Submission: The NDIS Participant Journey

QDN

QUEENSLANDERS WITH DISABILITY NETWORK

NOTHING ABOUT US WITHOUT US

Submitted to the NDIS Review June 2023

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 value statement

QDN believes that:

- All people with disability have a right to a place in the community and have contributions to make to community. This is as empowered, free citizens who are as valued, present, participating and welcomed as members of any dynamic and diverse society.
- The place of people with disability in the community is not just about people with disability having a house in the community. Core to this is that they are welcomed in the community as ordinary citizens where they are genuinely given opportunities to contribute and actively participate. People with disability need to be in communities where their individuality, their talents, and their lived experiences of disability are recognised and acknowledged.
- Culturally and historically, people with disability are not afforded the same value, opportunities or access to community life.
- Any inclusion in community for people with disability is conditional and vulnerable to withdrawal.
- Many people with disability in Queensland are excluded from the most basic experiences of ordinary lives.
- Current exclusionary practices are unacceptable and must be challenged.
- These issues affect not only people with disability but the whole community.
- The responsibility is shared. It lies within government (federal, state, and local) and the community at large, to ensure that people with disability have a place and are resourced to belong in community.

Introduction

Queenslanders with Disability Network (QDN) welcomes the NDIS Review process. To date, the NDIS in Queensland has had a significant impact on the lives of over 120,000 Queenslanders with disability. For many people it is the first time in their life they have accessed disability support. However, people are still experiencing significant challenges to accessing the NDIS, and for those who are successful in gaining support, key challenges in the implementation of plans and plan reviews, gaining the right supports, the integration of support with mainstream services, and the processes and culture across the NDIA.

Over the past six years, QDN has undertaken extensive work through projects focussed on people with disability understanding the scheme and how it can support them, working to gain people access to the scheme, and hosting peer support groups to raise issues and provide support throughout the NDIS participant journey. Through this work, QDN has continued to identify and raise the systemic issues and challenges throughout the NDIS participant journey. These challenges impact especially upon people with disability who are marginalised and interact with several different complex systems. Fundamental to addressing these issues is meaningful engagement and consultation with people with disability, their families and supporters, so that the people most affected by the NDIS review have an authentic voice in what needs to change.

In this submission, QDN addresses key issues and recommendations in the NDIS participant journey including plans, plan reviews and tribunal cases. The key themes addressed have come from the voices and experiences of members shared in an online forum hosted by QDN on the 12th of May 2023, centred around the NDIS Participant Journey. Over 70 QDN members and supporters participated across Queensland, including from regional areas.

Recommendations

The *National Disability Insurance Scheme Act 2013* (Cth) s 3 (1) (e) establishes the Scheme's goal to enable people with disability to exercise choice and control in the planning and funding of their supports. The development, implementation and review of NDIS plans must be informed by quality data, evidence and professionals who have an ongoing relationship with the participant. Good planning also recognises every person with disability is unique, and that people with disability know best about what supports they need to achieve their goals. QDN members have identified that 'one-size fits all' does not serve diverse needs, and failure to recognise intersectionality of experience and disadvantage increases marginalisation and risk in relation to the NDIS journey.

The complexity of the NDIS system creates additional disadvantages and barriers for people with disability from 'hard to reach' and vulnerable cohorts. This includes rural, regional, and remote communities; Aboriginal and Torres Strait Islander people; people from culturally and linguistically diverse backgrounds; school leavers; adult prisoners; children in youth detention; children attending special school; and adults on community service orders; people with disability in caravan parks, supported accommodation, social housing, and transient and homeless people.

Access and planning

- **Expand the level of support for hard-to-reach people with disability and fund community-based organisations- with specific knowledge of, experience and relationships** with people within 'hard to reach' and vulnerable cohorts, through targeted outreach and access programs (like QDN Targeted Outreach Project, refer QDN submission on Access to the NDIS). This should include 'hands on support' for system navigation to ensure services can action referrals and support, including support for GPs. This support needs to particularly target the most vulnerable cohorts with a focus on those exiting government institutions, and those who are currently falling through the gaps.
- **Fund access assessments for people with disability to access allied health professionals** to create equity of access to the scheme for people with disability. The cost of assessments to provide evidence of level of impairment related to disability are expensive, often have long wait lists, and increase the barriers to the NDIS for already marginalised people with disability.
- **Improve the process to get assessments throughout the participant journey** so that when participants are required to submit new evidence for a change of plan or circumstance, this cost can be applied to their plan. The need for new assessments and evidence once a person has access to the NDIS, particularly for those with complex and permanent disability needs to be reviewed. If the impact of someone's disability has not changed, then there should be no need for additional

evidence.

