

Submission: NDIS Review Panel

QDN

QUEENSLANDERS WITH DISABILITY NETWORK
NOTHING ABOUT US WITHOUT US

23 December 2022

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The Independent Review Panel

Dear Independent Review Panel

We welcome this opportunity to make a written submission to the Independent Review Panel. Please accept the following submission from Queenslanders with Disability Network (QDN) to the NDIS Review.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Michelle Moss', with a horizontal line extending to the right and a small flourish at the end.

Michelle Moss

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About Queenslanders with Disability Network (QDN)

Queenslanders with Disability Network (QDN) is an organisation of, for, and with people with disability. The organisation's motto is "nothing about us without us." QDN operates a state-wide network of over 2,000 members and supporters who provide information, feedback, and views from a consumer perspective to inform systemic disability policy and disability advocacy.

QDN also operates 26 Peer Support groups across a range of metropolitan, regional, and rural and remote locations in the state, run by people with disability for people with diverse disabilities, members and supporters who provide information, feedback, and views from a consumer perspective to inform systemic disability policy and disability advocacy.

QDN undertakes a range of work activities and projects as outlined on QDN's website and detailed in our Annual Report. Our systemic advocacy work encompasses a range of responses – from community campaigns, formal submissions, evidence to commissions and inquiries, and membership of roundtables and working groups around national, state, and local government legislative and policy initiatives.

QDN's work is focused on the rights and full social and economic inclusion of people with disability, along with areas of key importance identified by Queenslanders with disability. This includes the National Disability Insurance Scheme (NDIS, or the Scheme), improving mainstream services that people with disability rely on every day, including health, housing, employment, transport, and the impact of COVID-19.

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Recommendations

- Simplification and demystification of NDIA language, particularly in participant correspondence.
- Provide better access to established peer support mechanisms for people with disability and their families to assist their navigation of the NDIS system.
- Resource LACs so they can be more responsive.
- Improve support and legal representation to ensure an equitable process for NDIS participants in AAT Reviews.
- Increase training for key staff in the NDIS workforce on supports associated with particular disabilities.
- Provide greater transparency around NDIA decision-making.
- Build the skills of people with disability to be informed and confident customers.
- Participants should have the same single point of contact within the Agency, where possible, and if they ask, receive detailed feedback on reasoning for funding decisions.
- Consider Alternative Dispute Resolution or mediation where an independent arbiter facilitates discussion between the Agency and the aggrieved party with a view to reaching a mutually agreed outcome.
- As part of this NDIS Panel Review, open a specific line of inquiry into housing, disability, home and living supports, particularly separation of housing and support safeguards.
- Mandate development of SIL quotations in conjunction with plans, so participants, family or decision-makers are not excluded, or support arrangements predetermined by the provider and the NDIA.
- People with disability and their networks, housing organisations and disability support organisations need practical information about separation of housing and support and about good practice in coordinating service delivery when housing and disability services are provided by different organisations.
- Emergency and disaster planning should be part of NDIS planning, including provision of capacity building supports to assist in development of the participant's plan.
- Reassess school transport assistance for parents or guardians with disability who need to accompany children to school.

Introduction

Overwhelmingly, the NDIS has had net positive impact: for Queenslanders with disability in general, and for our Queenslanders with Disability Network (QDN) members. Nevertheless, a variety of NDIS-related problems and challenges have also been raised by QDN members since the completion of the Queensland NDIS transition in late 2020. For this 'opening of accounts' with the Independent Review Panel, QDN has chosen to centre selected QDN-member stories and statements covering the following subject areas:

- Communication with the NDIA
- Plan Goals, Funding, and Dispute Resolution
- Specialist Disability Accommodation (SDA) and Supported Independent Living (SIL)
- Disaster Planning, and
- Parenting Support.

1. Communication with the NDIA

Summary

- Participants report poor communication experiences with the NDIA call-centre, planners, and Local Area Coordinators.
- Members Are frustrated LAC roles Are not clearly defined. LACs increasingly are inaccessible and unresponsive, and participants are missing out on critical services they urgently need.

