

Submission

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# NDIS participant experience in rural, regional and remote Australia

February 2024



**DANA** Disability Advocacy  
Network Australia

## About DANA

DANA is the national representative body for a network of independent disability advocacy organisations throughout Australia.

### Our Vision

DANA's vision is of a nation that includes and values people with disabilities and respects human rights for all.

### Our Purpose

DANA's purpose is to strengthen, support and provide a collective voice for independent disability advocacy organisations across Australia that advocates for and with people with disability.

We achieve this by

- promoting the role and value of independent disability advocacy
- providing a collective voice for our members
- providing communication and information sharing between disability advocacy organisations
- providing support and development for members, staff and volunteers of disability advocacy organisations
- building the evidence base to demonstrate the value of disability advocacy
- promoting the human rights, needs, value and diversity of people with disabilities

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## Introduction

Our organisation appreciates the opportunity to make a submission on the important topics covered by this inquiry in relation to the experience of accessing the National Disability Insurance Scheme (NDIS) in rural, regional and remote Australia. Although not specifically mentioned in the terms of reference, this submission will highlight the availability, functions and impact of independent disability advocacy as highly relevant to these matters. The *NDIS Act 2013* specifically acknowledges the role of advocacy in representing the interests and promoting their community participation and inclusion, control, choice, and independence.<sup>1</sup>

Many of our member organisations, including a diverse range of independent advocacy organisations around Australia working on individual and systemic levels, operate in or cover rural, regional and remote areas. In our engagement with organisations, especially those operating in jurisdictions with populations spread across vast distances such as Western Australia, Queensland, and the Northern Territory, advocates frequently raise the additional challenges faced by people with disability living outside of metropolitan areas. They point to thin, failing or even non-existent markets where a dearth of supports for people with disability means that the barriers to community access, inclusion and participation are heightened.

We are aware that a number of our member organisations and networks with particular expertise in this area (like the Victorian Rural Advocacy Network (VICRAN), are making submissions to this inquiry. Several other member organisations have provided input into this DANA submission.<sup>2</sup> From previous engagement work, we have also heard many advocacy organisations describe the problems and challenges for people with disability living in rural, regional and remote locations who they assist and advocate for.<sup>3</sup> In addition to centring the voices of people with disability and their representative organisations in this inquiry, DANA urges the Committee to give attention and weight to the experiences of advocacy organisations working in these areas, and the detailed insights of advocates as to what has been going wrong and how NDIS processes, interactions with the NDIA and disability services could be improved, especially for multiply marginalised people with disability.

By now, it is well established and documented that people with disability living in rural and remote areas are particularly marginalised and disadvantaged due to the limited services and support generally available within proximity of where they live.<sup>4</sup> As we've heard throughout the recent NDIS Review, and in relevant hearings and findings of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the

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<sup>1</sup> The "role of advocacy in representing the interests of people with disability is to be acknowledged and respected, recognising that advocacy supports people with disability by: (a) promoting their independence and social and economic participation; and (b) promoting choice and control in the pursuit of their goals and the planning and delivery of their supports; and (c) maximising independent lifestyles of people with disability and their full inclusion in the community." [Section 4](#), Subsection 13.

<sup>2</sup> Organisations who sent us input for this submission include: Disability Advocacy Service (NT); Rights in Action (QLD); VALID (VIC); Spinal Cord Injuries Australia (NSW).

<sup>3</sup> For instance see [discussion transcripts](#) from: WA – October 2020 Workshop with the DRC; NT November 2020 Workshop with the DRC – DANA Submission to DRC "Advocates Zoom In On... *Advocacy for First Nations People*"; April 2021 Solutions focused workshops with DRC.

<sup>4</sup> Monica Cuskelly (2022) Challenges for the National Disability Insurance Scheme in regional, rural, and remote areas. *Research and Practice in Intellectual and Developmental Disabilities*, p1-10.

Disability Royal Commission or DRC), there are thin or absent markets of disability supports providing limited or no choice to people with disability in remote and rural areas, exacerbating the existing disadvantage, neglect and exclusion of people with disability.

'The Aussie Battlers' research report,<sup>5</sup> authored by one of our member organisations Disability Advocacy NSW in 2022, identified four themes of "double disadvantage" affecting many people with disability living in regional, rural and remote NSW: namely, thin markets, financial disadvantages, evidentiary requirements and inaccessible information. This failure of service systems is even more stark for people with disability who are from First Nations or culturally diverse backgrounds and/or other intersectional identities. Many of the recommendations that have been made by the NDIS Review and DRC have great potential to strengthen the local supports and service systems to meet the needs of people with disability in rural, regional and remote communities, both within and outside of the NDIS.

However, co-design with people with disability and their representative organisations to develop and implement the actions outlined by these processes is essential, as reforms must be guided by the "nothing about us without us" principle at the heart of the disability rights movement.<sup>6</sup>

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<sup>5</sup> Cherry Baylous and Demi Woods (2022) *The Aussie Battlers: Life with a disability in regional, rural and remote NSW*, Disability Advocacy NSW Scoping Research Report: [Disability Advocacy NSW website \(da.org.au\)](https://www.da.org.au), Accessed 4 November 2022.

<sup>6</sup> See further discussion in Disability Advocacy Network Australia (2024) *The Australian Government response to the Royal Commission into Violence, Abuse, Neglect and Exploitation*.

## Recommendations

**Recommendation 1:** Increase funding for independent disability advocacy by \$91.225 million, including:

- \$20 million as a dedicated funding boost for independent disability advocates facing increased operating costs in rural, remote, and very remote areas
- Further sector capacity building: \$5.225 million to be spread across disaster management, First Nations cultural safety training, resources and pilot projects, and awareness of supported decision making.

**Recommendation 2:** Establish a National Disability Advocacy Data Taskforce with relevant expertise to redevelop and strengthen data and information systems, enabling efficient collection, analysis and utilisation of high-quality accessible data about disability advocacy outcomes and demand.

This would enable the promotion of benchmarks for access to advocacy in regional, rural, remote, and very remote areas, and accurate data collection and reporting against these benchmarks at a national, state/territory, regional and local level (to monitor and drive progress).<sup>7</sup>

**Recommendation 3:** Enhance cultural safety for people with disability, particularly First Nations people with disability.

**Recommendation 4:** As reforms are pursued following the DRC and NDIS Review, ensure that people with disability and their representative and advocacy organisations, including those in regional, rural and remote communities, are meaningfully included in the co-design of proposed solutions to address the:

- problems with inaccessible, frustrating and overly complex processes to access disability supports and information in regional, rural and remote areas.
- market failures and gaps (through measures including provider panels and providers of last resorts schemes);
- safeguarding gaps (through improved oversight, outreach and access to independent advocates)
- acute marginalisation experienced by First Nations people with disability and culturally and linguistically diverse people with disability (through meaningful co-design with these groups and their representative and advocacy organisation)

**Recommendation 5:** A Disability Reform Implementation Council is established urgently to oversee Disability Royal Commission and NDIS Review changes, led by people with disability and our organisations<sup>8</sup>

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<sup>7</sup> This has been identified by the National Regional, Rural, Very Remote Community Legal Network as key priority. National Regional, Rural, Remote and Very Remote (4Rs) Community Legal Network (2024) *Federal Pre-budget submission: Towards a landmark National Regional, Rural, Remote and Very Remote Access to Justice Plan*.

<sup>8</sup> See further discussion, [Disability Royal Commission Response Consultation – A joint submission from Disability Representative Organisations](#). (January 2024).

## Experiences of NDIS processes

- a. *the experience of applicants and participants at all stages of the NDIS, including application, plan design and implementation, and plan reviews.*

Since the scheme was established, NDIS processes have been subject to change, complex and difficult to navigate.<sup>9</sup> It has been well recognised and acknowledged that the processes for gaining access to the scheme, and for plan development, implementation and review have frequently failed to be responsive to the individual needs of people with disability, especially those who require support for decision making or communication or experience multiple forms of marginalisation, discrimination or disadvantage.<sup>10</sup> The NDIS has often placed large administrative burdens on individuals with disability and their families, carers and advocates.<sup>11</sup> A number of examples and case studies from our member organisations detailing negative experiences with the scheme are included below in Appendix A.<sup>12</sup>

The processes for people with disability to challenge NDIS decisions, have been especially problematic and frustrating for people with disability.<sup>13</sup> This includes both internal review at the NDIA and appealing decisions about eligibility or supports included in plans to external merits review at the Administrative Appeals Tribunal. In central Australia, an NT advocate observed that very few people wish to lodge NDIS appeals and are generally not seeking out advocates, unless they have pre-existing relationships.<sup>14</sup> Another organisation observed

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<sup>9</sup> Ali Lakhani, Donna McDonald and Heidi Zeeman (2018). Perspectives of the National Disability Insurance Scheme: Participants' knowledge and expectations of the scheme. *Disability and Society*, 33(4),783–803.

<sup>10</sup> Karen Soldatic, Georgia Van Toorn, Leanne Dowse, and Kristy Muir (2014). Intellectual disability and complex intersections: Marginalisation under the National Disability Insurance Scheme. *Research and Practice in Intellectual and Developmental Disabilities*, 1(1), 6–16.

Susan Collings, Angela Dew and Leanne Dowse (2019) “They need to be able to have walked in our shoes”: What people with intellectual disability say about National Disability Insurance Scheme planning’, *Journal of Intellectual & Developmental Disability*, 44 (1) 1-12.

<sup>11</sup> Gemma Carey, Eleanor Malbon and James Blackwell (2021). ‘Administering inequality? The National Disability Insurance Scheme and administrative burdens on individuals’, *Australian Journal of Public Administration*, 80(4), 854-872.

<sup>12</sup> See [Experiences of NDIS processes](#) in Appendix A.

<sup>13</sup> Libby Brookes and Tom Ballantyne (2019). ‘Review and appeal rights in the NDIS’. *Precedent*, (154), 8-11.

Louise St Guillaume, Georgia Coe, and Madeleine Murray (2021) *An Evaluation of NDIS Appeals and Review: Experiences of Culturally and Linguistically Diverse People with Disability, their Families and Carers*. The University of Notre Dame Australia - Prepared for Multicultural Disability Advocacy Association NSW.

Alyssa Venning, Eloise Hummell, Michele Foster, Kylie Burns, and Susan Harris Rimmer (2021). Adjudicating reasonable and necessary funded supports in the National Disability Insurance Scheme: a critical review of the values and priorities indicated in the decisions of the Administrative Appeals Tribunal. *Australian Journal of Public Administration*, 80(1), 97-113

Mitchell Skipsey, Di Winkler, Michelle Cohen, Peter Mulherin, Alecia Rathbone and Melissa Efstathiou (2022) *Housing Delayed and Denied: NDIA Decision-Making on Specialist Disability Accommodation*. Public Interest Advocacy Centre and Housing Hub (Summer Foundation).

<sup>14</sup> NT advocacy organisation, input gathered from conversations, for DANA's pre-Budget submission (July, 2023).

that housing instability and food insecurity are such big issues in the NT that accessing the NDIS becomes a lower and less immediate priority.<sup>15</sup>

Another area that has been unclear and fraught for people with disability and their advocates are the processes to effectively report abuse or neglect, raise safeguarding concerns about violence, neglect or exploitation, or make complaints about poor quality supports.<sup>16</sup> In regional Victoria, an advocate observed in their submission to the DRC:

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*“...since the NDIS Quality and Safeguards Commission has become operational, services registered under the NDIS and support workers working in these service often ask me about scenarios people with disability they are supporting are facing, most of the scenarios stem from neglect, yet I have found the services do not understand what neglect is, let alone how to report on this, or even transform this for the person with disability, this is a big job.”<sup>17</sup>*

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Many organisations have expressed deep concern about exploitative providers, particularly in the area of accommodation. These “whole of life” supports and “service capture” exacerbates the risk of service providers gatekeeping to obscure victimisation in group homes, boarding house or equivalent environments or otherwise keep people from being aware of their rights to safe, quality supports. During engagement in 2021, one advocate called for:

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*“increased information about the [NDIS Quality and Safeguards] Commission to people living with disability, information sessions in regional and remote areas through community engagement to increase awareness.”<sup>18</sup>*

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We have heard about many agonising experiences of NDIS processes failing to be accessible or efficient, to meet the needs of people with disability, or to deliver them with timely, fair and consistent outcomes. One North Queensland advocate lamented the rigidity of the NDIS processes and frameworks, including through being overly “focused on data collection, compliance and adherence to complicated decision trees”, rather than on finding solutions and engaging collaboratively with people with disability.<sup>19</sup> A WA advocacy manager observed that many people are unaware of independent advocacy as a potential support and the effectiveness of Local Area Coordination (LAC) has deteriorated in their region, with the new LAC model not possessing the local knowledge or networks to resolve issues: “Now

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<sup>15</sup> NT advocacy organisation, input gathered from conversations, for DANA’s pre-Budget submission (July, 2023).

<sup>16</sup> See further Disability Advocacy Network Australia (2022) *Rights, Safety, Quality – Voices of Advocacy*.

<sup>17</sup> Grampians disAbility Advocacy Association (2021) Submission on Promoting Inclusion issues paper.

<sup>18</sup> Response to survey question about improving the NDIS Commission - *Advocates on Quality and Safeguarding – April 2021*.

<sup>19</sup> Rights In Action Inc. (Cairns, QLD) input (received by DANA February 2024).



people just flounder along”.<sup>20</sup> They also noted NDIS information as a big gap, observing that the limited or inadequate local knowledge received through contacting the Disability Gateway means they do not use or value it as an information source. One of our member organisations located in NSW highlights that (due to the lower age for access) many First Nations people with disability are being directed to My Aged Care, even when an NDIS plan would be more appropriate and better meet their needs.<sup>21</sup> Elsewhere, an NT organisation has noted that there are LACs in Darwin but not elsewhere in the territory, observing the lack of face to face assistance from the NDIS in recent years:

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*“despite the community having complex needs and being survival mode – no face to face support – people just give up... It isn’t until police or family services get involved, that then triggers an emergency response.”<sup>22</sup>*

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Another common theme that we hear expressed by advocates is the importance of face to face and in-person interaction in achieving good outcomes and building relationships of trust with people with disability, whether in their own work or in the NDIS processes they observe. Although information sharing through the website, eNews, portal and interaction over the phone or email is sometimes appropriate and adequate some have expressed dismay at the NDIA and NDIS Commission being overly reliant on these modes of communicating. This can heighten the existing ‘digital divide’ or ‘digital gap’ experiences by populations in rural, remote and very remote areas<sup>23</sup> especially for people with intellectual disability or complex communication support needs t.<sup>24</sup> Information dissemination by the NDIA generally relies on people being able to understand written information, navigate websites and access stable internet and electronic communications devices.<sup>25</sup> Yet people living in regional, rural and remote communities may have limited access to internet, mobile phones or experience unreliable digital infrastructure.<sup>26</sup> This lack of local understanding is also discussed further below.

One advocacy organisation recommended that many of the inequities, frustrations and increased challenges created by poor or inconsistent information could be remedied through

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<sup>20</sup> WA advocacy organisation, input gathered from conversations, for DANA’s pre-Budget submission (July, 2023).

<sup>21</sup> See Appendix A: [First Nations experiences](#).

<sup>22</sup> NT disability organisation, input gathered from conversations, for DANA’s pre-Budget submission (July, 2023).

<sup>23</sup> Daniel Featherstone, Lyndon Ormond-Parker, Lauren Ganley, Julian Thomas, Sharon Parkinson, Kieran Hegarty, Jenny Kennedy, Indigo Holcombe-James (2023) Mapping the digital gap: 2023 outcomes report

<sup>24</sup>Morsillo, R. (2011). One down, two to go: public policy in service of an available, affordable and accessible National Broadband Network for people with disability. *Telecommunications Journal of Australia*, 61(2), pp. 28.1-28.13;

Goggin, G., Hollier, S. and Hawkins, W. (2017). Internet accessibility and disability policy: lessons for digital inclusion and equality from Australia. *Internet Policy Review*, 6(1).

<sup>25</sup> Stewart, V., Visser, K., & Slattery, M. (2020). Supporting choice, recovery, and participation: Clear and easy to understand information is the key to NDIS access for those with psychosocial disability. *Journal of Social Inclusion*, 11(2), 33-46.