- **Apply continuity in the length of plans, ensure participants are notified of upcoming plan reviews or changes to their plans and are involved in this process,** particularly for those with complex and profound disability whose circumstances will not change significantly. While acknowledging that this is already happening to some degree, and some people have been receiving two-year plans, this needs to be extended so that carers and support people have certainty, can plan better for goals and outcomes, and are not continuously proving the need for crucial support.
- **Ensure (LACs) are able to carry out their originally intended role of building capacity on the community level.** This role is integral to community inclusion and sustainability of the NDIS. Since the inception of Local Area Coordinators, their role in practice has looked quite different as many LACs have been pulled away from community connectivity to assist participants with NDIS plans. While the responsibilities of the LACs are clear in policy, in practice there is not enough capacity to focus on real community linkages. As a key access point to the NDIS in relation to access, planning, review, goal setting and community linkages, there is not enough support for individuals to navigate the NDIS and their access to supports and services from this role with long timeframes, inconsistent support, and community linking to services often just a directory, with participants left to navigate themselves.
- **Information, Linkages and Capacity Building grants recipients need to be integrated with the LAC providers so that they are strengthening and supporting local inclusion for people with disability, and that there is a coordinated plan across communities to support inclusion.** The ILC grant program, while no longer administered by the NDIA is essential to supporting this role in community. While being reviewed separately, there needs to be more consideration and coordination in relation to tier 2 supports and mainstream services in community and connection to the LAC suppliers. This could include LAC providers hosting an ongoing community of practice for ILC recipients and LACs at a regional/local level.
- **Support Coordination model needs to shift to be more flexible so that it can adapt to meet the changing support needs of participants.** There needs to be a minimum skill set, or professional qualifications in social work/human services and/or disability for Support Coordinators while also taking into account lived experience and work experience to ensure that they have the ability to support those with complex needs. People need additional access to specialised support coordination to meet changing and complex disability- and at different life stages. The model needs to include additional safeguards and oversight so that there is a safety net in place and participants are not falling through the gaps of services and supports. Support coordinators need access to flexible block funding that can be accessed locally to ensure that people are supported in crisis, emergency and unplanned circumstances. The intention of support coordination is to build capacity and ensure a range of supports are used to achieve goals and community inclusion. Successful support coordination requires a holistic approach that considers all types of support someone may require to live a meaningful life.

Planning reviews and complaints

- **Improve support processes and access to legal representation** to ensure an equitable process for NDIS participants in Administrative Appeals Tribunal (AAT) reviews. With participants' lack of direct access to decision-makers as well as a lack of understanding by key NDIS staff of what is reasonable and necessary, many participants end up having matters unnecessarily go through the AAT. Improving access to free and accessible disability-specific advocacy and legal support from the beginning is crucial to reduce the number of cases getting to the Tribunal as well as to support people with disability adequately when they do need to go through the AAT system. In addition, having these types of legal and non-legal supports available for people with disability wanting to lodge complaints through the NDIS Quality and Safeguards, Human Rights Commission and other safeguarding bodies is equally as important.

- **Continue the provision of alternative dispute resolution/mediation** where an independent arbiter facilitates discussion between the NDIA and the affected party. QDN welcomes the introduction of alternative processes prior to engagement with the AAT, for unresolved issues, however there is still significant wait times and a backlog of dispute resolution that needs to be addressed to ensure the safety of people with disability.
- **Tracking complaints through the NDIS Quality and Safeguards Commission** so that people putting in complaints can track its progress as it moves through the system. There are no ways currently for participants to understand where their complaint is in the process, and no transparency or communication in relation to time for resolution. A clear process, communicated at different stages would increase accountability and reduce the stress of waiting indeterminate periods for an outcome. QDN welcomes the review of the QSC as a mechanism for keeping people safe.
- **Ensure that NDIS participants are included in each plan review** so that people with disability have a chance to influence the review of their own plans with decision makers and alongside other supports/advocates present where preferred. Instances of people with disability having their plans reviewed by the agency without their knowledge and/or input or the knowledge or input of plan nominees has been consistently reported to QDN.
- **A clear set of principles or a checklist of criteria endorsed by the NDIA would be useful to create greater explanation, clarity and transparency around what is considered 'reasonable and necessary,'** so that NDIS participants can be better informed around what may reach this threshold and use this as a guide. Some organisations have already developed similar tools that could be built upon or endorsed.
- **Publish de-identified data or case studies on pre-AAT dispute resolution,** as data about resolutions made before cases reach the AAT is important to improve understanding about processes and the issues that are able to be resolved through mediation. The data on reasons for how and why cases get resolved are important to understand, as in many cases, participants do not wish to proceed with taking a claim to the AAT and may settle on a resolution before proceeding with the AAT. This may not always be based on the resolution being a better outcome for the participant, but potentially for financial reasons, for fear of losing the case and the emotional toll of going through the Tribunal.
- **NDIS Supported Decision Making Implementation Plan needs to include co-design with people with disability in the development of the Operational framework** and associated resources for people with disability, families, carers, supporters and staff across the NDIA and NDIS workforce. This co-design process needs to include people with disability and their families from First Nations communities and families, and people from culturally and linguistically diverse backgrounds to ensure the framework reflect different cultural contexts, and relationships.

Workforce capacity and safeguards

- **Continue to support place-based workforce strategies in regional, remote and rural areas and where thin markets exist, but where this is not working, review impact and outcomes to identify different models of service delivery that ensure equity of access to supports.**
  Where the market has failed completely to deliver support to people with disability there needs to be a provider of last resort, which ensures there is a safety net of service provision and support for

those who need it. A provider of last resort will also provide safeguards against people being at risk of abuse, neglect and exploitation (both physical and financial) and contribute to eliminating any twin pricing regime, exacerbated by limited provider choice in regional, rural and remote areas.

- **Invest in consumer rights capacity building and a central place to raise the issues and seek help as a consumer** (not related to safety and/or service provision) for participants so that they better understand their rights in relation to purchasing services and products under the NDIS. This capacity building and awareness raising needs to include a range of inclusive information channels.
- **Include funding for disability specific training for key staff in the NDIS workforce and for NDIA staff, t**o ensure that existing staff across the system and future staff have the skills and expertise in relation to a wide range of disability, the social model of disability and access and inclusion to support people with disability accessing the scheme, as well as those who are ineligible. Training needs to include trauma informed practice so that people with disability are not being retraumatised by the organisation designed to support them.
- **Increase the targeted numbers of NDIA staff with expertise in disability and enable a connection point for continuity of relationship and service support for participants to reduce the numbers of staff with whom each participant must communicate, as well as** waiting times for applications, requests and reviews of plans. 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. This can assist with more cohesive support for participants and avoid the need for repetition of their story to multiple workers.
- **Develop a key inclusive workforce strategy within the NDIS and associated services that employs people with disability.** The NDIA should be a best practice employer in relation to inclusion, with high targets and adaptive roles within the organisation. QDN welcomes that 18% of NDIA staff identify as having disability,[1] however, this number could be much more ambitious. Having more staff in the NDIA who understand what it’s like to participate in and navigate the scheme is crucial to ensuring fairer decisions and outcomes are made. This includes people with specialists' knowledge of different disabilities, people with social work backgrounds in the disability sector and who have had specialist training.

