths that the human rights and legal rights of people with disability, and others who are vulnerable in 4Rs Australia, attenuate with distance from the metro.

2.4 While intersectionality is now well developed in relation to the human rights of people with disability, and while the 'rural' (meaning non-metro location) is increasingly included as an intersectional factor[36] - 'rurality' does not have a similar level of legal normative development as non-discrimination on other intersectional grounds such as gender, race, disability, age and sexual orientation. It is noteworthy that there is no international Convention or Declaration relating to the rights of people in rural areas as a group for visible inclusion in rights regimes. In Australia, this appears to contribute to the 'rural' or 'non-metro' being used to derail the human and legal rights of people with disability, and other vulnerable groups, in these areas.

2.5 The Convention on the Rights of Persons with Disability ('**CRPD**') refers to 'rural' in Articles 9 ('both in urban and in rural areas'), 25 and 26 ('including in rural areas').[37] Arguably:

- *inclusion in the CRPD* is a strong reason for inclusion in the proposed new Act, and
- *insufficient inclusion in the CRPD* is also a strong reason –because insufficient inclusion has a diluting effect[38]which should be addressed (and not repeated) in the proposed new Act.

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[35] World Health Organization, Commission on Social Determinants of Health, Closing the gap in a generation: health equity through action on the social determinants of health, Final Report of the Commission, 27 August 2008 (WHO, Geneva); World Health Organization, World Health Topics, Social determinants of health (WHO, Geneva); Australian Institute of Health and Welfare 'Social determinants of health' (AIHW, 2022)

[36] Committee on the Rights of Persons with Disabilities, *General comment No. 6 on equality and non-discrimination*, 19th sess, UN Doc CRPD/C/GC/6, (6 April 2018), para [19]; Royal Commission into Violence, Abuse Neglect and Exploitation of People with Disability, Final Report Vol 4 Realising the Human Rights of People with Disability, September 2023, especially 54-56 and Final Report Vol 1: Final Report - Executive Summary, Our vision for an Inclusive Australia and Recommendations; First Person's Disability Network submission to the Productivity Commission Review of the Closing the Gap National Agreement, 13 November 2023; Taylor Fry 2023 (n 17) 140

[37] Convention on the Rights of Persons with Disabilities, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008).

[38] The concept of a 'diluting effect' has been developed by Dr Scott Avery in analysing the effect of only one reference to Indigenous people in the CRPD which is in the Preamble. See: Scott Avery, 'Intersections in Human Rights and Public Policy for Indigenous People with Disability' Chapter 11 in Franziska Felder, Laura Davy,

2.6 The Royal Commission noted the insufficiency of CRPD in relation to First Nations people and recommended that the objects of the new Act should be to respect, protect and fulfil all the rights in the CRPD and the rights of 'First Nations people with disability not specifically articulated in the CRPD'.[39]

2.7 Also to note that:

- the Declaration on the Rights of Indigenous Peoples[40] (**'DRIP'**) does not refer to the 'rural' (or similar), and

- among the core human rights treaties other than CRPD, only CEDAW refers to 'rural, but only in only in Article 10 and 14 ('rural as well as in urban areas') and 14 ('rural woman' 'women in rural areas' 'equality of men and women, that they participate in and benefit from rural development'.

2.8 This adds to reasons to specifically include 'rural' (or approved term) it in the new Act.

Recommendation 3: new Disability Rights Act and 4Rs location

The rights of people with disability in regional, rural, remote and very remote areas should be made visible included in the proposed federal Disability Rights Act.

Recommendation 4: reference to Australian Human Rights Commission about human rights in the 4Rs

The Attorney-General should ensure that the Australian Human Rights Commission receives a reference to undertake a holistic national inquiry into human rights in 4Rs Australia focusing on people with disability and all other vulnerable groups with a view to evaluating how Australia's human rights frameworks are responding to the 4Rs and whether legislation should be amended to make the rights of people in 4Rs more visible.

3. ADVOCACY AND LEGAL ASSISTANCE FOR PEOPLE WITH DISABILITY IN THE 4Rs

3.1 Advocacy of many kinds, by, with and for people with disability is required for people with disability in 4Rs areas to exercise their rights of self-determination and lead the improvements and reforms required. Disability advocacy is described as follows by the National Disability Advocacy Framework 2023 – 2025[41] under Australia's Disability Strategy 2021-2031:[42]

Rosemary Kayess (eds), *Disability Law and Human Rights: Theory and Policy* (Palgrave Macmillan 2022) 221–38. This analysis was discussed with approval by the Disability Royal Commission First Nations people with disability, Final Report 9, September 2023 24-25.

[39] Disability Royal Commission Final Report Vol 1 (n 29) 57

[40] *United Nations Declaration on the Rights of Indigenous Peoples*, GA Res 61/295, UN Doc A/RES/61/295 (2 October 2007, adopted 13 September 2007).

[41] National Disability Advocacy Framework 2023-2025, 3 which also highlights that this is not a complete list of advocacy types that may be available in each jurisdiction ('**National Disability Advocacy Framework**')

[42] Australia's Disability Strategy (n 12).