<sup>26</sup> Park, S. (2017). Digital inequalities in rural Australia: A double jeopardy of remoteness and social exclusion. *Journal of Rural Studies*, 54, 399-407.

targeted education being provided to new and existing participants entering the scheme to build awareness and capacity and understanding on navigating NDIS processes and exercising choice and control.<sup>27</sup> They also noted that disability advocates are already providing this kind of support to some people with disability.

However, the scale on which advocacy organisations can currently deliver such education, capacity building and navigation support is severely constrained by their need to prioritise people with disability in high-risk situations and crisis.<sup>28</sup> This often diverts organisational focus from the preventative and developmental work of rights education and awareness raising, capacity building and early stage problem-solving and dispute resolution, which in turn has led to increased demand, longer waiting lists and greater strain on organisations.<sup>29</sup>

Another advocacy organisation underlined that although more costly and difficult to deliver, accessible forms of information and capacity building may be more crucial and impactful in non-metropolitan locations:

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*“...lots more happening in metro than regional and rural areas for NDIS participants. ... It is easier for VALID to run workshops in Melbourne metro – but more beneficial to work in regional and rural areas because people don’t tend to get the same access to information.”*

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## **Need for independent advocacy support**

Federally, advocacy organisations are funded through the National Disability Advocacy Program (NDAP), with some also or only receiving state or territory funding. The disability advocacy sector is very efficient in achieving outcomes for people with disability within the constraints of available resources and limited capacity to reach out into the community. There is a diversity of organisations in the sector - in terms of size, types of organisations, capacity, location and approaches to disability advocacy provision.

- Local and regional organisations can be particularly valuable with their detailed local knowledge and networks.
- Specialised disability advocacy organisations provide familiarity and knowledge of specific issues for particular groups of people.

The National Disability Advocacy Framework 2023-2025 (NDAF) is an associated plan under Australia’s Disability Strategy 2021-2031 and represents the shared commitment of the Australian, state and territory governments to ensure there is access to advocacy services available for all people nation-wide, with the intended outcomes including:

- *All people with disability can access quality and independent advocacy support, regardless of where they live.*

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<sup>27</sup> Rights In Action Inc. (Cairns, QLD) input (received by DANA February 2024).

<sup>28</sup> Disability Advocacy Network Australia (2022) [Independent disability advocacy – DANA submission to the Disability Royal Commission](#).

<sup>29</sup> Disability Advocacy Network Australia (2023) Intake Project Summary Report, Commissioned by Department of Social Services.

- *All people with disability, including those experiencing multiple disadvantage, are supported to have effective interactions and access to disability supports and services and/or mainstream services and facilities including supportive, flexible and timely access to justice and legal advocacy.*
- *All people with disability are empowered and have opportunities to express their views and wishes about supports and services they access and how service provision could be improved; and can access a complaints mechanism and independent support and advice when providing feedback or making a complaint in relation to the supports and services they purchase or engage.*

Unfortunately, years of inadequate funding levels, opaque and inconsistent data collection and lack of sector support and investment means that meaningful access to disability advocacy is not currently the reality for many Australians with disability living outside of metropolitan regions.<sup>30</sup> One of the commitments listed under Responsibilities, Reform and Policy Directions section of the NDAF is for government to ensure “funding of disability advocacy is transparent, accountable, supports equitable outcomes, including identifying and addressing geographical and services gaps”. Addressing these gaps and improving geographical coverage of rural, regional and remote communities is vitally important, especially for First Nations people with disability.<sup>31</sup>

Cost benefit analysis has shown that independent disability advocacy delivers a substantial positive net economic benefit to Australia that far exceed its economic costs. A recent DANA study found that every dollar used by Australia’s independent disability advocacy agencies delivers \$3.50 in benefits.<sup>32</sup> As we argue in our pre-Budget submission<sup>33</sup> (and heard throughout the DRC hearings),<sup>34</sup> independent disability advocacy plays a critical role in both facilitating and safeguarding Australia’s disability and NDIS ecosystems, including through:

- helping to prevent NDIS exploitation by supporting people with disability to advocate for their rights and to address unfair treatment or plan utilisation by providers;
- building capacity, understanding and confidence so people with disability can better use their NDIS funding and meet their goals;
- keeping mainstream systems accountable for providing equitable access to people with disability;
- helping people to navigate and engage with safeguarding and complaints processes;

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<sup>30</sup> Disability Advocacy Network Australia (2022) [Independent disability advocacy – DANA submission to the Disability Royal Commission](#).

Disability Advocacy Network Australia (2023) [A strong sustainable future: addressing capacity shortfalls for a strengthened disability advocacy sector](#).

Disability Advocacy Service (Alice Spring, NT) input about advocacy in central Australia, 2023 (received by DANA February 2024).

<sup>31</sup> Damian Griffis at Royal Commission into Violence, Abuse Neglect and Exploitation of People with Disability - *Public Hearing 18: The human rights of people with disability and making the Convention on the Rights of Persons with Disabilities a reality in Australian law, policies and practices*. Transcript of proceedings - Day 1, Monday 8 November 2021, p68.

<sup>32</sup> Anne Daly, Greg Barrett and Rhiân Williams (2017) *A Cost Benefit Analysis of Australian independent disability advocacy*

<sup>33</sup> Disability Advocacy Network Australia (2023) [A strong sustainable future: addressing capacity shortfalls for a strengthened disability advocacy sector](#).

<sup>34</sup> See: [Spotlight on Advocacy | Disability Advocacy Network Australia \(dana.org.au\)](#)

- preventing and solving problems through education and building skills, sometimes intervening before situations escalate to crisis;
- working to fix barriers in local, state and national systems and frameworks; and
- working with people with disability to build their own capacity to self-advocate, building trusted relationships over time.

DANA expects advocacy demand to increase significantly in the coming months in response to proposed sector changes arising from both the DRC and the recent NDIS Review. That is why our member organisations are united in calling for significantly higher injections of funding in the next Federal budget.<sup>35</sup> (For more detail about the urgent need to increase funding for independent advocacy see the section below, and Appendix A for additional examples and case studies demonstrating the positive impact that access to advocacy can have in the lives of individuals.)

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<sup>35</sup> See current campaign: [SPEAK UP for independent advocacy \(speakupadvocacy.com.au\)](https://speakupadvocacy.com.au)

## People with disability in rural, regional and remote areas and the NDIA

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

Some policies and approaches from the NDIA have a disproportionate impact on people with a disability in rural and remote areas.

One such area is transport. The NDIA will regularly refuse to fund the transport costs required to ensure that capacity building supports can be delivered on site at plan reviews. Due to the lack of direct service availability in their local area, some support services will travel in order to provide a client with a service. Even though this is regularly the difference between a person being able to access a service and not accessing anything at all, advocates spend significant time helping people to try and get these additional costs included in a person's plan on review and at the AAT – indicating that they have been rejected at first instance in a person's plan review.

This type of service delivery is usually limited to therapists or other capacity building supports, whose pricing rules permit travel to homes. It does not address core supports or other services.

While it is possible to secure additional transport funding if you can find a provider in the city or in a regional hub who is willing to travel, that is not something that is provided for people who themselves travel to urban areas to access supports. This, along with systemic market barriers, is another barrier to accessing supports, particularly if someone requires additional support to undertake that travel. These issues have been long-standing and have been addressed in Federal Court previously,<sup>36</sup> but have greater impact on rural and remote communities who rely on the scheme.<sup>37</sup>

Often the NDIA will advise that these additional costs are accounted for in the higher rate for rural and remote service provision in the NDIS price guide. However, as we are nearly 10 years into a market based scheme and many rural and remote areas are still experiencing these difficulties it is clear that additional efforts are required.

Many people, even after navigating the complexity of Access and Plan Reviews, experience great difficulty in utilising those funds. This is discussed in further detail below. However, the ongoing reviews by the NDIA will generally seek to claw back funds that are not utilised within a plan. This presents a significant problem for market development in rural and remote areas as unless an entire market can be generated within a year's plan cycle, the revenue base for any providers can evaporate within a year. This is your classic chicken and egg problem, but instead the egg is taken away before it gets a chance to be incubated.

This may be partly addressed by efforts to extend plan lengths as recommended by the NDIS review,<sup>38</sup> but reflects the scheme's short-term focus is hampering market development

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<sup>36</sup> McGarrigle v National Disability Insurance Agency [2017] FCA 308

<sup>37</sup> See transport and travel examples in Appendix A, particularly those at p 27 and 31.

<sup>38</sup> NDIS (2021) [We're making Participant Plans Longer](#)

in rural areas. There is a perception that the NDIA has been unwilling to stump up funds in advance of their utilisation to allow these markets to come to fruition.

Existing issues around accessing and discussing matters directly with NDIS staff are more acute in these areas. LACs also vary in quality and generally lack the capacity to meet or travel to people on the ground who require support. This lack of community connection needs to be addressed as we proceed towards a very significant change in the way disability supports will be provided following the NDIS Review and Disability Royal Commission. An advocate put it best:

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*The lack of forward planning to educate the community at large about changes to the NDIS Scheme and the roles of the PITC [Partners in the Community]'s morphing has been inadequate. I flagged my concerns to the NDIA's Community and Mainstream Engagement team... and in a separate email as well, as these changes came into play in November last year and there are now plans afoot to communicate to the community the change of roles that the PITCs have undertaken from a Planning perspective to a Community Connector type role.*

*These PITCs in my area do not attend network meetings and from what I hear do not connect with mainstream and alternate services, so it is difficult to understand how they can be connecting clients to services whilst they either wait for the NDIS or in lieu of the NDIS when they do not know what supports are out there.*

*Again, if the NDIA or a PITC is not connected to a community or on the ground so to speak, how do they know who does what and more importantly what a provider's capacity might be?<sup>39</sup>*

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<sup>39</sup> Deidentified input from an advocate working in rural and remote areas (received February 2024).



## Limited choice, accessibility and availability of supports

- c. *participants' choice and control over NDIS services and supports including the availability, accessibility, cost and durability of those services*

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*"There is no real choice."<sup>40</sup>*

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While there have been gaps in service provision that pre-date the introduction of the scheme,<sup>41</sup> people with disability in rural and remote areas continue to experience a very different NDIS to those in urban areas. There is generally speaking less choice in who can provide services, some areas completely lack large swathes of crucial services at all.<sup>42</sup> Many organisations face increased difficulty in hiring and attracting workers with the right qualifications,<sup>43</sup> as well as higher operating costs resulting from additional travel expenses.<sup>44</sup>

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*"Being in a regional community, we have limited choice in what service providers are available."<sup>45</sup>*

*"Due to locality and geographic remoteness, NDIS participants living in regional, remote, and very remote areas are experiencing multiple disadvantage such as lack of service provision when it comes to quantity and quality of providers."<sup>46</sup>*

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<sup>40</sup> Rights In Action Inc. (Cairns, QLD) input (received by DANA February 2024).

<sup>41</sup> Angela Dew, Kim Bulkeley, Craig Veitch, Anita Bundy, Michelle Lincoln, Jennie Brentnall, Gisselle Gallego, and Scott Griffiths (2013) "Carer and service providers' experiences of individual funding models for children with a disability in rural and remote areas." *Health & Social Care in the Community* 21, no. 4 (2013): 432-441

Stuart Wark, Rafat Hussain, and Helen Edwards. "Rural and remote area service provision for people aging with intellectual disability." *Journal of Policy and Practice in Intellectual Disabilities* 10, no. 1 (2013): p62-70.

<sup>42</sup> Cherry Baylous and Demi Woods (2022) *The Aussie Battlers: Life with a disability in regional, rural and remote NSW*, Disability Advocacy NSW Scoping Research Report: [Disability Advocacy NSW website \(da.org.au\)](https://www.da.org.au). Accessed 4 November 2022.

<sup>43</sup> Gilroy, J., Veli-Gold, S., Wright, W., Dew, A., Jensen, H., Bulkeley, K., & Lincoln, M. (2023). Disability workforce and the NDIS planning process in regional, rural and remote regions of Australia: Scoping review. *Australian Journal of Rural Health*, 31(5), 839-854.

Monica Cuskelly (2022) Challenges for the National Disability Insurance Scheme in regional, rural, and remote areas. *Research and Practice in Intellectual and Developmental Disabilities*, p1-10.

<sup>44</sup> Disability Advocacy Service (Alice Spring, NT) input about advocacy in central Australia, 2023 (received by DANA February 2024).

Rights In Action Inc. (Cairns, QLD) input (received by DANA February 2024).

<sup>45</sup> DANA's 2015 *Quality and Safeguards* survey - VIC advocate

<sup>46</sup> Rights In Action Inc. (Cairns, QLD) input (received by DANA February 2024).

Many therapy and other capacity building services have to be delivered via telehealth methods which aren't suitable or effective for all people or all therapy types. As discussed above, there is also an additional administrative burden on the back of rural and remote participants who often have to request additional amounts to ensure that services are affordable.

In practical terms, the development of the NDIS has left some people worse off. In the 'Aussie Battlers' report from Disability Advocacy NSW, a case study details the difficulty experienced in both obtaining and NDIS plan and then having to seek out supports that may not actually exist in their area.<sup>47</sup> The practical supports they receive were also reported to be a step below what was available through general block-funded services pre-NDIS.<sup>48</sup> This report also articulates a perception that those services feel transactional and less embedded in the community.

These concerns have been relevantly picked up in the NDIS Review and Disability Royal Commission. Relevantly for this inquiry, the NDIS Review recommended improved market monitoring,<sup>49</sup> the introduction of provider panels<sup>50</sup> and ensuring providers of last resort in market failure.<sup>51</sup>

Large questions remain about the implementation of these recommendations.

An improved and active effort to assess and detail market shortages specific to local areas is crucial to give policy makers and the community understanding about the problem. Local communities often rely on their own networks to address policy gaps, and there's little opportunity for top-down assessment of people's support options to take place.<sup>52</sup> This is especially key given the upcoming shift towards foundational supports, where we would expect these problems around service availability and choice all the more acute.

The provider panel proposal does appear to address some of the concerns around the lack of developed markets by side-stepping that requirement entirely, which we view as a positive step. Direct provision of supports that adopts a more universal approach rather than individual plan funding alone is likely to be more effective, and should be front of mind as we proceed to developing foundational supports as well. Our primary concern is that these supports need to be developed quickly, and there are a number of areas that have seen the ways in which markets fail for nearly 10 years. These programs need have the participation and oversight of local people with disability in their implementation and design, and shouldn't be developed with service providers alone.

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<sup>47</sup> Cherry Baylosis and Demi Woods (2022) *ibid*, p5.

<sup>48</sup> Cherry Baylosis and Demi Woods (2022) *ibid*, p6.

<sup>49</sup> NDIS Review Panel (2023) *Working together to deliver the NDIS – Independent Review of the National Disability Insurance Scheme* pp178-182.

<sup>50</sup> NDIS Review Panel (2023) *ibid*, pp183-184.

<sup>51</sup> NDIS Review Panel (2023) *ibid*, p185.

<sup>52</sup> NDIS Review Panel (2023) *Working together to deliver the NDIS – Independent Review of the National Disability Insurance Scheme Supporting Analysis*, p772.



Along with exploration of provider panels, considerable attention has been directed to developing 'provider of last resort' schemes, which have been recommended by the NDIS Review and the DRC.<sup>53</sup> This is an important recommendation to ensure support continuity and is likely to be especially pertinent in rural and remote areas. It will need to be implemented in a way that preserves choice and control for users as well as accountability for service providers. It appears less relevant, however, to addressing the lack of services in the first instance. Specific work will also be required to ensure that people who require these urgent services are able to raise any concerns effectively and have them actioned promptly. This will require practical access to advocates present in the community and effective supervision by the Quality and Safeguards Commission in the event of a service provider collapse. The winnowing of this provision over time should also be noted. As the Darwin Community Legal Service note in their report on thin markets that the promise of a safety net by the NDIA has fallen away "and substituted with the more lowly aim of 'Maintaining Critical Supports.'<sup>54</sup>

A broader view of the role providers of last resort can play is present in the Disability Royal Commission, which recommends it be introduced in areas of "failed or thin markets, particularly for First Nations people with disability in remote or very remote areas."<sup>55</sup> It recommends that this be done through block funding arrangements, which may be the method of support that provider panels would apply. Where private service providers are unable or unwilling to step in and provide services through provider panels or other mechanisms, government bodies may need to take more direct action and funding to stand up additional services. Again, this needs to be developed with local people with disability at the centre of the decision-making process.