Processes

- **Activate the sharing of draft plans with participants so that there is accuracy of plan information, the opportunity for discussion, understanding of decisions, and request for changes prior to finalization.** This will enable participants to feel more included in the process, develop more of an understanding of decision making and have greater choice and flexibility in the providers that they choose**,** can budget more effectively and avoid lengthy approval processes. It also reduces complaints, anxiety and builds trust and accountability for fair and consistent decision making within the NDIA.
- **Consumer-led and owned mechanisms** across the NDIS as well as at tPhe interface of the NDIS and mainstream services. People with disability are the experts in their own lives and know what data needs to be shared with whom and how. Having more processes around information sharing not only within the NDIS workforce but also with other mainstream services can prevent participants having to re-tell their story and justify the need for supports in an ongoing way, resulting in re-traumatisation. This will result in better outcomes for people with disability, achieving goals and enhancing wellbeing.

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[1] National Disability Insurance Agency, *Annual Report 2021–22*, p.151. https://www.ndis.gov.au/about-us/publications/annual-report#annual-report-2021-22

- **Review NDIA mechanisms for participant data and information and build on trials in this area,** so participants are not asked repeatedly to tell their stories or explain goals and support needs. Reviewing mechanisms for participant data and information may assist with improving the ways in which information is collected and recorded to have more detailed information about participant's disabilities, backgrounds and needs. This needs to be undertaken with clear processes and information in relation to participant consent. One way of approaching this issue would be to create a hierarchy of review, which requires staff to read and review previous plans and evidence for existing participants, rather than each review beginning from a 'blank slate'.

Integration with mainstream services

- **Increased awareness and understanding of the integration of NDIS and mainstream services as set out in the Applied Principles and Tables of Support (APTOS), and a review of how roles of all agencies are coordinating support and responsibility.** It is clear that there are significant gaps in services and support for people with disability ineligible for the NDIS, however there is also a clear need for a revision of the APTOS in practice, as agencies continue to silo programs and services, and a lack of understanding of NDIS responsibility results in government agencies also relying on the NDIS as the "oasis in the desert". While the Disability Reform Ministerial Council (DRMC) has a key role in ensuring shared responsibility for delivery of the NDIS across states, this is clearly not filtering down to practice at a service level. Key points of tension in the system are for people with disability exiting government institutions, including health facilities; residential aged care and aged under 65 years old; corrective services and youth justice facilities; child safety systems and voluntary out of home care; residential services (privately owned hostels and boarding houses); and crisis and short-term homeless accommodation or sleeping rough. For a significant number of people with disability living in these environments, they have a range of support needs and experience challenges navigating across complex systems and have often been labelled as complex people instead of acknowledging the complexity of the systems they are interacting with.
- **Increased integrated and outreach support for "harder-to-reach" cohorts** within harder to reach locations, in access, planning and implementation phases, in order to recognise and respond to people with complex needs and in more vulnerable situations. Some of these groups include:
  - People with disability who are transient, homeless, living in caravan parks, hostels, boarding houses, and social housing, accessing neighbourhood centre services
  - People with disability exiting the Child Safety, Juvenile Justice, and Criminal Justice service systems.
  - People with disability residing in regional, remote and rural areas.
- **Increase specific and personalised support for people with disability from marginalised groups** including but not limited to:
  - People with disability whose needs are considered and/or categorised as 'complex.'
  - People with disability who identify as Aboriginal and/or Torres Strait Islander.
  - People with disability who identify as Culturally and Linguistically Diverse.
  - People with disability who identify as Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, Asexual +
  - People with disability who identify as gender diverse, including non-binary and/or gender fluid.
  - People with disability who identify as female.
  - People with disability who identify as elderly.
  - People with disability who have multiple intersections.

Having separate disability-specific services that cater to each of the communities, for example, an disability-specific service for Aboriginal and Torres Strait Islander people with disability, that specialise in both NDIS support as well as providing culturally appropriate care support and systems advocacy to the community they are working with and representing can help support participant safety, likelihood of engaging in NDIS mainstream service and supports and holding the NDIS accountable to supporting people with disability from a diverse range of backgrounds and identities. Workforce training for mainstream NDIS services around cultural competency and responding to the needs of diverse groups and people with multiple intersecting identities is just as important.

Digital inclusion

- **Acknowledge and increase support for digital inclusion for people with disability.** People with disability are one of the most excluded groups in relation to digital inclusion. For people in the most vulnerable and hard to reach groups, there is limited access to digital devices, ability to afford an ongoing connection and skill in using digital devices for basic information and engagement. With many services and information increasingly only provided in digital formats, it is essential that all people with disability are included in the digital world. Key strategies and programs are needed that increase access to digital devices and have hands-on digital literacy support, so that people with disability are able to access the NDIS more readily, are able to use online portals and navigate the NDIS as well as other important mainstream services which are transitioning to more online support and app-based interactions, such as the Department of Human Services, for example. QDN has a proven project that addresses this, the Access, Affordability, Ability Digital Inclusion project. QDN will submit the evaluation report from the project to the NDIS Review submission portal separate from this document.