Much like communication with national utilities like Telstra, Optus or AGL, NDIS participants talk to multiple NDIA employees but rarely to the same person more than once. The call-centre has become the first and last resort for communication.

If I wanted to find out about, for example, capital funding supports, I would attempt to talk to a planner by going through the call-centre. But the planner says "No, I'm not talking to a participant' ... and it gets sent to Carer's Queensland or to a Support Coordinator, if the participant has one, but ultimately goes back to where it started, at the call-centre. This isn't how the system was meant to be.

There is a disconnect between the relatively lengthy and often vulnerable self-disclosure characteristic of participant conversations with planners, on one hand, and with plan decision-making. In conversations with planners, participants share details of their disability, life goals and support needs. Sharing intimate details with a stranger when there is no existing relationship can be

difficult.¹ Decision-makers, on the other hand, are distant and unaccountable. Participants do not receive detailed feedback on reasoning behind funding decisions.

'Call-centre contacts, Planners and LACs ask me the same stuff over and over again. It's poor record-keeping'.

Local Area Coordinators appear to be overworked. Some members expressed concern that too much was expected from LACs. Members had spoken to LACs who had explained that due to their increased workload, they were not able to have the presence in the community that initially was planned. Members strongly believe the NDIA needs more staff to meet demand so LACs could prioritise their local community. Without being able to spend time in the community, LACs are unable to provide participants with information on and access to other mainstream community supports, a key part of their role that many members feel is currently not being delivered on.

Additionally, members felt many LACs had little to no understanding on disability inclusion, community, history and barriers to equality. LACs and other NDIA staff would benefit from a greater understanding about the social model of disability, disability rights and the barriers and discrimination still faced by people with disability. With the right training in these areas, staff would be able to better respond to the needs of NDIS participants and improve their communication. Members suggested LACs and planners be required to undergo disability education before starting in the role, so they have a better understanding of the key challenges and real-life issues of people with a disability.

'The LAC never rings me back - except if it's a week or so before the plan is due for review, probably because it's getting flagged on the system - because LACs are doing Plan reviews, which they were never meant to do'.

The Local Area Coordination role has been shifting in scope and intention, leaving gaps. Members were frustrated that LACs' roles are not clearly defined. Increasingly, they are inaccessible and unresponsive to participants. As a result, participants are missing out on critical services they urgently need.

General communication could be improved by implementing simple accessible communication strategies, such as ensuring participants are not bombarded by unnecessary acronyms and overly bureaucratic language which currently prevents them from fully utilising their plan. QDN members believe more information should be made available in user-friendly, accessible ways about "financial sustainability" issues with the NDIS, so that participants can engage in an honest and open discussion about its future.

¹ Ibid.

People with disability and their families have a strong vested interest in seeing a funded and successful scheme, but without all the information they do not feel there can be a productive debate. Greater transparency includes more publicly available information about financial assumptions, what represents ‘value for money,’ and how NDIA decisions are made. More complete information would assist participants understand and communicate at each stage of plan development, lead to better outcomes, and pre-empt lengthy reviews and appeals.

2. Plan Goals, Funding, and Dispute Resolution

Summary

- Fundamental goals of people with disability still fall into the gaps between NDIS and mainstream funding.
- Dispute resolution is slow, daunting, and costly.
- QDN suggests consideration be given to Alternative Dispute Resolution or mediation.

QDN members reported a significant increase in the number of people with disability they knew in their local community going through either the internal NDIA review process or an AAT appeal. The increase in reviews and appeals – combined with there being not enough NDIA staff to meet demand – has led to long waits and delayed responses to plan reviews.²

Some participants feel their goals and stated support needs are lost in the NDIA’s bureaucratic maze. When there is a dispute about funding, participants feel the dispute process is onerous. They must accept what they are told or go through the NDIA’s complaints and review processes. There was agreement it feels like a forgone conclusion their internal review would be rejected and they would be left with only one option – to go to the Administrative Appeals Tribunal (AAT). Members questioned the purpose of mandating the internal review and forcing people with disability to “jump through extra hoops” when reviews take up NDIA resources for predetermined results. Participants tell us they find the AAT appeal process daunting and difficult. In the example below, Daniel decides to represent himself through review and the AAT.