While we and others have noted the lack of service availability more generally, the Royal Commission specifically highlights the lack of availability of Positive Behaviour Support Practitioners in Rural and Remote areas. In similar terms to the above, it recommends direct additional incentives for providers.<sup>56</sup>

Relevantly, given the seriousness of topics raised at the Disability Royal Commission, the poor state of the market in rural and remote areas have various flow-on effects, particularly around safeguarding. The following are relevant examples from advocates detailing what this can look like in practice for people:

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*"There are various influences on a person's decision not to make a complaint, pursue recognition and/or resolution, seek a remedy, and compensation or report unethical or unsafe practices or criminal behaviour... there is little choice of support services able to provide the services needed (particularly in rural and regional towns), and left with*

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<sup>53</sup> NDIS Review Panel (2023) Working together to deliver the NDIS – Independent Review of the National Disability Insurance Scheme – Supporting Analysis, p776.

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2023) Final Report – Volume 10: Disability services, p224-227.

<sup>54</sup> Darwin Community Legal Services (2019) Thin Markets Project (Submission), p 2.

<sup>55</sup> Disability Royal Commission Final Report, Vol 10, Rec 10.10, p 16.

<sup>56</sup> Disability Royal Commission Final Report, Vol 10, Rec 10.24.

*receiving the support from the same people that the complaint was made against.”<sup>57</sup>*

*“Supported decision making is so important and if we had more funding for this it would certainly help in preventing abuse and neglect by having this readily available. It is really hard to get this support for our clients and even harder in our rural areas. If we gave people an opportunity and took the time for them to communicate their own needs, it would be really helpful.”<sup>58</sup>*

*“I think in regional and remote areas of Queensland, people are often frightened to make complaints because of the lack of alternative solutions or services. If there is limited availability, then they are not encouraged to complain because there is no other provider to use instead.”<sup>59</sup>*

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Where choice and control are not practically available to people - as is very commonly the case in rural and remote areas - there is a greater risk of abuse, neglect, and exploitation. People should not have to choose between getting the services they need and being safe while doing so. Addressing these issues is a crucial part of safeguarding.

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<sup>57</sup> DANA's 2015 *Quality and Safeguards* survey - NSW person with disability.

<sup>58</sup> VIC advocate, "Advocates Zoom In On... *Safeguarding rights and wellbeing*", December 2020 Zoom discussion

<sup>59</sup> DANA's 2015 *Quality and Safeguards* survey- QLD family member of person with disability

## Intersections of disadvantage

- d. *the particular experience of Aboriginal and Torres Strait Islander participants, participants from culturally and linguistically diverse backgrounds...with the NDIS*

### Experiences of First Nations communities

Given the profound history of mistreatment, racism and colonial violence, many First Nations people with disability feel distrust and suspicion when interacting with government agencies,<sup>60</sup> and disability services.<sup>61</sup> Many advocates speak about the NDIA displaying a lack of cultural safety and poor cultural responsiveness in NDIS processes including access and planning.<sup>62</sup> This can compound the disadvantage created by the additional barriers that are faced by Aboriginal and Torres Strait Islander people interacting with and seeking support from government systems.<sup>63</sup> One advocate observed:

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*“In my experience, the [Partners in the Community] staff representation does not match the numbers of First Nations clients or potential clients in any given community. The roles of Community Connectors was funded and then defunded around 2 or 3 years ago and these Community Connectors focused on CALD and First Nations and the need is still as real today as it was back then.*

*I am involved in a case where the client requested that an identified First Nations Case Manager from the NDIA be assigned to [their] matter. This request was not actioned, despite the Advocate flagging a lack of cultural competency [of the existing Case Manager].”<sup>64</sup>*

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<sup>60</sup> Dew, A., Vaughan, P., McEntyre, E., & Dowse, L. (2019). ‘Our ways to planning’: Preparing organisations to plan with Aboriginal and Torres Strait Islander people with disability. *Australian Aboriginal Studies* (Canberra), (2), 3-18.

<sup>61</sup> Michelle H. James, Valerie Prokopiv, Michael S. Barbagallo, Joanne E. Porter, Nicholas Johnson, Jan Jones & Tanisha Smitherson (2023) Indigenous experiences and underutilisation of disability support services in Australia: a qualitative meta-synthesis, *Disability and Rehabilitation*.

<sup>62</sup> For instance, see Darwin Community Legal Service (2022), *Submission into the Disability Royal Commission - Lived experience highlights multiplicity of factors in the NT continuing to expose people with disability to violence, abuse, neglect and exploitation*, p51-52, 64, 118.

<sup>63</sup> Dr Scott Avery, (2018) *Culture is Inclusion: A narrative of Aboriginal and Torres Strait Islander people with disability*. pp95-151.

Michelle Fitts and Karen Soldatic (2018) ‘Disability Income Reform and Service Innovation: Countering Racial and Regional Discrimination’, *Global Media Journal – Australian Edition* 12 (1).

<sup>64</sup> Deidentified input from an advocate working in rural and remote areas (received by DANA February 2024).

Poverty, which people with disability experience at disproportionate rates,<sup>65</sup> is even more heightened for First Nations communities.<sup>66</sup>

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*“...everybody is trying to live on nothing, ... everybody is experiencing neglect, but they're making the choice to live out there because connection to country is so important that people will put up with things that would be totally unacceptable to me, so that they have that capacity to continue living on country. Because the only other option is bring them in to Alice Springs or somewhere where they're hundreds if not thousands of miles away from everything that is important - family, someone who speaks your same language, access to cultural activities, being part of the community, that inclusiveness....”<sup>67</sup>*

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The inadequacy of supports, cultural safety and responsiveness, underemployment and overcriminalisation of First Nations people with disability heightens the risk of violence, abuse, neglect and exploitation. As we discuss in the next section, this increases the importance and urgency of increasing access to independent disability advocacy, particularly through strengthening First Nations advocacy organisations who can develop and draw on local relationships and understanding, and skills in cultural safety.

At one of the Disability Royal Commission public hearings, The CEO of First Peoples Disability Network (FPDN) Damian Griffis asserted: “the demand certainly from a First Nations perspective is so great that it's impossible to meet individual advocacy needs...”<sup>68</sup> June Riemer, Deputy CEO of FPDN also underlined that:

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*“The funding of the NDAP program needs to be further monitored and supported, there's currently not enough advocates nationally.... There is not enough First Nations advocacy groups, and we need more work around supporting self-advocacy for people with disability.”<sup>69</sup>*

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## **Experiences of culturally and linguistically diverse communities**

For many years National Ethnic Disability Alliance has been drawing attention to, significant access issues affect culturally and linguistically diverse (CALD) communities:

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<sup>65</sup> Jennifer Mays, Karen Fisher, and P. Saunders. "Disability and poverty." *Revisiting Henderson: Poverty, social security and basic income* (2019): 237-256

<sup>66</sup> Karen Soldatic, (2018) "Disability poverty and ageing in regional Australia: The impact of disability income reforms for indigenous Australians." *Australian Journal of Social Issues* 53 (3): 223-238.

<sup>67</sup> NT Advocate, November 2020 Zoom workshop with DRC

<sup>68</sup> Damian Griffis at Public Hearing 18: The human rights of people with disability and making the Convention on the Rights of Persons with Disabilities a reality in Australian law, policies and practices. Transcript of proceedings - Day 1, Monday 8 November 2021, p64.

<sup>69</sup> June Riemer at Public Hearing 18: The human rights of people with disability and making the Convention on the Rights of Persons with Disabilities a reality in Australian law, policies and practices. Transcript of proceedings - Day 1, Monday 8 November 2021, p68.

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*“Making sure that CALD people have equity and access to the NDIS is really important, but there is still a big lag time and CALD people are still finding it hard to engage,”<sup>70</sup>*

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As several of our member organisations can speak to in detail, people with disability from CALD communities have limited access to culturally appropriate and responsive supports even in major metro areas,<sup>71</sup> and the choice of supports is even narrower in regional, rural and remote areas. (Case studies illustrating the specific challenges experiences by people from non-English speaking and culturally diverse backgrounds in getting access to or navigating NDIS processes are included below in Appendix A.)<sup>72</sup>

Some jurisdictions have one or two advocacy organisations that specifically address the needs of CALD people with disability and the issues they face, but culturally appropriate support is not available everywhere. Targeted approaches are needed, but most organisations have limited time to build relationships of connection and trust with each cultural community. One Victorian advocate noted:

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*“We are really aware of our lack of reach into other communities. We have made some gains in the local Sudanese community, but COVID-19 made that enormously difficult to maintain supports in .... in terms of accessing interpreters in a timely way... we are very aware that different community groups have different ways of working...”*

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One advocate from Victoria suggests that what’s needed is to:

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*“Ensure trained culturally and linguistically diverse people are employed in advocacy, promoting disability advocacy within the communities from a human rights perspective,”<sup>73</sup>*

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<sup>70</sup> Dwayne Cranfield, NEDA CEO quoted by SBS News, 28 August 2020: [Advocates for culturally diverse Australians with disability cautiously welcome new NDIS reforms \(sbs.com.au\)](https://www.sbs.com.au/news/article/2020/08/28/advocates-for-culturally-diverse-australians-with-disability-cautiously-welcome-new-ndis-reforms)

<sup>71</sup> Settlement Services International (2018), Still outside of the tent: Cultural diversity and disability in a time of reform – a rapid review of evidence, p 20.

Federation of Ethnic Communities’ Councils of Australia, National Ethnic Disability Alliance, Refugee Council of Australia and Settlement Council of Australia, (2019) op. cit. pp12-24.

AMPARO, *The NDIS and Culturally and Linguistically Diverse Communities: Aiming High for Equitable Access in Queensland* (AMPARO Advocacy Inc, October 2016), 18. Available on the [Amparo website](#).

<sup>72</sup> See [Culturally and linguistically diverse experiences](#) subsection.

<sup>73</sup> DANA’s 2020 survey, Advocacy for people from culturally and linguistically diverse communities - Response from VIC Advocate.

## Importance of increasing funding for independent disability advocacy organisations

In our pre-Budget submission last year, we drew attention to the massive challenges faced by the disability advocacy sector due to the inadequacy of current funding to service the levels of demand and need.<sup>74</sup>

Approximately half of people with disability who seek support from advocates are turned away due to lack of available advocates – and this number is only indicative of services demanded, not services required overall. This ‘capacity crunch’ has been compounded over time by the growth of the National Disability Insurance Scheme (NDIS) and the reduction of accessible services for people with disability outside the NDIS. The two major recent reforms, the Disability Royal Commission final report and the NDIS Review, both recognise and require a very significant role from disability advocates and organisations. However, there is no dedicated funding allocated to independent disability advocacy to support the change management activities that will be needed flowing from both these major reform processes.

We have heard for a long time about the inadequacy of funding for independent advocacy to address both the unmet demand and need. DANA appreciates that the Joint Standing Committee has previously acknowledged and made recommendations to remedy the lack of funding and clarity around advocacy supports,<sup>75</sup> as far back as the first progress report made by the Joint Standing Committee in 2014.<sup>76</sup>

Though national hotlines can be very valuable for some people with disability to receive information over the phone and we have welcomed the development of the Disability Advocacy Support Helpline now accessible through the Disability Gateway, there are many people with disability needing support who need face-to-face engagement and/or interaction over some time to build relationships of familiarity and trust.

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*“Regional and rural advocacy [organisations] have very strong connections and a hotline approach is not ideal. [People with disability] prefer to pick up the phone and speak with the person they already have a relationship with.”<sup>77</sup>*

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A boost in funding is needed to resource face to face local support to be available to those whose needs cannot be met by phone or internet communication (including some people with intellectual or psychosocial disability or complex communication support needs). As

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<sup>74</sup> Disability Advocacy Network Australia (2023) [A strong sustainable future: addressing capacity shortfalls for a strengthened disability advocacy sector](#).

<sup>75</sup> See relevant recommendations from past reports in [Appendix B](#).

<sup>76</sup> Joint Standing Committee on the National Disability Insurance Scheme, Parliament of Australia (2014) *Progress report on the implementation and administration of the National Disability Insurance Scheme*, 127-129.

<sup>77</sup> 2022 consultation about advocacy – comment from VIC regional organisation



discussed above, advocates are keenly aware that many of the most marginalised and disadvantaged people with disability require more time-intensive, face to face support, especially when there risks of violence, neglect or exploitation to be identified:

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*“...enough resourcing including in rural and remote areas because ...we work with people with intellectual disability in response to extreme marginalisation and complexity. We're not really doing anything on the phone or in emails or any of that. It's just ridiculous. We need to be able to go and sit with people and there are occasions. we're going to regional areas and we'll take two advocates because taking two sets of eyes to a situation...can be really helpful because we can't be there all the time and so it provides the opportunity for one of the advocates to be sitting with the person directly and the other one to be...unpicking what's going on with that service so that we get a much broader understanding of something”<sup>78</sup>*

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## **The need for local connections and place-based approaches**

A key strength of independent disability advocacy organisations is their connection to their local communities, working in partnership to solve individual and systemic barriers for people with disability. They often play a vital role in adding local knowledge and capacity to national systems, such as the NDIS. Research has found that local disability advocacy organisations are essential ‘market stewards’,<sup>79</sup> due to their intimate knowledge and understanding of gaps and capacities within local NDIS service provision:

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*“Advocacy organisations are uniquely positioned to be able to provide information to the NDIA on what is happening at the local, on the ground level, from an independent participant (rather than provider) focused point of view. This is instrumental for good market stewardship and functioning of the system.”<sup>80</sup>*

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In addition, the current reforms recommended by the Disability Royal Commission and the NDIS Review will require deepening these local connections and relationships to ensure that there is increased access for people with disability to inclusive mainstream public services and the community.<sup>81</sup>

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*[Local Government Areas] their councils, corporate sector, government agencies and private businesses in these regions, need to take the lead in*

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<sup>78</sup> 2022 consultation about advocacy – comment from SA organisation.

<sup>79</sup> Celia Green, Gemma Carey & Eleanor Malbon (2022): Advocacy as market stewardship in social care quasi-markets, Public Management Review,

<sup>80</sup> Ibid.

<sup>81</sup> Sue Olney and DANA (2023). *NDIS Review: Mainstream and Tier 2—Discussion paper*. Disability Advocacy Network Australia.

*their own regions/communities to develop infrastructure. This can be done by ...administering accessibility audits within their towns, and seeking public consultations with all residents, including [people with disability], their families and supporters to identify what is needed for improved access (a unified, local level approach)<sup>82</sup>*

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DANA members were surveyed for our recent submission to the DSS consultation on “A stronger, more diverse and independent community sector”.<sup>83</sup> Respondents spoke of valuable connections to their local community and how being place-based is often an essential component to delivering effective advocacy with people with disability. There is also recognition of specialist skills that may not be locally based but are equally important:

- *We are often contacted by both the Disability Gateway and the Carer Gateway staff seeking advice and support for people living all over WA. This is because the centralised services are based in the eastern states with no understanding of the geographic distances in WA and the services available on a local level.*
- *Advocacy services are generally small and place-based grassroots organisations. This is much more conducive to being controlled by people with lived-experience of disability. It also means that we have strong links to our local communities and understand local issues. We also have stronger ties and working relationships with the local service providers who are best placed to help resolve issues being experienced by people with disability. Local services are generally also trusted more by local people with disability.*
- *Enormous benefits from reaching and working with people in their local lives and contexts. It makes the work, and associated referrals as relevant and accessible to clients as possible. It ensures people can be reached across the digital divide and in modes and terms that respect their needs and circumstances. It makes services attuned to barriers and able to advocate for systemic policy and service reforms that address them.*
- *Every area has its own culture and way of doing things and it is vital that organisations know what this is. We see a number of city-based organisations with contracts for country regions that are never serviced. People with disability want to see local people they know and trust deliver their services.*
- *Local knowledge can help us know who is doing what, organisational specialisations and projects. It can help us be known and develop a relationship of trust with vulnerable people in the local area. This can result in more trauma informed, impactful advocacy. It can also help us build relationships of trust with service providers so that referrals are more likely to be made. At the moment, poor quality search engines (Ask Izzy), and poor dissemination about who is doing what make local knowledge imperative to make appropriate referrals.*

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<sup>82</sup> Rights In Action Inc. (Cairns, QLD) input (received by DANA February 2024).

<sup>83</sup> Disability Advocacy Network Australia (2023) [A stronger, more diverse and independent community sector](#).