Communication

- **Simplify and demystify NDIA language**, particularly in participant correspondence. Feedback from our members has been that the NDIS website is not accessible enough. Ensuring that information is available in the following formats is important: Easy Read versions, audiovisuals, web content designed for screen readers, audio recordings for information/articles/any text documents, Auslan videos, 'Say Less, Show More' formats for all media files, braille for text and written documents as well as more video and visual formats.
- **NDIS to influence the mainstream media and political messaging** to ensure that the NDIS is not solely represented as a cost but economic benefit. Too often we see the NDIS being weaponised as a drain on the economy. In recent times, the media has discussed cutting the growth of the NDIS as well as potential participants with psychosocial and mental health disabilities no longer being able to access the scheme. These media stories negatively affect the way that disability is viewed at large, further perpetuating unhelpful narratives around the cost of critical supports rather than focusing on outcomes and dismissing 'invisible' disabilities such as psychosocial and mental health disabilities. These attitudes can also negatively impact decisions around creating more societal accessibility at large and the health and wellbeing of people with disability.

Building capacity

- **Designated funding to establish new and strengthen existing peer support mechanisms for people with disability and their families to assist their navigation of the NDIS system.** Peer support is a proven way to empower people with disability and connect them with other people who understand their experience.[2][3][4] This can assist in the context of the NDIS as often people with disability rely on guidance and support from their peers with disability and can feel safer and more comfortable with these forms of informal supports over formal agency supports. It is critical that ILC funding can continue to fund peer support programs, to connect people with disability to others with lived experience, but provides a mechanism to provide current information, build their capacity for leadership, and ensures a strong feedback loop for the systems that impact on them.

- **Build the skills of people with disability to be informed and confident participants,** to ensure that people with disability are able to successfully navigate the NDIS and are empowered to do so. Transparency and information sharing is a critical part of skilling participants, particularly in the context of self-managed plans. Ensuring that people with disability managing their own plans are supported to self-manage and have accessible information and guidelines to empower them to continue with self-management.

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[2] Hughes, R., Fleming, P., & Henshall, L. (2020). Peer support groups after acquired brain injury: a systematic review. *Brain injury*, *34*(7), 847-856.

[3] Brock, M. E., Schaefer, J. M., & Seaman, R. L. (2020). Self-determination and agency for all: Supporting students with severe disabilities. *Theory into practice*, *59*(2), 162-171.

[4] Richardson, L. J., Molyneaux, V., & Murray, C. D. (2020). Being a peer support mentor for individuals who have had a lower limb amputation: an interpretative phenomenological analysis. *Disability and Rehabilitation*, *42*(26), 3850-3857.

Key issues

Assessment Costs

QDN Members report the financial cost of accessing the NDIS as well as making requests for essential supports is a significant burden. Currently, many people with disability are required to pay for their own assessments to be able to provide evidence of their disability and evidence for needing certain supports through the NDIS such as equipment.

"I need a bidet installed. I can do it for $400...to get it on the NDIS will cost $2500 + $350 for the OT to approve it!" (QDN member)

Assessments can be expensive for many people on low incomes, for example an OT, Autism and/or ADHD assessment can easily cost thousands of dollars. Issues of access are exacerbated by postcode and identity. NDIS access is more challenging for people with psychosocial disability, "invisible disabilities" and/or disabilities that are episodic in nature and they often have limited support options outside of the NDIS.[5][6][7][8] Often, after investing in the cost of allied health professionals to provide evidence of impairments or support needs, the NDIS will still dispute the necessity.

"for all the reports that we do have to go through and pay for doctors' appointments out of our own pocket, it would be nice that the person who does the review of these specialist's reports, believes that these are from specialists...if they believed what specialists actually say, would actually help, I think, in a lot of cases." (QDN member)

Thin Markets

For groups such as people with disability living in regional, remote and rural areas, people with disability who have complex needs, as well as people with disability who identify as Aboriginal and Torres Strait Islander, LGBTQIA+ and/or Culturally and Linguistically Diverse, NDIS support is under resourced due to thin markets. Thin markets can limit choice and control and be a barrier for people with disability being able to access the supports most appropriate to meet their needs, even at times on a very basic level.

Timing

Long wait times occur at every stage of the NDIS process, from access, to plan reviews, to requests decisions, to AAT decisions. Members experience NDIA applications taking months to conclude. Issues of timing impact people with disability in regional, rural and remote areas more considerably due to the lack of services and for shipments of equipment, for example. Scheme planners are not able to make final decisions about a participants' plans. This slows down the progress of a plan and denies the participant a role in decision-making: a participant cannot converse with the person responsible for making decisions.

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[6] Dickinson, H., Yates, S., & West, R. (2022). Exercising meaningful choice and control in the NDIS.

[7] Mellifont, D., Hancock, N., Scanlan, J. N., & Hamilton, D. (2022). Barriers to applying to the NDIS for Australians with psychosocial disability: A scoping review. *Australian Journal of Social Issues*.

[8] Dickinson, H., Yates, S., Smith, C., & Doyle, A. (2021). Avoiding Simple Solutions to Complex Problems: Independent Assessments are not the way to a fairer NDIS.

"It does take a long time (NDIS requests and reviews), I don't have a solution for how to make it faster... but I would like to see it a lot faster...when we don't agree with what we're given, the only recourse we have, or hold is go to the appeals and if you don't like that go to the tribunal." (QDN member)

"There is very little recognition by the NDIA that living in regional areas has a big impact on access to NDIS services, for example, it takes a lot longer to get supplies if you're in a regional area, and therefore maybe fast-tracking their reports could be a way to better serve the regional participant." (QDN Member)

Funding reductions and reviews without participants

Members often experience funding reductions to their plans without explanation and sometimes plans are reviewed without them and significant changes are made. Participants expressed that they would like to be "met where they are at," having more flexibility to have reviews occur in the home, workplace or over the phone based on personal preference and capacity, and to always be included in the review process, with decisions transparent and justified.