‘My Plan Goal regarding my Tertiary Education is to be on an equal footing with my student peers’.

² NDIS: 2021 Year in Review and looking forward to 2022 Summary Report – January 2022 p 4.

Daniel (pseudonym) is assertive, intelligent, and capable. As a totally blind person he reads braille and uses text-to-speech technology. His access needs are specific but often poorly understood. State and federal government departments and statutory bodies operate with disability service plans committed to accessible communication, but few communicate with Daniel without his having repeatedly to request screen reader accessible HTML or word.doc formats.

After a segregated education to high school level, Daniel entered the workforce. Each of his paid positions failed. Employers were unprepared and provided inadequate support: they failed to do workplace access audits and inevitably underestimated the required adjustments.

In 2021, Daniel decided to try tertiary studies and included in his NDIS plan the goal to study “on an equal footing with my student peers”. Daniel immediately became stranded in the disputed no-man’s-land between ‘reasonable and necessary’ NDIS supports and mainstream education’s duty to make reasonable adjustments.

Daniel quickly realised he would need a Surface Pro Laptop 8 Generation and a Braille Keyboard (or equivalent) to function at university, so in July/August of 2022 he applied for his NDIS plan to fund it. “Although we don’t have to accept it”, the NDIA asked Daniel, who is self-managed, for a letter of recommendation for the technology from a service provider.

Daniel commissioned Guide Dogs to do a (2 hour) technology assessment. The NDIA responded to this assessment with “no, it’s not financially sustainable for the scheme to fund this technology”. Daniel approached his Tertiary Education Provider to see if they could assist, but they advised they could not fund assistive technology for students.

This matter now is heading to the Administrative Appeals Tribunal, where Daniel will represent himself against the NDIA’s outside counsel. The bilateral agreements and the NDIS Act are clear the NDIS must not fund supports more properly funded by a mainstream service. A recent AAT decision clarified the NDIA is not responsible to fund supports just because a mainstream service will not do so.

Nevertheless, in rejecting and opposing Daniel’s request, the cost to the NDIA exceeds the quoted cost for the technology itself, indeed, the cost for translation of Tribunal documents into an accessible format exceeds the cost of the assistive technology, let alone the cost to the NDIA for third-party legal counsel. The NDIA’s decision not to fund because it is ‘not financially viable’ seems at odds with spending considerably more money defending the decision not to spend money. Should Daniel fail at the AAT, an appeal to the Federal Court is not an option except for those without substantial resources, and potential costs of a lost cause deter all but a few participants.

QDN suggests consideration be given to Alternative Dispute Resolution or mediation where an independent arbiter facilitates discussion between the Agency and the aggrieved party with a view to reaching a mutually agreed outcome: not dissimilar to the case conference approach used at the AAT.

3. Specialist Disability Accommodation (SDA) and Supported Independent Living (SIL)

Summary

- Separation of accommodation and support remains an ideal, not the experience of many NDIS participants. People transition to shared SIL arrangements without awareness of superior alternatives or increased opportunities. Accommodation and support contracts actively discourage alternatives instead of enabling participants to bring in other providers.
- There is limited or no choice and control available to some SIL participants. SIL arrangements nominally are portable but practically sit with the accommodation not the individual. Participants find it difficult to leave, knowing others' supports may be reduced or rent and utilities increased.
- SIL quotes are better developed in conjunction with plans. It is common practice for the NDIA to ask providers to submit quotes well prior to planning meetings. This excludes participants, family or decision-makers and predetermines support arrangements.
- People with disability and their networks, housing organisations and disability support organisations need information about what separating housing and support means in practice, and about good practice in coordinating service delivery when housing and disability services are provided by different organisations.