## Targeted funding boost for independent disability advocacy organisations operating in rural, remote, and very remote areas

In order for independent disability advocates to provide equitable service in rural, remote and very remote areas, there must be a significant boost to funding to support the increased complexity of remote engagement. The NDIS uses an established maximum price loading of 40%/ 50% for rural/remote and very remote service delivery using the Modified Monash Model, and DANA has recommended that the same model is applied to independent disability advocates operating in rural, remote and very remote areas with some additions.

Many NDIS providers, registered or unregistered, operate in a for-profit model, meaning their income from service provision is taxable. This allows providers to subsidise and 'write off' assets and expenditures, including vehicles, maintenance, fuel, travel, training, and other costs related to running a business. Most, if not all, independent disability advocacy services are registered not-for-profits or charities and do not have these privileges; instead, many organisations have access to salary packaging, which benefits employees directly but does not subsidise assets and everyday expenditure. This means that vehicles, training and employee support, travel and accommodation and other necessary expenditures are not adequately resourced. For advocacy organisations operating in rural, remote or very remote areas, these costs are significantly increased.

The NDIS market also has many large providers who can apply economies of scale to both the services they offer in rural and remote areas and the resources they have available; in contrast, many disability advocates are very small organisations with small amounts of funding and small staff teams, some of whom are unsure of the future of their organisation beyond the next funding 'cliff'. Organisations operating in remote areas are subject to additional costs, including safe vehicles for rural and remote travel, travel costs, accommodation, and training (which can include driving on dirt roads, first aid, advanced first aid, and cultural safety practices).<sup>84</sup>

To address these shortfalls DANA recommended in our pre-Budget submission an additional investment of \$20 million into supporting regional, rural and remote advocacy work.<sup>85</sup> This investment would ensure independent disability advocates can do their jobs safely and people with disability can access equitable advocacy support – no matter where they live.

For addressing longer-term needs in future years, the National Regional, Rural, Very Remote (4Rs) Community Legal Network has advocated for the development of standards or benchmarks about access to independent advocacy and legal assistance for people with disability in rural, regional, remote and very remote areas.

The 4Rs network has also underlined the urgent unmet need in across the country and proposed the allocation of funding for:

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<sup>84</sup> Queensland Independent Disability Advocacy Network (2022) *Data Analysis January to June 2022* – Submission to Department of Seniors, Disability Services and Aboriginal and Torres Strait Islander Partnerships, p28. [QIDAN data analysis – Pathways](#).

<sup>85</sup> For more detail of our proposals refer to: Disability Advocacy Network Australia (2023) [A strong sustainable future: addressing capacity shortfalls for a strengthened disability advocacy sector](#).

- *community based research and problem solving projects relating to user journey experience of people in rural, regional, remote and very remote areas seeking to access the NDIS or receive proper supports focusing on: access to independent advocacy, and access to legal assistance (With priority for areas where there is little or no apparent in-person access to either or both of these.)*
- *Funding for local and regional independent disability organisations in rural, regional, remote and very remote Australia to integrate legal assistance from community based non-profit legal services<sup>86</sup> and funding for these services for staffing and costs to enable collaboration in these initiatives.*

Such work must be undertaken in close consultation with people with disability and the disability advocacy and legal assistance sectors to ensure it effectively address the current inequities and gaps in support.<sup>87</sup>

## **Developing culturally safe resources, training and projects for First Nations people with disability**

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*“Advocacy is critical for people with disability in remote indigenous communities.... It would be almost impossible for people with disability to manage all the requirements of Government without advocacy support.”<sup>88</sup>*

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The Disability Royal Commission has collected a wealth of knowledge from First Nations people with disability. As Damian Griffis of First Peoples Disability Network, the peak body for First Nations peoples with disability, explained at one of the public hearings:

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*“...our advocates must have capacity to get out into regional and remote Australia. I think that still remains an untold story in many ways... The situation for many First Nations people with disability in regional and remote Australia, to be blunt, is one of abject poverty. The only way to get meaningful support to our community members out there is to go see them on country and try and seek support. So the National Disability Advocacy Program is inadequate in funding...”<sup>89</sup>*

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In its final report, the Commission has acknowledged the ‘unique marginalisation’ faced by Aboriginal and Torres Strait Islanders with disability and the critical need for culturally safe

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<sup>86</sup> This includes community legal services, Aboriginal and Torres Strait Islander Family Violence Prevention Legal Services and Aboriginal and Torres Strait Islander Legal Services.”

<sup>87</sup> National Regional, Rural, Remote and Very Remote (4Rs) Community Legal Network (2024) *Federal Pre-budget submission: Towards a landmark National Regional, Rural, Remote and Very Remote Access to Justice Plan.*

<sup>88</sup> NT advocate, April 2021 Solutions focused workshop with DRC

<sup>89</sup> Damian Griffis at Public Hearing 18: The human rights of people with disability and making the Convention on the Rights of Persons with Disabilities a reality in Australian law, policies and practices. Transcript of proceedings - Day 1, Monday 8 November 2021, p68.

and appropriate services and safeguards, as well as First Nations-led development and delivery of services, supports and advocacy.<sup>90</sup> The DRC recommendations include changes to NDIS structures and documents to include cultural life and safety, as well as the stronger representation of First Nations people with disability by establishing a First Nations Disability Forum.

In preparing our pre-Budget submission DANA worked with FPDN, as they move to becoming an accredited NDAP provider. FPDN is developing their community-controlled NDAP services, with a specific focus on First Nations people with disability with significant marginalisation and complex support needs. FPDN is already working with very marginalised First Nations people with disability, particularly people who are homeless and not able to access culturally appropriate disability services, but this work is severely underfunded. FPDN advocates work with communities, taking the time to develop the trusted relationships and flexible service delivery that quality advocacy relies on.

DANA recommended a strong investment in FPDN to understand First Nations specific advocacy needs and to develop resources, training and pilot offerings. DANA also strongly recommended funding specialised advocates to work with First Nations people with disability. This work should also engage First Nations people with disability living in rural, remote and very remote areas, and allow for in-person, place-based outreach and training development and delivery. This approach aligns with the Disability Royal Commission recommendation on remote workforce development and strengthens the employment of First Nations people with disability. This work also aligns with the Strengthening a Culturally and Disability Inclusive Workforce element of the [National Disability Footprint](#).

DANA, in partnership with FPDN, has recommended a total investment of \$2.725 million for FPDN over the period to end of June 2025. To better define this work, DANA recommends further engagement and discussion with FPDN on needed projects, project scope and potential costings. We also call for a strong investment in culturally safe advocacy and resources for First Nations people with disability. Please refer to our pre-Budget submission for greater detail as to these immediate proposals we have recommended, involving funding to First Peoples Disability Network to:

- explore First Nations workforce upscaling with a dedicated scoping project;
- develop training resources for advocacy organisations working with First Nations people with disability;
- develop culturally safe and accessible resources to inform people about independent disability advocacy;
- pilot a new community hub in Far North Queensland; and
- map First Nations advocacy needs going forward.<sup>91</sup>

There is a strong need to understand what advocacy supports are needed by First Nations people with disability, what capacity the sector currently has to deliver these supports, and how supports should best be delivered to ensure cultural safety and accessibility. To this end, DANA recommended an investment of \$1.5 million into mapping the First Nations

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<sup>90</sup> Royal Commission

<sup>91</sup> Disability Advocacy Network Australia (2023) [A strong sustainable future: addressing capacity shortfalls for a strengthened disability advocacy sector](#), pp21-25.

disability advocacy sector in preparation for new advocacy funding arrangements after mid-2025.

Other key areas that we highlighted in our pre-Budget submission for sector capacity building were for:

- a specific disaster fund for advocacy organisations to draw from to provide high intensity emergency supports.<sup>92</sup>
- Investment in supported decision making outreach and awareness.

The latter emerged as a theme during our consultation with advocates on the prevention of violence, abuse, neglect and exploitation during the DRC:

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*“Supported decision making is so important and if we had more funding for this it would certainly help in preventing abuse and neglect by having this readily available. It is really hard to get this support for our clients and even harder in our rural areas. If we gave people an opportunity and took the time for them to communicate their own needs, it would be really helpful.”<sup>93</sup>*

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<sup>92</sup> Extreme weather events, like intense heat, drought, bushfire and floods often disproportionately impact rural, regional and remote populations – public health crises such as COVID-19 may severely affect already thin or failing markets of disability supports and leave people with disability isolated and unsupported. During our NDIS Review Engagement and Solutions project, we selected ‘Fires, Floods and COVID-19’ as one of four topics of focus during our engagements to inform the NDIS Review last year. We published a [Discussion Paper](#) authored by Elly Demarschelier that summarised evidence, articulated problems and proposed solutions that would assist in future pandemics and in other emergencies or disasters. To read examples and additional solutions that DANA heard during our engagement with advocates and people with disability, please refer to the [Summary Report](#).

<sup>93</sup> VIC Advocate, "Advocates Zoom In On... *Safeguarding rights and wellbeing*", December 2020 Zoom discussion

## Meaningful co-design

Co-design to develop and implement the actions outlined by the DRC and NDIS Review area a common component of many of the recommendations in their final reports. DANA strongly endorses all future reforms be guided by the “nothing about us without us” principle at the heart of the disability rights movement. Yet to genuinely support the inclusion and involvement of people with disability in co-design and decision making (and oversight and governance), resources and development are crucial, particularly to ensure that the most marginalised people with disability have their voices and expertise heard.

DANA is hopeful much co-design will flow from both the DRC and NDIS Review, to address the urgent problems discussed above,<sup>94</sup> which paint a very bleak picture of the current state of play for people with disability in regional, rural and remote areas. Effective, locally adapted and responsive implementation of a range of proposed improvements to market monitoring and stewardship, safeguarding, equity and accessibility could potentially have profound impacts in the lives of some of the most disadvantaged and marginalised Australians.

However, the voices, experiences and perspectives of those who will be most affected by these reforms will not be heard or able to genuinely inform their development, if the capacity of representative and advocacy organisations is overstretched by the pace of reform and lacking the resourcing to respond to consultations and opportunities to provide input, advice and expertise. Rather than being considered one of the stakeholder groups, people with disability must be at the centre of the reform processes. If disability representative and advocacy organisations are not at the table, we fear that design, implementation and oversight of new policies and laws will retrace the past mistakes of exclusion, inaccessibility and discrimination and miss the mark in preventing violence, abuse neglect and exploitation of people with disability.

In our detailed recommendations to the DRC, DANA specified the need for “dedicated funding for advocacy and disability representative organisations to support building the capacity of people with disability in:

- Self-advocacy and advocacy skills;
- leadership and representation; and
- advisory and decision-making processes, including in community, public and private sectors at local, regional and national levels.”<sup>95</sup>

To support meaningful co-design and consultation, the advocacy sector needs to be resourced or this engagement will run the risk of being tokenistic and inauthentic, and of perpetuating exclusion without properly incorporating or reflecting the needs and perspectives of people with disability.

We have therefore joined with fellow national disability representative organisations to call for the swift establishment of a Disability Reform Implementation Council, led by people with

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<sup>94</sup> See also further examples and case studies included below in Appendix A.

<sup>95</sup> Disability Advocacy Network Australia (2022) [Independent disability advocacy – DANA submission to the Disability Royal Commission](#). See Attachment A, Recommendation 2.f.

disability and our organisations, to oversee Disability Royal Commission and NDIS Review changes.<sup>96</sup> Disability representative organisations must receive additional systemic advocacy funding for the next five years to engage and lead on reforms from the Disability Royal Commission.

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<sup>96</sup> See Disability Royal Commission Response Consultation - A joint submission from Disability Representative Organisations.

# Appendix A - Case studies and examples

## Experiences of NDIS processes

*“Access to support services are limited at best to rural and remote clients.*

*In relation to access, there is lack of organisations that will provide pro-bono support for participants in the access phase and the Partners in the Community (PITC) who are meant to help people complete Access Request Forms (ARFs) can be disinterested in providing support. There seems to be a lack of clarity from Partners in the Community (PITCs) about what their role is or interpretation on how they will deliver their contract.*

*In the rural region where [advocate] is located, in the post-COVID period, the NDIA and the PITCs used to undertake home visits for planning conversations for both initial plans and for reviews, however these services are no longer offered and many of the PITCs have reduced their vehicle fleet limiting access to face-to-face appointments if the client requests a home visit either due to their disability or lack of transport.*

*Many clients have no access to transport, be it private or public and the costs of accessing services can be inhibitive and often for people with complex disability, intellectual disability and a range of co-morbidities, telehealth is not a preferred option and can be dismissive, intrusive and in many instances triggering for clients and potential scheme participants.*

*The review process as well – due to there being a lack of client visibility – means that an often nameless and faceless person make decisions around funding upgrades and downgrades on perception and even the Guided Planning Tool that the NDIA and formerly the partners used appears to allow for funding allocation based on a sense or individual judgement.*

*Making a participant Agency Managed could be used as a punitive arrangement and this simple plan type change severely limits access to supports in rural and remote settings meaning clients need more assistance to connect with supports are unable to access them as providers must be agency registered and in rural and remote areas, this limits the talent pool or supports and workers.”<sup>97</sup>*

- *“High numbers of unregistered and unscrupulous providers – fraudulent practices, and tying a person up for all services under the one provider or linked providers--*
- *Providers, particularly sole operators do not understand their obligations – few resources or opportunities for people to understand*
- *NDIA Community engagement roles have reduced to a ridiculously low level making it impossible to increase knowledge of the scheme for either providers or participants*
- *[Re Quality and Safeguards] Lack of responsiveness, transparency, proactive education and training, on the ground action make it ineffective at the day to day to*

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<sup>97</sup> Deidentified input from an advocate working in rural and remote areas (received by DANA February 2024).



*day level – there needs to be a much stronger, responsive and transparent approach”<sup>98</sup>*

### **Factors contributing to demand for NDIS-related advocacy in central Australia:**

- *“...Skill levels of Support Coordinators appear to have declined, and many have reduced their roles to pretty much a service broker, as the complexity of the client’s needs are not able to be addressed in the allocation of support coordination hours*
- *Case management is desperately needed to ensure both a coordinated approach across service providers and a response to the severe disadvantage of the client group.*
- *Most Aboriginal people on the NDIS remain on the advocacy caseload for an extended period as they cannot manage the NDIS related issues without assistance*
- *The lack of access to diagnostic and support services in prison has led to increased workload in supporting the completion of Access Requests for people awaiting release.*
- *Staff shortages across the NT have led to shifting of responsibility or issues arising – e.g. Office of the Public Guardian and Trustee*
- *Overreliance by government agencies on telephone or web based service delivery excludes people without access to these resources, which means they need an advocate to assist”<sup>99</sup>*

### **Examples - Information deficiencies causing poorer outcomes and increased vulnerability**

- *“Client could not obtain the needed information to a lack of appropriate internet service.*
- *One client reported not knowing the pathway to access information and did not know what to ask, whom to ask.*
- *Clients receiving the DSP presume they are automatically eligible for access to the NDIS.*
- *Persons were unaware of Advocacy, what it means and what Advocates can assist with.*
- *Clients receiving inconsistent and contradictory information from the NDIS enquiry line.*
- *Advocates receiving inconsistent and contradictory information from the NDIS enquiry line.*
- *Clients receiving inconsistent and contradictory information from different NDIS partners/services (LAC vs NDIS vs Plan Manager vs SC) and are unable to effectively make decisions.*

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<sup>98</sup> Disability Advocacy Service (Alice Spring, NT) input about advocacy in central Australia, 2023 (received by DANA February 2024).

<sup>99</sup> Disability Advocacy Service (Alice Spring, NT) input about advocacy in central Australia, 2023 (received by DANA February 2024).