Reasons behind funding reductions or ways to contest these cuts have not always been clearly explained to our members. Sharing information around decision-making is critical to ensuring that participants understand why their funding may reduce, whether they can contest a decision at a planning review and how their funds can be used to give them access to the best supports for themselves. Some members have recounted experiences of NDIS staff not checking in for further information about their situations when making critical decisions around their plan.

"Last year, I tried to get linen services, I got accepted by someone and then someone rejected it...they didn't ask for more information, they just decided and that's it...no double checking. They are not allied health people or disability informed." (QDN member)

"Recently my NDIS plan rolled over and with the (home) modifications, I lost $99 000 in allied health supports which means I had to cut down on essential supports such as gym, my dietician, physiotherapy, podiatry, social work support, speech therapy and hydrotherapy and now I only have enough for physio, gym and podiatry in the plan. I'm going through the s100 process, and I may only have my support worker for 6 more months and allied health workers for 3 more months due to the funding decrease to my plan." (QDN member)

Difficulties in plan variations/re-assessments/change of circumstance

Members report difficulties when needing to make adjustments to their existing plans with the constant repetition of information and evidence they need to provide, the anxiety that the support needs they are putting forwards could be declined and the time it takes to both put through requests and receive outcomes.

"my marriage broke down and I went through a divorce. My partner provided a lot of informal care at home as I am legally blind. I put in a request for a change of circumstance, and I asked for more support hours. The response was that I haven't supplied enough evidence of the need for more support. Its obvious that when one person leaves a household, there's more work for the other one to do and why I'm treated as different as a person with a disability. In order to get more support I have to undergo all the assessments again and provide reports. I never did get those extra hours because it's not worth it mentally for me." (QDN member)

Lack of support and information sharing for self-managed plans

NDIS participants are a lot less likely to have self-managed plans.[9] [10] A lot of the onus is put onto the participant when they are self-managing their plan to know exactly what they are doing. A 2020 Study found that little is known about the people who are missing out on self-management, how people are self-managing, which responsibilities people who are self-managing are taking care of themselves, delegating or paying for, avoidance of misuse by formal and informal supports, and what self-management means for the quality of their lives and fairness for other people using disability support. [11] There can be more penalisation of participants for making mistakes than the agency, despite not always having the information and knowledge shared to them by the NDIA to support their self-management. Members report being fearful of self-management for these reasons.

"I will not go anywhere near self-managed...I'm scared I'll make one mistake and it will all be on me and I'll be in trouble. There is no accountability on the other side." (QDN member)

"Just as an example, and there's plenty to choose from... we worked with a lady who acquired her disability, got her first plan, had no idea what the NDIS or NDIA or what a plan is. They made it self-managed, she lived regionally had no idea what she could and couldn't do within the boundaries of her plan. She incorrectly, but not intentionally, used the funds for something not included, went to her next review and the planner said to her you've misused your funds... as a consequence you are now going to be agency managed ." (QDN supporter)

Lack of Clarity around "reasonable and necessary" determinations

The NDIS determines what is "reasonable and necessary" through the NDIS Act – Section 34, declaring that "the support will assist the participant to pursue the goals, objectives and aspirations included in the participant's statement goals and aspirations included in the participant's statement of goals and aspirations.[12]" Without clarity around how these terms are interpreted in different cases, inconsistency, and therefore some people missing out on crucial support will continue to be the norm. QDN welcomes that the NDIS is working on guidelines and documents in Easy English and has produced resources around the types of supports that can be funded under the NDIS and examples, however, many members still report a lack of consistency in what seems to constitute "reasonable and necessary" to the NDIS.

Many of our members have had the experience of declined requests to the NDIS for items and/or supports that will assist them to pursue their goals, objectives and aspirations in their participant's statement as well as funding cuts to their plans without any changes in their circumstances and abilities.

With greater explanation, clarity and transparency around what is considered "reasonable and necessary" and what is required to show these qualities, many cases could be prevented from reaching

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[9] Blaxland, M., Fisher, K.R, Purcal, C., Robinson, S., Quan Farrant, F., Pearson Gotting, M., Kayess, R. (2020). National Disability Insurance Scheme: People who self manage their NDIS plan, Sydney: Social Policy Research Centre, UNSW Sydney. http://doi.org/10.26190/5f56b3c1d3c0d

[10] Purcal, C., Savage, L., Fisher, KR. (2021). National Disability Insurance Scheme self managed plans Family Advocacy survey, Sydney: Social Policy Research Centre, UNSW Sydney.

[11] Blaxland, M., Fisher, K.R, Purcal, C., Robinson, S., Quan Farrant, F., Pearson Gotting, M., Kayess, R. (2020). National Disability Insurance Scheme: People who self manage their NDIS plan, Sydney: Social Policy Research Centre, UNSW Sydney. http://doi.org/10.26190/5f56b3c1d3c0d

[12] National Disability Insurance Scheme Act 2013. Section 34,1(a). *Australian Government*. https://www.legislation.gov.au/Details/C2016C00934

the AAT.

Plan Goals, Funding, and Dispute Resolution

The fundamental goals of people with disability are still falling into the gaps between NDIS and mainstream funding. Dispute resolution is slow, daunting, and costly. 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.[13] Some participants feel their goals and stated support needs are lost in the bureaucracy of the NDIA. 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. If there was no 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 question 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.

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.

"There is a lot of uncertainty when your plan comes up for review, uncertainty about the LAC." (QDN member)

If members were faced with the choice of taking their issues to the AAT, most were unable to access independent advocacy services. As a result of the increase in cases being taken to the AAT, independent individual advocacy services in Queensland are at or over capacity. Without independent advocacy support and guidance through the process, many participants do not have the capacity to understand or ability to access the information they needed to progress their cases to the AAT. This meant many members felt too overwhelmed to take their issues to the AAT.