From time to time, the United Nations Committee for the Rights of Persons with Disabilities offers specific commentary on articles of the Convention on the Rights of Persons with Disabilities (CRPD). *General comment No. 5 (2017) on living independently and being included in the community*, states:

Neither large-scale institutions with more than a hundred residents nor smaller group homes with five to eight individuals, nor even individual homes can be called independent living arrangements if they have other defining elements of institutions or institutionalization. Although institutionalized settings can differ in size, name and set-up, there are certain defining elements, such as obligatory sharing of assistants with others and no or limited influence over whom one has to accept assistance from; isolation and segregation from independent life within the community; lack of control over day-to-day decisions; lack of choice over whom to live with; rigidity of routine irrespective of personal

will and preferences; identical activities in the same place for a group of persons under a certain authority; a paternalistic approach in service provision; supervision of living arrangements; and usually also a disproportion in the number of persons with disabilities living in the same environment.³

Mandatory “package solutions” which, among other things, link the availability of one particular service to another, expect two or more persons to live together, or can only be provided within special living arrangements **are not** in line with article 19.⁴

Institutionalized arrangements such as these are commonplace for NDIS participants in 2022. All ‘defining elements’ above - shared assistants, lack of choice, isolation, limited decision-making, paternalism, congregate care and linked services – are present for Alice (pseudonym):

Alice – “For seven years I’ve been one of more than a dozen residents living at a modern, formerly block-funded facility. It has a mix of single- and two-bedroom apartments, a shared dining room where meals are served 3-times per day from a central kitchen (2x choices at lunch and dinner) and a laundry service. Mine is a two-bedroom apartment with a share bathroom in-between the bedrooms.

‘I call it a ‘facility’ because that is how it is referred to over and over in the contract, for example: “You are responsible to be courteous to the other residents at the facility”’.

I’ve been there with two other women but I’m alone now. I wasn’t consulted before living with my co-residents. Both have now passed on but the empty room that was theirs is now off-limits to me. I prefer the privacy now I’m the only occupant in my unit. Currently I don’t share the bathroom. When we did, the additional staff interaction and the associated lack of privacy is the most difficult thing to endure.

The property owner and the service provider are the same entity. This is never an ideal situation. My accommodation agreement is separate to my support agreement, but the two

³ Committee on the Rights of Persons with Disabilities *General comment No. 5 (2017) on living independently and being included in the community*, p 4. <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G17/328/87/PDF/G1732887.pdf?OpenElement>

⁴ Committee on the Rights of Persons with Disabilities *General comment No. 5 (2017) on living independently and being included in the community*, p 5. <https://documents-dds-ny.un.org/doc/UNDOC/GEN/G17/328/87/PDF/G1732887.pdf?OpenElement>

are linked by clauses such as the one that prohibits residents from purchasing supports (other than Community Access) from any other provider.

I have looked at other independent living arrangements including a brand new one with low benches and light controls and extra-wide corridors, but I have felt disinclined to move, even when the provider increased my rent by just over 44% because that was “the amount on the NDIS Price Guide”, with very little notice and no consultation. If I move, everything must change if I do.

‘We recognize the right of personal choice however restrictions on the consumption of alcohol at the facility may be imposed. Excessive use of alcoholic beverages leading to unacceptable behaviour may jeopardize your continued stay’. **SDA/SIL Resident Handbook**

Use of Community Access hours in individual packages has almost been commandeered by the service provider. Individuals are strongly encouraged to use staff they are familiar with for receiving personal care *and* for outings. The attitude seems to be, “this as a workplace first and individuals’ homes somewhere further down the line”. This would be less the case in truly independent living in a genuine community setting.

When Chair of the NDIA, Bruce Bonyhady spoke about the importance of separating the provision of housing and disability services⁵ and no doubt the Review Panel is well aware, funding and the current approach to SIL implementation perpetuates congregate, institutional living.

There is potential for SIL to be a way for people to exercise choice: two people could choose to live together, for example, and use SIL to share supports and build their capacity for independent living. However, this is not the way SIL widely has been adopted. Instead, SIL often is coupled with shared Specialist Disability Accommodation, which should be a separate provider but in practice often is not; or SIL sustains support in non-SDA group homes owned or managed by the same organisation providing SIL-funded supports.

⁵ For example, separation was a theme of a speech in 2014 by the then Chair of the NDIA, Bruce Bonyhady at a Community Housing Federation of Australia forum on disability housing.