- *Complex, confusing, and inaccessible NDIS processes and related bureaucracy limits and often stops clients from completion of documentation and access to information.*
- *Family members and carers of participants with average and high levels of education struggle to navigate the complexity of the NDIS processes.*
- *Participants do not fully understand the nature and effect of NDIS packages; many participants see NDIS as an intrusion in their lives.*
- *Potential participants have no grasp / are unaware of what supports are possible / available.*
- *Residents of rural and remote areas have developed a resistance and “can do it on my own” attitude where they do not ask for help, don’t want to be vulnerable, don’t want people to know their business.*
- *Privacy concerns in small communities as everyone is connected. People do not want to reach out because it means sharing their private information and situations.”*
- *[NDIS Communications] “needs to focus more on inclusivity of cultures and language barriers.”*
- *“Government agencies do not communicate with each other, neither do regulatory and statutory authorities and even the NDIA & NDIS Quality & Safeguards Commission have poor communication between those agencies.”<sup>100</sup>*

### **Examples – Interaction with NDIA causing feelings of distress, anxiety and hopelessness**

- *“Clients/participants often feel NDIS is intrusive.*
- *Participants with a NDIS package not aware of how/if they should be accessing NDIS supports, particularly to avoid crisis situations (i.e. homelessness, entering the justice system or child protection systems)*
- *Families, particularly parents with young children or adults with reduced capacity, compare their child’s packages with other participants, this causes anxiety, a sense of injustice (inequities in funding) and emotional turmoil*
- *Individuals, either participants, plan nominees or parents have unrealistic expectations about what exactly “reasonable and necessary” is.”<sup>101</sup>*

### **Gaps in information, quality and safeguarding**

- *“Education is the key and providers should be penalised and made to pay back exhausted funds, particularly if the participants are unaware of what their funds are being accessed. There is a systemic failure in the lack of accountability and duty of care, which is prevalent within a regulated scheme*
- *More education to NDIS participants & plan nominees is needed (how to know when your NDIS funds are being exploited & mismanaged)*

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<sup>100</sup> Rights In Action Inc. (Cairns, QLD) input (received by DANA February 2024).

<sup>101</sup> Rights In Action Inc. (Cairns, QLD) input (received by DANA February 2024).

- *NDIS providers need to review service delivery models to ensure that [disability support workers] are adequately trained and fully aware of individual care plans, routines, preference, and choice over their day-to-day activities.”*
- *LACs should have more accountability in providing accurate, information to new participants (and their families/plan nominees) regarding the NDIS, principles, code of conduct and how it is to be applied*
- *NDIS provider performance should be subject to a “Star Rating System” which measures the relative success of providers in providing quality care and supporting their participants to achieve their individual goals...*
- *The existing regulatory body, the NDIS [Quality and Safeguards Commission] is already responsible in monitoring providers, but what needs to improve are outcomes for participants which is evidenced-based.*
- *There needs to be more accountability in the NDIS Workforce Capability framework, that ensure providers are upholding their organisational responsibilities as it applies to their workforce recruitment, selection, training, service delivery, communication with participants and educating participants & families on their support capabilities as it applies to the individual participant’s needs”.<sup>102</sup>*

### **Case study - G**

*Client G is an NDIS participant living in a SIL [Supported Independent Living] property organized by provider XYZ. G’s first language is not English, and he does not have a mobile phone or means of contacting his DCLS advocate directly. G depends on XYZ staff to help set appointments. Part of G’s advocacy matter relates to the conduct of service provider XYZ, including breaches of the NDIS Code of Conduct<sup>69</sup> and Restrictive Practices. <sup>70</sup> XYZ consistently delays G’s advocate’s contact attempts. XYZ’s property is based in a rural area, which incurs significant travel time, making unsuccessful visits a large drain on time and resources, but the only way to assist H. During the course of assistance, G’s advocate also attended G’s residence to find that XYZ had moved him to another rural property in a different area, without informing G’s advocate of this move.*

### **Examples - No travel, no access**

*“While services are not available in remote locations, NDIS plans do not include travel to required services so participants in thin markets miss out.*

*M - a two-year-old client diagnosed with Autism Spectrum Disorder (ASD) severity level 3 - required interventions of speech and language therapy, occupational therapy and physiotherapy. There is only one speech therapist in the whole of NT, only limited occupational therapy and physiotherapy, and no substantive language therapy. None of these services apart from physiotherapy is available in Nhulunbuy where the client lives. Incredibly, flights to Queensland - where he was able to access intensive therapy sessions with all providers - have not been approved by the NDIA, who maintained that the cost should be met by his parents.*

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<sup>102</sup> Rights In Action Inc. (Cairns, QLD) input (received by DANA February 2024).

Another client, non-verbal and severely disabled, sought assistance to fly from Maningrida to attend a review meeting of his plan in Darwin. He was refused because travel is not allowed under a plan. Previously DCLS had arranged for him to attend in Darwin for plan meetings by combining the visit with respite, but respite is no longer allowable under his plan.”<sup>103</sup>

“One of things we have talked a bit about here at DAS is about how to ensure that people living in a very remote setting do not have their plans eroded by extremely high travel costs or having to come into town to receive services necessitating use of core funds for short-term accommodation. One solution is to consider having a very small handful of preferred providers (support coordination and allied health in particular) attached to towns so that there can be more efficiencies achieved in service delivery. The reason for this is so that when a provider goes out they are encouraged to see more than one client so travel costs can be shared.”<sup>104</sup>

“people with disabilities do have a lot of specialist and medical appointments that can be quite a far distance away from their properties, especially now with SILs, more moving into the regional areas. So I've worked with a lot of clients that are struggling with funding that transport and having to pay for some of it with their pension, which has been really difficult, and I guess as well working with people with disabilities that can't reach NDIS access, and are trying to fill out paperwork for things like the taxi subsidy scheme, and the patient transport subsidy scheme, and it is not a straightforward process, which is really frustrating for people that do need that extra support to fill out that paperwork as well.”<sup>105</sup>

### **Examples – exploitation by providers**

“...we put a lot of effort into getting NDIS access for people, particularly with acquired brain injury and mental illness. The local area coordinator here has been referring people to [QLD service provider] for some reason when there are other service providers that are supporting people very appropriately with psychiatric illness.

It's just because the clients have told me, so-and-so, or my support coordinator has contacted me, they want to come in and sign some documents. So I come in with them and suddenly they're signing forms to have to pay for a cleaner to come in every week for \$100 when their unit is only about four by four metres and already spotless. So we're going to keep an eye on that.

... One client just wanted to join a certain service provider because they have ten pin bowling and other things. [QLD service provider] had forms for him to sign, and I think the plan management is external, but they go to a speech therapist, etc, and he can speak fine.

Anyway, the reason I'm bringing that up is that is very subtle. I'm fearful for someone who is non-verbal and more vulnerable being at the hands of this sort of practice. Where you could tell by the look on the face she didn't really like the advocate, even though [she had] a very friendly smile and was quite generous with her time, and it was interesting to observe. It was

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<sup>103</sup> Darwin Community Legal Services (2019) Thin Markets Project (Submission), p4.

<sup>104</sup> Disability Advocacy Service (Alice Spring, NT) input (received by DANA February 2024).

<sup>105</sup> QLD Advocate, Advocates discuss transport accessibility (DANA discussion September 2022).

*the same with people with cerebral palsy and non-verbal, [who] have been defrauded, workers taking money out for cigarettes and saying they will pay it back on payday.*

*And that just doesn't seem to alarm people. So I'm just trying to put things in a nutshell so, but it makes me extremely fearful for very vulnerable people having very complex medical needs being met when these seem to be the blatant practices that we just see first-hand.”<sup>106</sup>*

#### **Inequity of living in a remote community affecting plans**

*“Client F is an Aboriginal child with disability in a remote NT community. F received an NDIS plan, but F’s family received no assistance in understanding the NDIS or the supports they may be able to access. After one year, F’s plan is reviewed, and the funding is cut significantly, the NDIA reasoning that as it was underutilized the funding must not be necessary. F’s family sought assistance in appealing this decision. In the internal review our service argued for funding for therapists to travel to F’s community to provide early intervention supports. In the internal review meeting the IRO admitted to having no understanding of the location or attributes of F’s community. The IRO decision confirmed the decision under review. The plan was still cut. F’s family decided not to pursue the appeal further, as even though they have attempted to engage with the NDIS for over a year, they have not seen any benefits to F.”<sup>107</sup>*

*“B is a client from Ngukurr (635 km from Darwin) ... She initially received a large amount of funding in her plan which was directed at purchasing supports to allow her to stay living in her community. When her plan was reviewed recently, the NDIA reduced her core support funding by 45%. In an email explaining this decision, the NDIA advised that her core funding was reduced because of “under-utilisation and thin markets”. A further nine NDIS participants in Ngukurr incurred similar funding decreases during plan reviews because the services they so desperately need are not available. Participants on nearby Groote Eylandt are suffering similar reduction, with their plans being cut by an average 31% largely due to lack of services.*

*It becomes a vicious circle: where participants cannot access the NDIS, demand and service availability declines. Statistically, the extent of the problem is diminished and disguised, while some of the most vulnerable people in Australia are denied access to essential services.”<sup>108</sup>*

*“What we are seeing is that there are very limited options for core support delivery in remote settings, so people may have things like household assistance or community access in their plan, but they are not able to use it.*

*Points of contact at local level would be really helpful too e.g. with local councils or health services, so that there is someone on the ground who can assist people to keep*

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<sup>106</sup> QLD advocate, Advocates Discuss supported decision making, September 2022.

<sup>107</sup> Case study from Darwin Community Legal Service (2022), *Submission into the Disability Royal Commission - Lived experience highlights multiplicity of factors in the NT continuing to expose people with disability to violence, abuse, neglect and exploitation*, p50-51.

<sup>108</sup> Darwin Community Legal Services (2019) *Thin Markets Project* (Submission), p4.

appointments. As an example we have a client in a very remote setting who has been accepted onto the NDIS but his plan has never been developed because there is no one to make sure gets to a meeting, or he cant be located at the appointed time.

Another big difficulty in very remote settings is the high level of mobility of the client group – I'm not really sure of an answer to this but it would be great to have stronger 'buy-in' from local services or councils. The loss of the NDIS Community Engagement Team is a real shame. Education about the scheme needs to be ongoing. I don't think they understand how incredibly complex and incomprehensible it is to people in remote settings."<sup>109</sup>

## Impact of access to independent advocacy

### Case study – K

*"K is a young 17-year-old Indigenous woman with intellectual disability who lives in a small town in regional Queensland.*

*In early 2020, K was referred to [QLD advocacy organisation] by a local psychologist. K had disengaged from school nearly two years ago. She had been living with her father, however he passed away suddenly last year so she had to move back to her mother's house. She began getting into trouble with the 'wrong crowd' and engaging in criminal activity. She was drinking alcohol, using substances and was considered at high risk of pregnancy, offending, and suicide, particularly given her grief over the loss of her father with whom she had a close, supportive relationship.*

*K suddenly left town and became very hard to track down, but she was located through the extensive networks of E, the organisation's Indigenous liaison officer, that K had begun couch surfing with friends in a nearby city. E identified agencies that had a professional relationship with K and was able to obtain relevant reports that would serve as supporting evidence for an NDIA Access Request. The Access Request and supporting documentation was compiled and submitted to the NDIS by the Decision Support Advocate.*

*Within a fortnight, a delegate from the National Access Team phoned the Advocate to discuss K's situation in more detail as part of her decision-making role. When it became clear that there was no more formal supporting evidence that could be provided to support K's Access Request, that delegate sought further information about K directly from the advocate during a detailed phone interview. Later that afternoon, K was granted NDIS Access!*

*Since then, the Decision Support Advocate has been meeting weekly with K to help her to prepare for her NDIS Plan Meeting, by mapping her current supports, helping her to envision a future, determine her goals and become clearer about what supports would be required to achieve those goals. K is now ready to schedule her Plan Meeting and is about to embark upon a new life where she will have access to additional support to achieve her goals and where some of her incredible dreams may now become a reality."<sup>110</sup>*

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<sup>109</sup> Disability Advocacy Service (Alice Springs, NT) input (received by DANA February 2024).

<sup>110</sup> Case study from QLD advocacy organisation.



## **Case Study - C**

*“C is a 59-year-old man suffering from the degenerative neurological condition, Huntington’s chorea. He has a family history of this condition, and first noticed symptoms five year ago. He is estranged from his family. C became a client of a regional disability advocacy organisation.*

*Following extensive hospitalisation following injury during bush fires and diagnosis, he went to live in the local [supported residential service] after his property burnt down. The advocacy organisation supported C to engage with the NDIS and a change of circumstances reviews for the participants/nominees (NDIS) occurred. Referrals have been made to support to access neurological appointments at the specialist centre in Melbourne, using Red Cross Voluntary Transport. Referrals to appropriate allied health professionals, such as OT’s, physiotherapists, dieticians, speech therapists. NDIS assisted with purchase of walking frame to stabilise mobility. Referrals also made to local Planned Activity Group for social contact.”<sup>111</sup>*

### **Case study – parenting supports**

*“I have a client... it has been five years in the making, but the family now has full reunification and they both have mild intellectual disability, and they also lived in a rural area. There were supervised visits for a significant period of time. ...In one of the meetings, we discussed it. We said one of the parents has an NDIS package and one of the goals was for parenting, around parenting, to be supported in the NDIS package and to be a parent.*

*We worked on those dynamics, and at one stage Child Safety would not help ...it took a lot of work to get them to think outside the box using NDIS support workers and support services, to do some work with the support services on what they were hoping for them to do. So that they can start doing supervised visits for child safety, and because they were rural and coming out every 4-6 weeks, it was not a significant amount of time. This would start happening every week, and then twice a week, and then we went to semi-supervised and it was agreed that support services would report any concerns to child safety and at the same time it was using their NDIS package. So that is the way that they managed to get through, and to get through from supervised once a month to supervised twice a week and into semi-supervised and then unsupervised to then full days, sleepovers, and now that child is in full unification - that took five years.*

*The parents were a significant part of the child's life through that whole time. And I was very lucky because I became involved while the mother was pregnant. They did, at one stage, want to put the child in foster care in another region which would have meant that they would not have ever seen the child. I took that one to court and we did win that.*

*It was a long process but it can work. You have to make sure it’s part of the parent’s goal and then you have to really try to negotiate with child safety. It did work, but we had to give them*

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<sup>111</sup> VIC regional advocacy organisation - Bushfire effects in East Gippland– May & June Report 2020

*the ideas. We had to get them to start thinking outside the box of how they could do this, supervised visits and unsupervised, through using the person's package.*"<sup>112</sup>

## First Nations experiences

*"...Some families have high levels of English literacy and have had a lot of engagement with services over a long period of time, and are pretty comfortable with using complaints processes. We've got other families who might have huge issues.*

*One family I'm thinking of, there's five adult children who all have brain injury from petrol sniffing. The mother of those adult children has a psychiatric disability, the father of those adult children was an alcoholic who has since passed away, and that family just don't have the capacity despite lots of support. And often they're really focused on the here and now, today, have we got enough food, have we got shelter, is there some domestic violence going on in some aspects of that family? They're not interested in a process that's going to be protracted. They want a fairly immediate response, and a lot of complaints processes are quite protracted. So that's another disincentive to people to actually follow through with those processes.*

*But some families just don't have the capacity. They're in survival mode and they let a whole lot of really inappropriate things happen, and they don't care because it's more important to worry about whether you've got food that day..."<sup>113</sup>*

*"From our perspective... that family that I just talked to you about, what's made a difference is one of the people in that family has met the threshold for an NDIS plan, and it looks like now she will end up in Supported Independent Living (SIL). Her plan is being reviewed. That has made a huge difference to her life. ...We're saying to people that services can actually help you and support you and you can have better life outcomes. So she's gone into a SIL situation which is extremely flexible and culturally appropriate, so not like normal SIL. She's really, really, well supported, and she is getting the care that she needs and that care, the kind of upshot of that, will be that she will be able to better look after her own children and make sure they go to school. And hopefully they will have, kind of, better life outcomes than her because she ended up at 16 having a stroke from petrol sniffing. She's had three children, one of them cared for by another family member, two others are still in her care, and the SIL is going to make the difference to her being able to provide adequate parenting.*

*I guess from [our organisation's] perspective... often people have the solutions themselves. Those solutions involve being able to stay in community. You shouldn't have to go away to get the support that you need. You shouldn't be told if you need services you've got to be in an urban centre. But listening to the innate wisdom that people have about what they need to resolve their situation, and doing everything you can to act on that, yeah, trusting that individuals actually do have the capacity to identify what they need to have a good life."*

*"... there has been a few stuff ups, there's no doubt about it, but all along the way they've maintained a commitment to trying to provide a culturally appropriate service, and for this*

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<sup>112</sup> QLD Advocate, "Advocates Zoom In On... Child Protection Systems", November 2020 Zoom discussion

<sup>113</sup> NT Advocate, November 2020 Zoom workshop with DRC.