Some members who don't have access to informal supports or advocacy services, were relying on Support Coordinators to help collect evidence to bolster their internal and external reviews. This means that fewer Support Coordination hours were then available to link people with services, build capacity to manage NDIS plans and ensure plans are used to their full potential.

Many members noted that the lack of support and advocacy services stood in stark contrast to the resources being spent by the NDIA on defending cases at the AAT. This power imbalance, without adequate support for people with disability is counterproductive to the values of the scheme and allocates resources that could be better invested in advocacy and support for participants.

Local Area Coordinators

Local Area Coordinators are under resourced and do not have the capacity or skills to undertake what the role initially intended and be a presence in local communities. Members strongly believe the NDIA needs more staff to meet demand so LACs could prioritise their local community. Without being able to

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

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.

"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 LAC's are doing Plan review, which they were never meant to do." (QDN member)

Members reported that LACs had little to no understanding of 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, improve their community engagement and approach, and communicate in inclusive ways with participants. 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 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.

Support Coordination

Members have expressed that the role of Support Coordinators remains a significant issue for participants moving forward and requires greater oversight, monitoring and training. Members remain confused about the role and responsibilities of Support Coordinators. While the NDIA's intention may be for Support Coordinators to build the capacity of participants to manage their supports independently, members who were funded for supports coordination overwhelmingly reported that this was rarely the focus of their work.

Capacity building is often given little focus during the implementation of a person's first plan because most of the coordinator's time is spent finding and establishing supports. However, members also reported that supports coordination is rarely funded beyond the first plan and therefore they are not given the opportunity to build the skills to manage their plans independently, with the safety net of a Support Coordinator in place. Members felt that supports coordination funding should remain in NDIS plans until participants could show they had capacity to manage a baseline level of supports.

People with disability can enter into crisis if their support coordination ceases, which can put their health and safety at risk. The quality of supports coordination services varies widely and finding a skilled Support Coordinator often relies on word-of-mouth recommendations. Members expressed disappointment that there is still little oversight, accountability and checks and balances for Support Coordinators. Additionally, many regionally based members experienced working with Support Coordinators who are not connected with the local communities they service, which means they were providing advice that is often impractical, particularly for small towns with limited services. Members in regional, rural and remote areas were also often unable to meet their Support Coordinators in person. Members spoke about how this meant their services weren't tailored to their individual day-to-day life experiences.

Another issue regarding support coordination is that Support Coordinators are not required to hold any mandatory minimum qualifications or training. This in turn can limit the quality of service Support Coordinators are able to provide and illustrate why it can be difficult for our members to find quality Support Coordinators.

"In reading back over Bill Shorten's address to the national media hub last month...support coordination was not recognised as an area for change... I am aware of the issues arising for a lot of people (with support coordination) and this needs to be part of the (NDIS) Review." (QDN Member)

Support workers

Feedback from members has also centred around lack of reliability when it comes to support workers. QDN welcomes the government's acknowledgement of needing to attract more support workers to the disability sectors by creating supportive and sustainable working environments for workers.

Disability-specific training for support workers is critical. Hiring support workers who have experience in human services settings, identify as having a disability and/or have experience working with people with disability should be prioritised. Where the positions are unable to be filled by experienced workers, training and monitoring workers' progress in supporting people with disability ethically needs to be in place.

"There is a lack of quality of support workers - they are not good enough with passion and experience" (QDN Member)

Members have commented that there is high staff turnover and that it is difficult to find quality support workers who understand their disability and their needs. Other comments also surrounded support workers increasingly working for themselves as opposed to organisations, which makes it difficult when they get sick or need someone to replace them when they're on leave.

"Consistence is the hardest. If going through an agency the turnover of staff has been increased by staff going independent. Hiring independent leaves you in a hole if they are sick or need a day of or holidays. Compared to agency who will just replace a support worker until your regular one returns to work." (QDN Member)

There need to be minimum standards for support workers, more regulation and accountability mechanisms in place for NDIS providers to ensure quality support work as well as quality support and supportive environments for support workers.

Media representation of the NDIS

In the mainstream media, the NDIS should not just be discussed simply as a cost, but also as an economic benefit, which was highlighted by the Productivity Commission when it designed the Scheme. The economic benefit of the NDIS has been measured since its implementation, and Per Capita's analysis of the scheme shows for every dollar spent, the economy benefits by a factor of 2.25. In this context the

NDIS is estimated to have contributed $52.4 billion to the national economy in 2020-21 (EAC website). The current narrative about NDIS and “cost blowouts” and “cost burdens” has caused unnecessary fear in the disability community and has also failed to acknowledge the hundreds of thousands of jobs the NDIS creates, the small businesses it has helped to create and the almost 100,000 people with disability who – for the first time in their lives – are getting the supports they need to live full and equal lives. And

“We are all people first; we are not asking for special treatment just equal treatment.” (QDN Member)

Members have widely acknowledged that the NDIS is an important scheme and whilst there are areas of improvement to deliver a quality scheme, they wanted politicians to understand that when you invest in people with a disability, it not only benefits the individual, but the entire community, both socially and economically and this message should be promoted loud and clear.

Disaster Planning

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 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”.[14] 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.

Gaps in advocacy/Need for improved complaints process

Currently there is a lack of support available for people with disability who need access to anti-discrimination legislation and who require additional support to lodge claims through the Human Rights commission.