4. Disaster Planning

Summary

- Emergency and disaster planning should be part of NDIS planning, including provision of capacity building supports to assist in development of the participant's plan.

The Covid pandemic has been instructive on the need for better preparedness to support people with disability through disasters. The Committee on the Rights of Persons with Disabilities *General comment No. 5 (2017) on living independently and being included in the community* says "States parties must take into account in advance the obligation to provide support services to persons with disabilities in all disaster risk management activities (art. 11) and make sure that they are not left behind or forgotten".⁶ *Australia's Disability Strategy 2021 – 2031* Policy Priority 4 states, "Disaster preparedness, risk management plans and public emergency responses are inclusive of people with disability, and support their physical and mental health, and wellbeing".

QDN recently held a forum with people with disability on disaster preparedness, and outcomes included a determination to ensure people with disabilities participate in decision-making processes and are active stakeholders at all stages of disaster responses, for NDIS participants to have disaster preparedness included in their NDIS plans, and for plans to include a capacity building component so participants are part of plan development.

In January 2022, the NDIS Quality and Safeguarding Commission signed a legislative amendment which requires all registered service providers to:

- ensure continuity of supports which are critical to the safety, health, and wellbeing of NDIS participants before, during, and after a disaster, and
- work with their clients to undertake risk assessments and include preparedness strategies within their individual support plans.

The newly released NDIS Practice Standards incorporate these legislated requirements and require service providers to develop, test, and review emergency plans, and to plan for the continuity of critical supports during emergencies to ensure the health, safety and well-being of the people they support. Service providers should, for example, support clients to attend Person-centred Emergency Preparedness (P-CEP) workshops. In addition to these measures, QDN recommends NDIS planning processes include a question about disaster planning, and that plans include funding for capacity-building supports for participants to do disaster planning.

⁶ Committee on the Rights of Persons with Disabilities *General comment No. 5 (2017) on living independently and being included in the community* at 79.

5. Parenting Support

Summary

- The NDIS does not fund transport supports for parents or guardians who have disabilities when carrying out important parenting duties.

People with disabilities are parents, too. They face unique parenting challenges and have unique support needs. States parties to the CRPD “shall render appropriate assistance to parents and legal guardians in the performance of their child-rearing responsibilities”.⁷

Elsa’s disability makes it impossible, without support, to carry out some of her duties as her granddaughter’s guardian. Yet the NDIS will not pay for those supports.

Elsa (pseudonym) - Since becoming an NDIS participant, my self-managed supports have been ‘life changing’. I could go back to work and earn extra money. Private rental in a major city became less of a strain. I could volunteer three days a week at my granddaughter Margaret’s school.

About a year ago, my family circumstances and living arrangements changed, and so did my NDIS goals. There was a risk Margaret would go into state care, so I applied for guardianship and became her full-time carer.

‘I could use core funding to go on a fishing trip but not to care for my granddaughter. People with disability still have children removed because we cannot get support to look after them’.

In May 2022, I sought an increase in core funding so I could pay for extra supports – particularly supports to help get Margaret to and from school, a fourteen-minute return trip by private car or a ninety-minute one twice daily by public transport. I have a Queensland Taxi Subsidy Scheme card until 31 October 2023, but a typical one-hour-plus wait makes wheelchair-accessible taxis impractical.

At review in November 2022, the NDIA cut my core funding by \$30 000 pa, advising school trip support is “misuse”.

⁷ Article 18 (2).

Close family lives too far away to provide everyday transport assistance and I cannot afford to pay someone else to take Margaret to school. My Local Area Coordinator suggested a Companion Card but this subsidises only a support worker's public transport costs.

The cut is a reviewable decision, but the LAC advised internal review is unlikely to be successful. The wait to take a dispute right to the Administrative Appeals Tribunal is approximately 12 months and I do not want taxpayers to foot the bill, particularly for the NDIA's outside counsel. Instead of review, the LAC suggested I lodge a change of circumstances request and do not mention parenting support.

Elsa's experience demonstrates neither the NDIS or mainstream education provide school transport assistance tailored to parents or guardians with disability.