*particular lady and for others of ours who have come from remote, coming from remote into a SIL environment is a huge shock because people are used to just doing whatever they want to when they're out in community. So to have a SIL that is much more open, and flexible about supporting people in the way they want to be supported, is a real benefit.”<sup>114</sup>*

In a 2020 DANA workshop, one advocate from Queensland highlighted the time and resourcing needed to build relationships of trust with local First Nations communities to help facilitate NDIS access and planning:

*“We identified in one of our rural/regional areas, it was not being covered and there was a lot of people missing out on NDIS access. There were a lot of First Nations communities. We were able to get funding for one year for supporting NDIS access, but the barriers were still there, and that took a lot of building those relationships. Some of those areas still weren't covered and there is a massive concern out there that in remote and rural areas where a lot of communities are, that the supports are not there. ...It takes a long time and a lot of the areas are not covered. That's the barriers I feel that we face”.<sup>115</sup>*

An Aboriginal Self Advocate highlighted the importance of responding to the diversity of First Nations people and of building local connections:

*“... every Aboriginal community is not the same. We are very different, we are very diverse, we have different needs and different resources. We have different aspirations and different interests as well. We cannot do a blanket cover for everybody, you know? Everyone has to be looked at individually throughout Australia. You have got traditional people, you have got urban people, who all have different needs. Some are isolated, socially isolated as well as geographically isolated. One solution does not cover all.”<sup>116</sup>*

### **Case study – North QLD**

*“In March 2020, an advocacy organisation began assisting a 19-year-old First Nations woman from the Atherton Tablelands with suspected foetal alcohol spectrum disorder (FASD). The young woman was homeless and at a high risk of physical, emotional, financial and sexual abuse. Despite experiencing significant difficulties, she did not have access to disability supports or a disability support payment due to the lack of a formal diagnosis of her disability.*

*When advocacy commenced, she underwent specialist tests to obtain the medical evidence needed but missed or terminated many appointments due to her lack of appropriate accommodation, declining mental health and substance abuse. In December 2020, she moved into a Department of Housing unit as a result of close collaboration and advocacy support.*

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<sup>114</sup> NT Advocate, November 2020 Zoom workshop with DRC.

<sup>115</sup> QLD Advocate, "Advocates Zoom In On... Advocacy for First Nations People", November 2020 Zoom discussion

<sup>116</sup> NSW Self Advocate, "Advocates Zoom In On... Advocacy for First Nations People", November 2020 Zoom discussion



*In early 2021, the clinical psychologist at the Aboriginal Medical Centre was engaged through advocacy support and the formal diagnosis of FASD was provided. A private occupational therapist conducted a full functional capacity assessment to identify the young woman's support needs in day-to-day life with funding from a disability support service. The following month, a NDIS application was submitted.”<sup>117</sup>*

*“Aboriginal & Torres Strait Islander participants are concerned they must relocate to regional or urban areas to get NDIS supports to meet their specific disability support needs. This creates anxiety and fear of being dispossessed, reliving the intergenerational trauma of historical forced removal of children & young people (stolen generation), loss of culture, lore, and connection to country.*

*...[Possible role for] Aboriginal Shire Councils [in] creating a safety net for their community members, engaging and collaborating with NDIS service providers servicing indigenous communities.”<sup>118</sup>*

*“Having worked in an Aboriginal organisation for almost 18 years I have seen how important it is for Aboriginal people to access advocacy support through an organisation they know and trust.*

*Aboriginal people in our region are very reluctant to engage with services and staff they don't know and certainly would not comfortably raise issues and concerns with strangers.*

*The history of colonisation and the impact of the Stolen Generation and ongoing policy decisions by Governments which exacerbate the disadvantage experienced by Aboriginal people in this region have led to high levels of mistrust and fear of mainstream services.*

*It is critically important that these most disadvantaged Australians continue to have access to advocacy support through an organisation they own and have agency over.*

*Our model of individual advocacy is culturally safe & appropriate. It was developed by local ... people to reflect the specific needs of people with disability in [our] Region.”<sup>119</sup>*

## **First Nations Focus – gaps and recommendations from Spinal Cord Injuries Australia (SCIA)**

*SCIA has recently employed a First Nations Peoples Representative Advocate. This new role involves building relationships within communities to better understand the needs of First Nations peoples with SCI and similar disabilities, to develop targeted advocacy including self-advocacy resources.*

*Initially this role is focussed in NSW in the three Nations of Gomeroi, Wiradjuri and Gadigal, with conversations taking place in the rural and regional areas of Cowra, Queanbeyan,*

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<sup>117</sup> Queensland Independent Disability Advocacy Network (2022) *Data Analysis January to June 2022* – Submission to Department of Seniors, Disability Services and Aboriginal and Torres Strait Islander Partnerships, p28. [QIDAN data analysis – Pathways](#);

<sup>118</sup> Rights In Action Inc. (Cairns, QLD) input (received by DANA February 2024).

<sup>119</sup> 2022 consultation about advocacy – comment from NT advocate.

Moree, Tamworth, Bathurst, Orange, Dubbo, Parks and Forbes to date. Initial conversations have highlighted that:

First Nations people in rural areas are often:

- not even trying to access the NDIS and relying on community members for support. In this instance the community members are missing out on supports that would vastly improve their quality of life and are often withdrawing from their communities.
- being put immediately on to aged care. In this instance people receive some support but not appropriate supports that do not assist them to manage their (complex) disabilities.

First Nations peoples are reporting that their reasons for not trying to access the NDIS include:

- Not having sufficient information (or not having information provided in a culturally appropriate way) about how to apply for the NDIS.
- Feeling unsupported (or that support provided is not provided in a culturally safe way) and thus they do not know how to access the NDIS.
- Because of the access to Aged Care being set at a lower age for Aboriginal and Torres Strait Islander peoples, it is believed that support workers find it simpler to access aged care instead of the NDIS.
- Historical discrimination has left many of the older males in rural communities, unwilling to seek the medical supports that are a referral pathway into the NDIS.
- First Nations peoples will give up attempts to access services if the support worker is unable to build trust or they feel like they have not been engaged in a culturally appropriate way.

Because of the barriers and distrust in these communities, the clients report that the solution they would like to see is to have First Nations people who are trained to explain the NDIS and support, in a culturally appropriate way, First Nations peoples with disability to access the NDIS.

Whilst we acknowledge that the lower age for access to Aged Care services has merit because it enables people to be supported with complex health issues at an earlier age, it should not be a barrier to First Nations peoples having timely and appropriate access to the NDIS.

First Nations people need to be employed as a priority into the roles of Independent Advocates and NDIS information provision to assist First Nations peoples to access the supports they are entitled to.

## Culturally and linguistically diverse experiences

### Case study – Senait

*“Senait arrived in Australia two years ago, has limited English literacy and no extended family support in Australia. Both Senait and her partner are deaf and use Auslan as their primary form of communication. She presented with three issues of concern. Senait was concerned about her three-year old son’s language development and social isolation because both parents are deaf.*”

*She had commenced an English language course at TAFE; however, she did not have access to Auslan interpreters when attending classes and was concerned she would not be able to successfully complete her studies. She was not aware that disability support services were available at TAFE.*

*Senait's NDIS plan had recently been approved. She advised the advocacy officer that she did not feel understood during the planning or the implementation meetings, and that the plan did not meet her support needs.*

*The advocacy officer discussed family support service options with Senait and provided her with information about services close to her home. The advocacy officer provided information about disability support services available through TAFE and relevant staff contact details. After discussing strategies to negotiate for the services she needed, Senait felt confident to liaise with them directly. At all times Kin advocacy staff encourage clients to self-advocate with support from staff if required. The NDIS plan review process was explained to Senait and Kin helped her to gather relevant evidence and information to support her case. Kin provided advocacy support to lodge a plan review (review of a reviewable decision).*

*Senait now accesses a Child and Parenting Centre near her home where her son is enrolled in a program to support his development. The family are also participating in family activities at the centre. Senait contacted the Disability Support Service at TAFE directly and now has an Auslan interpreter during class and the support she needs to complete her course successfully. A review of reviewable decision application, including supporting documents, has been lodged with the NDIS. Senait is currently awaiting an outcome."<sup>120</sup>*

### **Case study - Mikal**

*Mikal is a 16-year-old living in a regional WA. Mikal has an intellectual disability and cognitive impairment. He was referred to Kin Advocacy by his school liaison officer as his primary carer's health was rapidly declining. The school liaison officer requested support to place Mikal in safe out-of-home care before his primary carer became so unwell that crisis intervention was necessary. Mikal's extended family were aware that his needs could not be met in his current living arrangements and it was not possible for anyone else in the family to provide the necessary support. The extended family and members of the local community had raised concerns with the appropriate authorities regarding Mikal's vulnerability. Even though Mikal's disabilities meet the criteria to access support services, the family had not been offered support from relevant services. Mikal was not attending school at the time of referral to our service. He needed advocacy to access supports through multiple agencies, re-engage with school and test eligibility for NDIS to develop an appropriate NDIS plan.*

*Due to COVID-19 restrictions and regional boarder closures, all meetings were held via teleconference. All agencies that had a necessary role in meeting Mikal's support needs were contacted. Our agency and a local community service provider worked collaboratively with Mikal's family to establish regular multiagency meetings to address Mikal's immediate needs, ensure he was safe and progress planning to meet future support needs. A meeting was held with the deputy principal at Mikal's school to discuss necessary supports to enable*

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<sup>120</sup> Kin Advocacy (WA) - case study featured on website: [Senait's Story - KIN \(kinadvocacy.org.au\)](https://www.kinadvocacy.org.au)

him to attend. The advocacy officer provided information about the NDIS to Mikal and his carer. She also liaised with local services to collate relevant evidence of disability. Mikal's NDIS Access Request form was submitted, and he was accepted for the scheme. The Kin Advocacy officer provided support at Mikal's planning meeting via telephone. Kin Advocacy provided Mikal and his carer information about the range of services available in the region.

Mikal is transitioning back to school and currently attends every day for a limited time. This will be increased as he builds his confidence with both staff and students. The timing of Mikal's NDIS plan approval coincided with the onset of COVID-19 restrictions and limitations on regional travel. Now that travel restrictions have been lifted, Mikal's NDIS plan supports are starting to be implemented. Mikal's carer is aware there is the option of requesting a plan review should the funded supports not meet his needs. Mikal is trialling an out-of-home care option with the view to eventually being provided with a safe place to live."<sup>121</sup>

### **Example – inaccessibility**

"... in [our area], it's a very multicultural area and we come across people with disabilities and their families that are not connected to services, don't even understand, never heard of advocacy. We've met somebody recently who's 45 years old, intellectual disability, not on the NDIS, being cared for by his 95-year-old mother from a CALD background that is no longer able to look after this person. So I think the Government needs to - and even advocacy organisations maybe have a little bit more funding to go to have more of an impact on people from cultural and linguistic backgrounds in a point of view from providing information, basic information, as to what services are out there and how to access advocacy organisations."<sup>122</sup>

### **Examples – need for time-intensive support to engage in culturally appropriate ways**

"We are linking in with the local multicultural service and wanting and requesting that we can do some sessions, information sessions, with their paid staff and their large volunteer contingent to share about our service in terms of its advocacy, general issues, NDIS and also the Disability Royal Commission.

We are really aware of our lack of reach into other communities. We have made some gains in the local Sudanese community, but COVID-19 made that enormously difficult to maintain supports in .... in terms of accessing interpreters in a timely way. Because we are very aware that different community groups have different ways of working, it will often be a drop-in session rather than a set appointment - we tried that, and it did not work - so it was a bit more responsive, but also extremely difficult off the back of that to get an appropriate interpreter who spoke that specific regional language.

When hearing was an issue as well, we obviously could not use a telephone interpreter because those are the ones that are the quickest to get. So those are some of the complexities of it, and why we are looking at trying to engage with this multicultural service, which does

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<sup>121</sup> Kin Advocacy (WA) - case study featured on website: [Mikal's story - KIN \(kinadvocacy.org.au\)](https://www.kinadvocacy.org.au)

<sup>122</sup> VIC Advocate, April 2021 Solutions focused workshop with DRC

*have that reach, and we'll hopefully be doing some shared training and upskilling of our staff to become more responsive and aware of how we can meet people's needs."*<sup>123</sup>

*"One challenge that the organisation had was whether this type of remote working with CALD families would work, because of the difficulty with meetings not being face-to-face and what have you, and forms that need to be sent, information that needs to be relayed, and using interpreters via phone and zoom and all of these issues and complexities.*

*What they are finding and what I am finding in my last two months is interesting. There are always pros and cons in every situation, but I think what I am finding personally is really fascinating... even though the families I am working with, that our clients and they might have carers, and they may have very little English, how generous and incredibly willing they are, even if it takes me three or four phone calls.*

*Phone calls might take a bit longer, but what I am noticing from this work at the moment is that when... we do reach that point of having that phone call or having that zoom meeting, it is almost like there is this kind of education empowerment they are gaining because prior to this they did not have some of these skills because they were not forced to use the Zoom or computers or things like that.*

*Now it feels like a lot of my clients have settled into the strange world that we are in, and it is interesting, with the right type of tools and the right type of sensitivity and communication skills and what have you, I think it is actually a real positive and strength in that... because they are walking away with more confidence as well.*

*So, coming back to the question, I guess having a platform for CALD families and clients to share their stories, I know from my experience so far with clients that they would be happy to... because there is this trust and rapport that we are establishing, and there is almost this kind of... Just a sense of more things are happening differently, and perhaps I do have more control than I think. Having stories, as we all know, with everything ... going on at the moment, the more stories that are told and shared by diverse communities, and it is not about understanding each particular culture, but understanding that each different cultures have complexities, and you don't need to get it all in one go.*

*But having those stories on a platform is so important because that is the beginning of true grassroots education. Because it is coming from the clients themselves. We are only here to support them and guide them. So that type of advocacy and empowerment for clients to speak about your own stories and share the neglect or abuse or discrimination or what have you, it is a grassroots way of entering the mainstream or the political debate. The more voices we hear from our clients from CALD backgrounds, the more we all benefit, and the more we are able to do our jobs. Communities are becoming aware of these issues, so the barriers that they face, we would hope, in time, lessen or decrease. There is more information, there is more knowledge out there from the communities themselves."*<sup>124</sup>

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<sup>123</sup> VIC Advocate, "Advocates Zoom In On... Advocacy for people from culturally and linguistically diverse communities", November 2020 Zoom discussion

<sup>124</sup> VIC Advocate, "Advocates Zoom In On... Advocacy for people from culturally and linguistically diverse communities", November 2020 Zoom discussion



## Experiences with the NDIA

*"I have several matters that are currently at AAT in relation to underfunding for participants, I can categorically state that if planning conversations for many of these participants had been conducted face to face, that underfunding of supports would not have occurred because people would have seen the risk and outcomes of not funding particular supports. I have examples of cases where once photos have been shown to decision makers to demonstrate the impact of underfunding, the matter was resolved. This can happen after significant time and effort and hardship of going through appeals and escalating.*

*The NDIS has no baseline to speak of around funding, meaning person A does not get access as they can't afford the necessary reports, person B might get \$5,000 of annual funding despite having the same diagnosis as person A and furthermore person C might have on paper the same disability yet they receive \$150,000 worth of annual funding.*

*The migration from the business system from CRM to PACE has further complicated the responsiveness of the agency and this is further complicated for people who are rural and remote. There is no consistency around planning and funding for any participants and once again for rural and remote clients, this is even more so the case.*

*The lack of forward planning to educate the community at large about changes to the NDIS Scheme and the roles of the PITCs morphing has been inadequate. I flagged my concerns to the NDIA's Community and Mainstream Engagement team... and in a separate Email as well as these changes came into play in November last year and there are now plans afoot to communicate to the community the change of roles that the PITCs have undertaken from a Planning perspective to a Community Connector type role.*

*These PITCs in my area do not attend network meetings and from what I hear do not connect with mainstream and alternate services, so it is difficult to understand how they can be connecting clients to services whilst they either wait for the NDIS or in lieu of the NDIS when they do not know what supports are out there.*

*Again, if the NDIA or a PITC is not connected to a community or on the ground so to speak, how do they know who does what and more importantly what a provider's capacity might be?"<sup>125</sup>*

### Case study - G

"Client G is an NDIS participant living in a SIL property organized by provider XYZ. G's first language is not English, and he does not have a mobile phone or means of contacting his DCLS advocate directly. G depends on XYZ staff to help set appointments. Part of G's advocacy matter relates to the conduct of service provider XYZ, including breaches of the NDIS Code of Conduct and Restrictive Practices. XYZ consistently delays G's advocate's

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<sup>125</sup> Deidentified input from an advocate working in rural and remote areas (received by DANA February 2024).



contact attempts. XYZ's property is based in a rural area, which incurs significant travel time, making unsuccessful visits a large drain on time and resources, but the only way to assist H. During the course of assistance, G's advocate also attended G's residence to find that XYZ had moved him to another rural property in a different area, without informing G's advocate of this move."