There is currently no function for people with disability to be able to track the progress of complaints through the NDIS Quality and Safeguards Commission. From consultation with our members, we have found that overwhelmingly there is a lack of independent advocacy support for people with disability navigating the NDIS at every stage of the planning process, including a lack of affordable legal and non-legal advocacy and representation for people with disability going through the NDIS AAT as well as the NDIS Quality and Safeguards Commission.

Gaps in models of support

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

The NDIS model as it stands does not use a case-management framework. QDN are concerned for some of the most vulnerable people with disability, including those who fall under the "complex needs" category, who require intensive support, and are not receiving the support they need under the NDIS. Whilst the NDIS Complex Needs Support Pathway provides beneficial, specialised support to participants who have complex needs, the pathway is rarely simple to engage and navigate.

"(the) complex support needs team...they have infrastructure, they need to ensure that there's capacity there...there is such a huge waitlist...they don't promote it...it's not being used to their fullest extent." (QDN member)

People with disability with complex needs, including participants living in shared living arrangements under the NDIS, need safeguards in place to ensure that they are utilising their NDIS supports to their full capacity. Some people with disability and complex needs don't have access to informal supports to help with their support needs or support them to navigate the NDIS. Members report that often times for participants with complex needs, they struggle to access support under the NDIS that caters for their needs and meet the support hours required.

"A lot of the providers we have had embellish their skillset, sometimes just so that they can get higher recognition for a complex needs skillset, as my son falls into the 'complex needs' category... they stay for a very short time, are often incompetent and then they leave...last year, we realised one of the workers was just aiming to get work on public holidays...he ended up leaving, told us something had happened in his family, but we saw him back online again in a couple of days...there is a lack of support in the complex needs space and filling shifts can be difficult for individuals and/or families with complex needs." (*QDN member)*

Invisible and psychosocial disabilities

Members with psychosocial and neurodivergent disabilities often report feeling "invisible." There is an existing grey area between the roles of the NDIS and the mainstream services and supports that sit outside of the NDIS in supporting people with psychosocial disability. The NDIS will say that health services are responsible for Mental Health support instead of NDIS funding covering psychologist/psychiatrist sessions. This can be difficult for people with disability who have more intensive and chronic mental health needs. Having access to ten sessions per year that are only partially covered by Medicare, is sometimes not enough for complex trauma as well as certain chronic disabilities. There are often still gap fees for psychology and psychiatrist appointments that are too expensive for people on lower incomes and who have struggled to access the NDIS.

Increasing psychosocial and neurodivergence specialists in the NDIS workforce could better support participants with psychosocial disability, especially given the experiences of invisibility of people with psychosocial disability.

"I have a psychosocial disability and a late diagnosis of autism and ADHD. My disability has prevented me from having the ability to apply for the NDIS as I also struggle to support my 20-year-old son to be a participant. I once had an OT in my house assessing my psychosocial disability by asking me to show her how I make a cup of tea." (QDN member)

"When will be the day for those with hidden invisible acquired disability, they were technically born with from start? Certain bodies like the NDIS & those so-called LAC's do not respect those like me. We all have

different types of acquired disability it's also our level of capacity. Not only in what we do each day of our life but also share our lived experience at times do not get heard the right way."(QDN member)

Transparency

A key issue raised by members is in relation to the culture of secrecy and gatekeeping within the NDIS. Increasing transparency in decision making and clear accountability will increase trust and reduce complaints processes. There are concerns around a lack of access to NDIS decision-makers. There is a lack of existing information around the experience of decision-makers at all levels of the NDIA – whether they are people with disability themselves, whether they have experience working in the disability sector or have specialist knowledge of the participant's particular disability.

The experience and understanding of a decision-maker holds considerable weight as it has the ability to impact on the outcome of a plan review. There are few accountability measures to ensure the NDIA implements recommendations from participants, family, supporters or disability advocates. Members report feelings of apathy: their feedback to the NDIA seems to go nowhere.

"I was asked by the NDIS to give feedback around creating more accessible processes for the vision-impaired community, and those recommendations weren't implemented. When are they actually going to implement our recommendations?" (QDN Member)

There is limited public data available surrounding authorised use of restrictive practices as well as whether behaviour support plans are effectively reducing the use of restrictive practices. Access to this data could support greater monitoring and accountability mechanisms.

Currently, there is a lack of published data surrounding the AAT: why and how certain cases are resolved by agreement instead of going through the Tribunal. Increasing the information available around dispute processes, access to legal representation, and reasons behind withdrawn cases would be useful in understanding barriers to disputing reviewable decisions.

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.

Evidence Requirements

There can be a lack of understanding by assessors on what is required- for evidence throughout the NDIS process from access, to plan reviews, to tribunal cases. Oftentimes people with disability are required to provide evidence time and time again. Good planning is based upon quality information. QDN members believe the development and review of NDIS plans must be informed by quality data, evidence and professionals who have an ongoing relationship with the participant. Good planning also recognizes every person with disability is unique. The *National Disability Insurance Scheme Act 2013* (Cth) s 3 (1) (e) establishes the Scheme's goal to enable people with disability to exercise choice and control in the planning and funding of their supports[15]. QDN members have identified that 'one-size fits all' does not serve diverse needs, and failure to recognize differences of age, gender, sexuality, cultural background, disability and location may increase marginalization and risk.

People with disability have voiced the importance of evidence from medical and support specialists that really understand them and their disability. Often, the person with the best understanding of a person's support needs is not the person whose evidence is most valued by the NDIA. Invisible and complex disabilities, particularly psychosocial or dual disabilities, can be misjudged or disregarded by assessors who lack expertise about a particular form of disability. Women and girls with autism, for example, have low Scheme participation rates partly because autism in females is under-recognized.[16]

Some members who don't have access to informal supports or advocacy services, are relying on Support Coordinators to help collect evidence to bolster their internal and external reviews. This means that fewer Support Coordination hours were then available to link people with services, build capacity to manage NDIS plans and ensure plans are used to their full potential.