NDIA being inaccessible and inflexible for First Nations people:

### **Case study - E**

*"E, an Aboriginal person who is a NDIS participant, lives in a remote community. E wants to move back to his home community, which is not the community he is in now. E's home community has some but not all service provider infrastructure in place to fully support E's needs. E has a supportive family member in this community, who would be able to provide the supports for E to on regular 'Return to Country' visits to explore if E might be able to move there permanently. E's family member asks the NDIA if they, as a family member, can provide paid supports to E as part of his NDIS plan. The family member provides extensive evidence, including proof of the cultural needs of E, as well as economic participation in E's home community that he is not able to achieve anywhere else. The NDIA initially does not make a decision, and then makes an unfavourable decision. E and his family spend 12 months at the Administrative Appeals Tribunal, where they finally receive permission to set up E's family member as a paid support."<sup>126</sup>*

### **Example – digital divide**

*"Advocacy is critical for people with disability in remote indigenous communities. Most people with disability in our region have English as a second or third language and literacy levels are very low. It would be almost impossible for people with disability to manage all the requirements of Government without advocacy support. The move away from having staff in offices that people can visit to get information and have problems resolved and toward having all systems eg. My Aged Care, NDIS, My Gov etc. online... assumes that everyone has English literacy and computer literacy. There are cohorts of people in community who cannot navigate these systems and will consistently require advocacy."<sup>127</sup>*

### **Case study – needing to go the AAT to get reasonable and necessary supports**

*Client is a quadruple amputee living alone with her sister. The client was funded by the NDIS for manual wheelchair but needed to upgrade to a powered version. One of the Perth hospitals had provided the use of a power wheelchair on loan (for over 12 months ) but had wanted it returned. Advocacy Action Kin was approached to assist and support the client in an appeal process at the Administrative Appeals Tribunal (AAT ). Originally the NDIA had said the request for a power wheelchair was a duplication of supports given they had funded a manual chair. They wanted our client to evidence the need for the wheelchair which meant the client having to pay through her plan funds, reports from her allied health providers. She was asked to identify the benefits of the power wheelchair compared with a*

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<sup>126</sup> Darwin Community Legal Service (2022), *Submission into the Disability Royal Commission*, p50

<sup>127</sup> NT Advocate, April 2021 Solutions focused workshop with DRC

manual wheelchair when she would use it and for what reason. The fact that she spent around 12 to 14 hours per day in a wheelchair seemed irrelevant to the NDIA. Evidencing the need for the wheelchair was a long process but once it was complete, there were problems with the NDIA accepting a quote for the powered wheelchair, stating that perhaps a cheaper colour could be found elsewhere and was that type of chair really suitable ( despite reports indicating it was ).

Funding for the wheelchair was granted after nearly 7 months fighting the case in the AAT. Prior to that our client had to go through an internal review process that took around 3 months. This was for a case where the need for a powered wheelchair was obvious. The difference between a powered chair and a manual chair was obvious. However, our client had no choice but to go through these processes to get the right outcome...<sup>128</sup>

### The interaction of NDIS processes with child protection systems

“There should be a lot more work that gets done through the pregnancy. I think that that's where things fall down. They wait for the crisis situation, when the child is removed and then all the parenting and everything goes in. It should be the other way round. There should be more considering of prevention, rather than waiting for that to happen... And of late, it's been about communication with NDIS. Child protection workers should have training with NDIS, and understand that system, because that is not marrying up. That's one of the issues. If they were all connected and communicating, and the training was there for the child protection workers, maybe some of that stuff would be coming natural to them to communicate, instead, they just don't have the training.”<sup>129</sup>

“In some situations, having an NDIS plan has made some difference for parents but only in the context of being able to be prepared and ready and get to access on time, which has been really difficult for some parents, as [QLD Advocate 1] said. And the child is out of the region and there tends to be more travel that has to happen for the parents.

I think the NDIS plan has helped make that work a little better but it is very hard to get them to think outside of the way that they have always done things. We have tried for decades to get them to think about shared care arrangements, anything that is a bit outside the box. They don't want a bar of it. They don't know how to make it work.

Again, you have to be the person that gives them the idea. They don't come up with anything on their own and they just do what they have always done which is reduce access, and parents lose... feel really done to in that process and parents can end up losing all contact altogether.

I think there is great potential for NDIS participants. The NDIS seem to be listening, that supporting a parent in their parenting is... a reasonable thing to do. We came up against quite a lot of barriers in the beginning, where they just said that if it was a child protection matter then family services take care of that. There are no family services other than child

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<sup>128</sup> Kin Disability Advocacy (2022) Submission to the Joint Standing Committee on the NDIS – Capability and Culture of NDIA, p2-3.

<sup>129</sup> VIC Advocate, "Advocates Zoom In On... Child Protection Systems", November 2020 Zoom discussion

*protection because if you try to engage with the service around any support around parenting, as soon as they know that child protection is involved, they just take their hands off and say, "No, we can't help." They just assume that they will be providing the parents with the support that they need, and we know that they absolutely do not.*"<sup>130</sup>

### The interaction of NDIS processes with legal and justice systems

*"...we have assisted a number of people who were in prison that we were able to keep in one place, get an NDIS plan, transition them out. It's been difficult to keep them, or to assist them, to stay on a plan. No matter how much pre-planning we do when a person is in prison or in juvenile detention, when they get out there's a lot of competing cultural stuff that goes on. Sometimes, they'll have a family and so they don't manage their money very well - just a variety of things, just trying to locate them to meet their appointments or for their community engagement person that's being supported through the NDIS to even be able to find them sometimes is hard. ... We've had a number of people that we've assisted to get phones and to do that. But when a person's priority is food, accommodation, family responsibilities, you know, that other stuff doesn't really work into their lives."*<sup>131</sup>

*"NDIS [support coordinators] dictate to OPG [Office of the Public Guardian] adult guardians about what is best for the client and there does not appear to be any scrutiny or exploration by the [guardians] when time to make decisions, and limited evidence that decisions are based on the client's views, will and preferences... Adult guardians should be utilizing NDAP/QDAP providers [funded advocacy organisations] more, to ensure their clients have access to an independent advocate to act as facilitators in the supported decision-making process."*<sup>132</sup>

*"Client H was in detention and had chronic documented disabilities including cognitive and behavioural. There were challenging behaviours and complex needs. Despite substantial prior statutory agency involvement, there had been no NDIS access application. The Superintendent had relevant responsibilities, but advocacy and assistance were required towards an NDIS access application."*<sup>133</sup>

*"Client J was in prison at the time he became a DCLS client. He has a disability and was a NDIS participant. J was eligible for Supporting Independent Living funding. J was eligible for parole, but was repeatedly unsuccessful in being granted parole, as he could not provide definite answers about his living situation and supports after leaving prison. This was because the NDIA would not finalise his NDIS plan based on a proposed Roster of Care, as the NDIA argued it could not make a final assessment on J's needs before knowing where he would move to upon release. Neither process provided the flexibility needed to progress J's parole."*

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<sup>130</sup> SA Advocate, "Advocates Zoom In On... *Child Protection Systems*", November 2020 Zoom discussion

<sup>131</sup> NT Advocate, November 2020 Zoom workshop with DRC

<sup>132</sup> Rights In Action Inc. (Cairns, QLD) input (received by DANA February 2024).

<sup>133</sup> Darwin Community Legal Service (2022), *Submission into the Disability Royal Commission - Lived experience highlights multiplicity of factors in the NT continuing to expose people with disability to violence, abuse, neglect and exploitation*, p62.

*DCLS submitted a complaint to the NDIA on J's behalf and assisted with the implementation of services when a NDIS plan was completed.”<sup>134</sup>*

## The interaction of NDIS processes with social security systems

Access to legal advice about social security and / or NDIA can help to answer questions and enable people to make informed decisions. Ideally, this happens before big decisions which can impact on entitlements – like the potential implications of receiving a compensation payment.

*“Client SS-8 has very limited work capacity due to an injury at work. SS-8 has received a workers compensation payout. Client SS-8 has a child with complex needs who is a NDIS participant. Client SS-8 wants to know if the social security preclusion period, which means preclusion from JobSeeker, would apply eligibility for Carer Payment as the child's primary carer. Additionally, SS-8 wonders about eligibility for Disability Support Pension.*

*Client SS-9 already has a social security preclusion period but now has an additional compensation preclusion issue as a result of receiving a letter from the NDIA indicating that the NDIA was considering whether the fact that Client SS-9 had received a large compensation payment meant preclusion from receiving NDIA supports for a period. The potential preclusion period was many years.”<sup>135</sup>*

## Lack of supports

*“Choice and Control on the ground and in reality are very different. Participants rarely have choice and control in rural and remote areas and it is often a case of clients taking what they can get or waiting considerable times for access to services.*

*In regional areas there is often only a small handful of providers available and if a client or family has a poor experience with one provider, this further limits options. This is further exacerbated if there has been a serious incident related to one of the few service providers that operate in the area. I have cases where this has occurred, yet the Agency suggests that the participant access this service.*

*A client of mine who resides in [location] was given the choice of [hundreds of] providers according to the NDIS portal that service their region that they could access, [however] an analysis of these providers whittled it down to only 30 that have a local presence in [the client's region] and many of that 30 did not provide the type of services the client needs. This discrepancy did not seem to be acknowledged in ongoing communications citing over 600 providers to choose from (most were interstate).*

*Providers charge travel time to visit clients and especially in the Support Coordination (SC) field, many of these SCs claim travel time to visit clients from home or work bases that are*

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<sup>134</sup> Ibid.

<sup>135</sup> Darwin Community Legal Service (2022), *Submission into the Disability Royal Commission - Lived experience highlights multiplicity of factors in the NT continuing to expose people with disability to violence, abuse, neglect and exploitation*, p134

several hours away and when you consider that SCs Level 2 earn around \$120 an hour and Level 3 around \$200 an hour, you can see how funds could quickly be expended with no real value being added to a client's support or wellbeing.

*I am seeing raft of clients at the moment that have SCs that are interstate and are now deciding to change to a local SC but their choices are limited.*"<sup>136</sup>

*"I think in regional and remote areas of Queensland, people are often frightened to make complaints because of the lack of alternative solutions or services. If there is limited availability, then they are not encouraged to complain because there is no other provider to use instead."*<sup>137</sup>

*"[Regarding]...the lack of service providers and the lack of choice. We've been doing a bit of outreach and I've been on Kangaroo Island fairly recently, and there isn't much choice there with the service providers. And what I'm seeing a lot of is people going to their GP and the GP suggesting perhaps they should look into NDIS, and they have quite serious disabilities that they've just been managing on their own, on their farms, and things like that, and also people having strokes and injuries later in life and then trying to access NDIS.*

*But there's nothing there that assists them... to help, so we're coming in and trying to do as much as we can, but there's also really low literacy because there's few jobs, so people leave school early. So they can't really just be given forms to fill out. We've got to go... it's a big-time commitment to read through with them, to make sure that they know what they're going into, and even if they do get NDIS, they have such a slim choice of providers. And if they don't... a lot of people know everyone, if they don't want to go with that provider, they choose not to engage and then they're just not getting any services or support.*

*So perhaps something linked in with the GPs, advocates, social workers, that they could be directly referred to as a third party that can help them with those processes, and encourage them to stay engaged, because I'm finding people are becoming engaged and then can't contact them again. It's too hard.*"<sup>138</sup>

*"There are not enough providers – sometimes we have had support workers come from Melbourne to support and cover complex needs in rural areas.*

- *CASE STUDY: A mainstream workplace in a regional location offered someone with disability work. But the person could not fulfil the role because they did not have support workers to settle them in. It got too expensive to send support workers from Melbourne.*
- *There may be more unregistered providers in regional/rural areas, which could be a problem if unregistered providers are no longer allowed to provide services for people paying for these with NDIS funding...*

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<sup>136</sup> Deidentified input from an advocate working in rural and remote areas (received by DANA February 2024).

<sup>137</sup> DANA's 2015 *Quality and Safeguards* survey - Family member of a person with disability from Queensland.

<sup>138</sup> SA Advocate, April 2021 Solutions focused workshop with DRC



- *There are limited options re choice and access for people – e.g., in one region, there are one or two disability providers.*
  - *Employment options in regional and rural areas are scarce across the board. So for people with intellectual disability, employment options are non-existent except for ADEs. E.g., a jobseeker with intellectual disability from a rural area applied for the VALID8 team, but the logistics were too tricky to make it work...*
  - *There are limited organisations and staff to adequately meet the needs of those with disability in their NDIS plan.*
  - *Disability agencies and organisations have difficulty attracting staff and quite often staff will move around to the organisation in the area that offers them the best conditions/pay. This can cause a lack of consistency in care for people with disability.*
  - *Often difficult for participants to access what is included in their NDIS plan due to lack of available staff from organisations or other allied health services.*
  - *Lack of specialist allied health staff for a variety of disabilities.*
  - *Many specialists choose not to be NDIS registered providers.*
  - *Support workers are also often scarce in rural and remote areas and matching a participant with a support worker can be difficult particularly if they do not want to engage a particular support worker.*
  - *Many support workers are unregistered as people with disability are choosing to enlist their relatives and friends rather than a support worker they do not want. This of course increases risk for participants around the level and quality of care received.*
  - *Agencies/organisations are often Melbourne-based and withdraw over time from rural and remote areas... E.g. VALID.. team has a direct relationship with the Surf Coast Shire. We know that the Surf Coast Shire has Geelong or Melbourne based agencies which have often withdrawn over time often due to issues of viability.*
  - *Travelling long distances to reach support is prohibitive and tiring for participants and families/friends as services are not always nearby.*
  - *Participants in rural and remote areas can be more vulnerable simply because of their location and many of the above factors.*
  - *Other mainstream services such as education and health in rural and remote areas have often passed responsibility to the NDIS for all participants needs and do not accept responsibility for many of a participant's needs.*
  - *Limited housing options for people with disability in rural and remote areas.*
  - *Young people [aged] 17/18 with disability who complete their time in Special Development Schools (SDS) often have limited or no options re employment, housing, etc. in rural and remote areas.”<sup>139</sup>*
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- *“Limited availability of [First Nations] supports and services in regional, rural, and remote areas*
  - *Poor comprehension to understand systems, program delivery, eligibility and what services can/can't do....*
  - *Living remotely where the gaps in service provision/infrastructure is significant issue, this is something the NDIS cannot fix, as infrastructure is a state issue*

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<sup>139</sup> VALID (Melbourne, VIC) input (received by DANA February 2024).



- *Lack of culturally appropriate support workers...*<sup>140</sup>
- *[What's needed]:*
  - *cultural appropriate entry into care work...*
  - *inclusive practices and accessibility in all aspects of the NDIS. RIA would like to see targeted, support for participants in rural, regional, and remote areas, while also addressing cultural and language barriers.*
  - *The revision and re-development of culturally appropriate resources, services and supports for Indigenous, CALD, and people with low literacy or socio-economic backgrounds ...promoting understanding and respect for diverse cultural perspectives*<sup>141</sup>

### Gaps in positive behaviour supports

*"...lots of those people do have NDIS plans now, especially on the APY Lands [Anangu Pitjantjatjara Yankunytjatjara], and yes, there's sometimes, not always, funding in those plans for positive behaviour support plans, but it becomes extremely complex because of it being cross cultural. What is acceptable if someone is in a residential service in town in terms of managing behaviour may not be so out in community. People don't want to behave, families don't want to behave differently to other families. So it's very, very difficult for families to put in place behaviour management strategies if those strategies are not culturally appropriate and culturally acceptable.*

*So often, there's a really good plan and it works well when the client is in town getting respite, but when they're home again, the family don't implement that plan because it's not culturally appropriate. It's not manageable for them, it's not the way that they would normally interact. So it kind of - unless you've got consistency - those behaviour plans are very difficult to implement and to get that really good outcome of the participant understanding what the expectation is."*<sup>142</sup>

*"The lack of community-based service provision and mid- to long- term support means that programs such as behaviour modification programs, where effectiveness is only possible through implementation in a person's home environment, are not available. There are currently no such programs operating in the NPY Lands, although they are needed, as evidenced by the number of referrals for this sort of program in people's NDIS plans. Over a quarter of the plans where we provide Coordination of Supports refer to behavioural self-regulation in the participants' goals. Another large fraction of participants' plans includes a goal of improving people's communication skills. Carrying this out effectively would involve education, training and support by Lands-based workers. ...Anangu NDIS participants are unlikely to be aware of what is involved in the idea of these programs when agreeing to undertake them. One 58 year old man's plan, specifying improvement in communication in*

<sup>140</sup> Rights In Action Inc. (Cairns, QLD) input (received by DANA February 2024).

<sup>141</sup> Rights In Action Inc. (Cairns, QLD) input (received by DANA February 2024).

<sup>142</sup> NT Advocate, November 2020 Zoom workshop with DRC - see [discussion transcripts](#)

*all environments, goes on to include this goal, which is clearly not a goal expressed by the participant, but rather is assumed by the NDIS Planner:*

*“I will attend the speech therapies and reviews and practice the training. I will learn how to read and write and be confident in dealing with government and non-government agencies such as Centrelink and the bank.”<sup>143</sup>*

DRC Recommendation 10.24 – Recommends particular focus on PBSP practitioners given the lack of supply available in regional and remote areas.

#### Gaps in mental health supports

*“We supported a young woman to engage with services after she had withdrawn from community and family. The young lady suffers from a mental illness condition and was bullied during her school years and lived with her mother who completely controlled her life. She had the courage to call us and sought our assistance to help her out of her rut, she was very hesitant at the beginning and lacked any confidence to be able to initiate actions. We were able to meet with her and after taking time to gain her confidence we have been able to assist her to beginning treatment for her illness, engage with a job network provider, help her to apply for NDIS and we are currently assisting her to find a place to live. This is one of many examples of young people struggling and the increase demand around mental illness and we would like to use these examples to highlight the gaps in mental health services in rural areas.”<sup>144</sup>*

#### Gaps in specialist health treatment or therapy

*“Mainstream services are thin on the ground or non-existent in areas beyond regional centres.*

*Diagnostic and specialist support services are not available – as an example there are no neuropsychological or specialist brain injury services at all in Central Australia despite us having the highest rate of brain injury and cognitive disability in the country.*

*NT has very high rates of disability compounded with high rates of chronic health conditions, hearing loss and unidentified developmental disability. We also have high rates of welfare dependence, homelessness and family violence, The more remote the higher the prevalence of these issues.*

*The loss of a holistic case management services through NT Disability Services is a tragedy.*

*It is also important to recognize that unlike in many other settings, the impact of poverty, social exclusion, intergenerational trauma and disruption means that a high proportion of the individuals we assist do not have a network of support with the skills or resources to navigate complex systems and are entirely dependent on advocacy services to support them in this regard. This can be compounded by cultural factors of not wishing to complain and a dependence on service systems across many aspects of their lives. Many remote Aboriginal*

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<sup>143</sup> NPYWC Submission to the Royal Commission into Violence, Abuse Neglect and Exploitation of People with Disability, September 2020.

<sup>144</sup> VIC regional advocacy organisation, 2017.

*people are accustomed to living in tough settings characterised by deprivation so expectations of service quality can be low.”<sup>145</sup>*

*“Service providers are aware of the chronic shortage of allied health therapists and a range of other professional services required by people with a disability in the NT. This among other things, results in long waiting times for assessments related to NDIS applications and planning processes.”<sup>146</sup>*

*“Services are limited on the NPY Lands. A minimal range of therapeutic services is available to people with a disability on a ‘fly in fly out’ basis, which in effect means that some service providers such as occupational therapists visit the community once every few months. There is no ongoing support available, so support is often limited to the provision of assistive technology, rather than to offering supported exercise or education programs in the use of, for example, communication devices. Despite the lack of services available in the Lands, many Anangu with disability have NDIS plans providing funds for services which are unavailable, such as social skills development and support, transport, behaviour support and early childhood intervention.”<sup>147</sup>*

#### Need for foundational supports (available outside the NDIS)

*“There are some really basic infrastructure issues including access to telecommunications, digital literacy, access to accessible housing, food insecurity and the dearth of services generally, particularly in very remote settings.*

*There are also needs to be concerted efforts to engage with people in remote and very remote settings about what they consider to be foundational – at a guess this will include housing, and associated infrastructure. Many people do not want more bureaucratic processes and professional staff or services. Their main concerns are secure accommodation, employment opportunities and affordable, food, petrol and household goods.*

*Overall there is very limited mainstream support services in the NT. This is due to our small population base, the dire economic situation in the NT and the tyranny of distance and workforce shortage which places severe limitation on availability of services in remote and very remote settings. What is considered standard State funded service delivery in more populous states is non-existent here. So it’s important to recognise we are not starting from the same spot.*

*A place to go for help or assistance to navigate the whole range of services and supports, not just disability related, in the community (like the old Community Advice Bureaus)*

- *Aids and equipment – there is now no pathway to fulfill a simple equipment or building modification request, or to respond to sensory loss*

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<sup>145</sup> Disability Advocacy Service (Alice Spring, NT) input about advocacy in central Australia, 2023 (received by DANA February 2024).

<sup>146</sup> Darwin Community Legal Service (2022) Submission to Capability and Culture of the NDIA Inquiry of the Joint Standing Committee on the NDIS.

<sup>147</sup> NPYWC Submission to the Royal Commission into Violence, Abuse Neglect and Exploitation of People with Disability, September 2020.

- *Community based activity programs responding to the diversity of the community – in the NT local councils/shires (and particularly those in very remote settings) do not generally have access to funds to support community services other than youth activities.*
- *Access to adult education – we do not have neighbourhood houses and learning centres in the NT which severely limits access to opportunities available in other states*
- *Community transport is almost non-existent*
- *Sine the introduction of the NDIS there is only time limited support for people with psychosocial disabilities that do not meet access to the NDIS (like we used to have with PHaMS [Personal Helpers and Mentors Service – Targeted Community Care Mental Health Program])*
- *Care coordination for people with complex needs – not all support coordinators see this as their job – many just act as brokers for NDIS funded services*
- *Adequate support for people with a disability in tertiary or further education environments – very limited availability in the NT*
- *Investment to support inclusive venues and community events*
- *Consultation with remote and very remote settings to ensure and developments occur in conjunction with community*
- *Since the loss of block funding there is far less networking, collaboration and information sharing – partly due to competition but largely due to lack of funding. No agency wants to pick up administrative load for unfunded activities*
- *Limited access to publicly funded diagnostic capacity and specialist interventions – e.g. neurological services, brain injury services, neurodivergent supports, vision services, specialist counselling etc.*
- *Very limited child psych services and parenting supports/ respite*
- *We would love to see support for volunteer programs e.g. Gig Buddies, Citizen Advocacy*
- *Workforce development to improve quality of service delivery*
- *Investment in transition support from Territory Families to Adulthood*
- *Prisoner access to aids and equipment*
- *On the ground employment supports*
- *Funding to support children in hospital settings”<sup>148</sup>*

*“Co-design’ can be compromised in current ILC projects. This is because the NDIA can narrow options for true co-design with participants by placing boundaries and conditions on projects before these start instead of giving organisations the ability to co-design first and then seek advice and review materials with the NDIA after initial development phases. This is relevant because it is a snapshot of what happens more broadly for people with intellectual disability: ‘Choice and control’ is said to exist, but what happens in practice is that the NDIA and disability system can greatly influence what ‘choice and control’ is and how it operates in people’s lives. This is a definitional drift.”<sup>149</sup>*

<sup>148</sup> Disability Advocacy Service (Alice Spring, NT) input (received by DANA February 2024).

<sup>149</sup> VALID (Melbourne, VIC) input (received by DANA February 2024).

[Local Government Areas] their councils, corporate sector, government agencies and private businesses in these regions, need to take the lead in their own regions/communities to develop infrastructure. This can be done by utilizing university students to conduct research, administering accessibility audits within their towns, and seeking public consultations with all residents, including PWD, their families and supporters to identify what is needed for improved access (a unified, local level approach)

#### Need for legal and advocacy supports

- *“Standards/benchmarks about access to: (i) independent advocacy and (ii) legal assistance for people with disability in rural, regional, remote and very remote areas*
- *Promotion of these standards/benchmarks in areas and data collection and reporting against these standards at a national, state/territory regional and local level - to monitor and drive progress*
- *Funding for community based research and problem solving projects relating to user journey experience of people in rural, regional, remote and very remote areas seeking to access the NDIS or receive proper supports focusing on: (i) access to independent advocacy, and (ii) access to legal assistance for access. (With priority for areas where there is little or no apparent in-person access to either or both of these.)*
- *Funding for local and regional independent disability organisations in rural, regional, remote and very remote Australia to integrate legal assistance from community based non-profit legal services (\*\*) and funding for these services for staffing and costs to enable collaboration in these initiatives.*

*(\*\* this means community legal services, Aboriginal and Torres Strait Islander Family Violence Prevention Legal Services and Aboriginal and Torres Strait Islander Legal Services).”*

## Appendix B – Previous recommendations

### Joint Standing Committee on the NDIS

Joint Standing Committee on the National Disability Insurance Scheme, Parliament of Australia (2014) *Progress report on the implementation and administration of the National Disability Insurance Scheme.*

**Recommendation 6:**

*“The Committee notes the importance of the role of advocacy services in ensuring quality plans and supporting participants in the planning process. The committee recommends that certainty regarding the role and support for advocacy services in the NDIS be urgently resolved through the Ministerial Disability Reform Council.”*

Joint Standing Committee on the National Disability Insurance Scheme, Parliament of Australia (2017) *Provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition.*

**Recommendation 8:**

*“The committee recommends the Department of Social Services and the NDIA collaboratively develop a plan outlining how advocacy and assertive outreach services will be delivered beyond the transition arrangements to ensure people with a psychosocial disability and those who are hard-to-reach can effectively engage with the NDIS and/or other support programs”*

Joint Standing Committee on the National Disability Insurance Scheme, Parliament of Australia (2018) *Transitional arrangements for the NDIS.*

**Recommendation 19:**

*“The committee recommends the Council of Australian Governments (COAG) Disability Reform Council work with the Department of Social Services to address the expected funding shortfalls for advocacy services beyond transition.”*

Joint Standing Committee on the National Disability Insurance Scheme, Parliament of Australia (2020) *Supported Independent Living.*

**Recommendation 40:**

*“The committee recommends that the Commonwealth, states and territories, through the Disability Reform Council, progress work to understand and address gaps in the availability of advocacy and decision support services as a matter of urgency”*

**Recommendation 41:**

*“The committee recommends that the National Disability Insurance Agency, working with the Australian Government, publish and distribute additional information on the availability of advocacy and decision support services.”*

**Recommendation 42:**

*“The committee recommends that the Australian Government increase funding for advocacy and decision support initiatives, to ensure that these initiatives reach the broadest range of people who require these services.”*



Joint Standing Committee on the National Disability Insurance Scheme, Parliament of Australia (2020) *NDIS Planning*.

**Recommendation 33:**

*“The committee recommends that the Australian Government review the amount of funding that it provides to advocacy organisations through the NDIS Appeals program and ensure that these organisations are sufficiently funded to support participants throughout the Administrative Appeals Tribunal process.”*

Joint Standing Committee on the National Disability Insurance Scheme, Parliament of Australia (2021) *General issues around the implementation and performance of the NDIS*

**Recommendation 1:**

*“The committee recommends that the Australian Government reconsider its responses to particular recommendations in the committee's previous reports.”* (This includes “Whether funding for advocacy services is sufficient”)

Joint Standing Committee on the National Disability Insurance Scheme, Parliament of Australia (2021) *NDIS Quality and Safeguards Commission*

**Recommendation 17:**

*“The committee recommends that the Australian Government allocate specific funding to advocacy organisations to assist complainants in their dealings with the NDIS Quality and Safeguards Commission. This funding should be in addition to existing funding provided through the National Disability Advocacy Program.”*

**Recommendation 18:**

*“The committee recommends that the Commission establish appropriate referral pathways with advocacy organisations, Community Legal Centres and State and Territory Legal Aid Commissions to ensure participants who are particularly vulnerable are supported through complaint and investigation processes. This process should be developed through a co-design process with people with disability, their families and representative bodies and advocacy organisations.”*

## **Australian Human Rights Commission**

Australian Human Rights Commission (2014) *Equal Before the Law: Towards Disability Justice Strategies*.

**Action 4.3.3:**

*Provide access to advocacy and legal services with disability expertise regardless of place of residence or geographical location.*

**Action 4.3.6:**

*Establish as a matter of urgency a national Aboriginal and Torres Strait Island disability individual advocacy program.*

## **Senate Community Affairs References Committee, Parliament of Australia**

Senate Community Affairs References Committee, Parliament of Australia (2015) *Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal*

and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability.

**Recommendation 15:**

*“The committee recommends all levels of government acknowledge the vital role that formal and informal advocacy plays in addressing violence, abuse and neglect of people with disability, by considering:*

- *increased training for people with disability to recognise violence, abuse and neglect so they can self-report;*
- *government service contracts to include provisions to enforce access to facilities for advocates, requirement for self-advocacy programs;*
- *further consideration of the Victorian Self Advocacy Resource Unit, with a view to roll out across other states and territories;*
- *funded advocacy programs to include training for informal advocates;*
- *States and Territories not to reduce advocacy funding with the rollout of the NDIS.”*

**Recommendation 16:**

*“The committee recommends the National Disability Advocacy Program implement the following recommendations:*

- *significant investment to National Disability Advocacy Program funded advocates, to deliver equitable access and representation of issues and to match the increased demand for advocacy anticipated under the NDIS;*
- *undertake a review to ensure delivered advocacy is appropriately spread across service types and complaint types, to ensure the most vulnerable are receiving advocacy;*
- *increase funding for self-advocacy programs;*
- *ensure that current model of funding peak bodies does not inadvertently result in the closure of smaller specialist or local advocacy organisations.*
- *Improved coordination between the National Disability Advocacy Program and the National Aged Care Advocacy Program.*

**Recommendation 17:**

*The committee recommends of the Government consider the following when rolling out the National Disability Insurance Scheme (NDIS):*

- *an urgent roll out of capacity-building and advocacy support for individuals undertaking negotiations for self-directed disability support;*
- *increased training for NDIS planners around intellectual impairment and guidelines on when to require decision-making support;*
- *further investigation of whether the current NDIS unit pricing will have an impact on incidents of violence, abuse or neglect.*
- *NDIS quality and safeguarding framework must ensure a zero-tolerance approach to restrictive practice, and be tied to the National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector; and*
- *amendment of the Quality and Safeguarding Framework to include advocacy as a key component to reduce and address incidents of violence, abuse and neglect.*

Senate Community Affairs References Committee, Parliament of Australia (2015) *Impact on service quality, efficiency and sustainability of recent Commonwealth community service tendering processes by the Department of Social Services.*

**Recommendations 7:**

*“The committee recommends that advocacy support be considered a vital component of community services in future funding arrangements and is given appropriate weighting in funding assessments.”*

**Recommendation 12:**

*“The committee recommends that the Auditor-General conduct its own review into the tendering process, including examining:*

- *The Department of Social Services' work pre-tender in identifying service needs by region;*
- *The extent to which successful tenderers have sub-contracted their work to local and regional providers, job losses that have resulted from the tendering process and outcomes, and the extent to which Department of Social Services has oversight over these subcontracts;*
- *The extent to which the capacity for community-based service delivery (particularly the capacity to provide services to CALD and indigenous communities) was factored into the tender selection process;*
- *The impact on service delivery, advocacy and the support available to vulnerable people and communities”*

Senate Community Affairs References Committee, Parliament of Australia (2022) *Purpose, intent and adequacy of the Disability Support Pension*

**Recommendation 15:**

*“The committee recommends that the Australian Government provides additional funding to advocacy groups and community legal services to support Disability Support Pension claimants.”*

**Recommendation 17:**

*“The committee recommends that the Australian Government increases funding for First Nation’s advocacy services and Aboriginal community controlled health organisations to allow these organisations to better support their clients through the Disability Support Pension claims process.”*