"Having to reprove our disability again at reviews is expensive and it's hard to keep proving your disability at every review." (QDN Member)

Improving shared access to data

A common frustration with the NDIS was the constant need to reshare information. Members strongly believe that the NDIS could be more efficient and easier to interact with if there was a focus on how to best share data internally and with other government departments. Members were frustrated that one of the promises of the NDIS was that you wouldn't have to tell your story repeatedly to get disability support. However, as it currently stands, that is how the NDIS is working. Members report having to resend reports and doctors letters to different NDIA staff or different agencies not having access to NDIS information. A new co-designed data sharing process made with people with disability at each step of the way would result in a better experience for participants and greater efficiencies for government.

Siloes between the NDIS and Mainstream service systems

"I feel a bit offended that disability is not considered mainstream." (QDN member)

Often the NDIS and mainstream services are working in siloes, significantly impacting the quality of support people with disability receive through both service systems. Our members report being confused about whether the NDIS or government departments are responsible for their care in certain circumstances related to health, housing and transport for example, and that these services often can't give them a clear answer.

"There is a big divide ever since the NDIS or NDIA has come into play...government services want to push everything onto the NDIS and then the NDIS say It's a government issue." (QDN Member)

The Taxi Subsidy scheme has been extended for 12 months, however, there is no stability or certainty

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[15] National Disability Insurance Scheme Act 2013. Section 31,1(e). *Australian Government*. https://www.legislation.gov.au/Details/C2016C00934

[16] National Disability Insurance Scheme (2020) 'Outcomes for participants with Autism Spectrum Disorder.'

around whether this scheme will continue to be extended. Many people with disability rely on taxis as a form of transport where public transport is sparse and often still inaccessible for many and accessible rideshare options have not been introduced in Queensland. Experiences of our members have often been that hospitals do not want to treat people with disability if they are NDIS funded and that the relationship between the health systems and the NDIS, if any, is very weak.

"Yep, being told it's not the responsibility of the NDIS and then having the health system not help... The amount of times I've had no help provided or wrong medical treatment illegally forced on myself by the health system is unbelievable. I'd rather get no treatment, get worse and then cost the NDIS more in the long run because of a short-sighted decision not to throw me a little bit extra funding to fix an issue in the first place." (QDN member)

Housing should be an important part of a participant's plan and not separated, as having safe, sustainable and accessible housing can impact on disability, functionality and plan goals.

"People assume that as soon as people get onto the NDIS there are housing options... this is not the case ...need more choice for housing." (QDN member)

Digital Literacy

An assumption cannot be made that all people with disability can access the NDIS through digital devices such as phones, tablets and computers as well as the internet and other digital platforms. The Australian Digital Inclusion Index (ADII) illustrates, many people with disability do not have access to digital devices, the internet, and therefore critical services such as the NDIS.[17] The national digital inclusion score for Australians with disability is 47.0, in comparison to the Australia-wide score of 56.5.[18]The index has also found that affordability and education impact significantly on access to technology. Australians with disability scored lower in the affordability rating in comparison to the National average, and experience lower levels of education than those without disability (21% left school before age 16 compared to 8.9% without disability). The statistics are even starker for completion of Grade 12 for people with disability; only 34% aged 20 or over completed, compared to 66% of those without disability).[19]

Many of the most vulnerable people with disability, particularly those with complex disability, psychosocial disability and intellectual disability do not have access to a digital device, cannot afford to be connected digitally in an ongoing way, and do not have the skills to use a device at a basic level (to send texts, email, or navigate websites). These barriers are increased for First Nations and culturally and linguistically diverse people with disability. We need more rigorous data on the needs of this group, as they are currently excluded from any online access and the choice and control offered by Platform Providers in connecting supports is out of their reach. Currently, most research into digital inclusion for people with disability has focused more on accessibility and usability of digital technologies and

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[17] Thomas, J, Barraket, J, Wilson, C, Ewing, S, MacDonald, T, Tucker, J & Rennie, E, 2017, Measuring Australia's Digital Divide: The Australian Digital Inclusion Index 2017, RMIT University, Melbourne, for Telstra. DOI: www.dx.doi.org/10.4225/50/596473db69505

[18] Thomas, J, Barraket, J, Wilson, C, Ewing, S, MacDonald, T, Tucker, J & Rennie, E, 2017, Measuring Australia's Digital Divide: The Australian Digital Inclusion Index 2017, RMIT University, Melbourne, for Telstra. DOI: www.dx.doi.org/10.4225/50/596473db69505

[19] Australian Institute of Health and Welfare (2022) People with disability in Australia, AIHW, Australian Government

content.[20]

QDN runs a Digital Inclusion program (Access, Affordability, Ability Digital Inclusion) that provides digital devices such as smart phones, tablets and computers to people with disability in areas of Queensland as well as workshops codesigned with and delivered by people with disability to build participants capacity to use their device and engage in the digital world, particularly in times of emergency and disaster. This project has provided invaluable information about this group of people. From data collected through the project delivered across four regions in Queensland, we know that over 50% of people could not send or receive emails, 30% we not confident in sending or receiving text messages, 35% were not confident in making or receiving phone calls or using a search engine to find information on the web (QDN, AAA Digital Inclusion Evaluation). Of the 850 individuals that engaged in the project over an 8-month period, 65% had an intellectual or psychosocial disability, and the majority of these were living in insecure or shared housing. These intersecting challenges indicate the complexity that many people with disability face in engaging in the digital world and is an important factor in considering the accessibility of online NDIS interfaces.

QDN recommends having widescale pre-NDIS support programs and services like QDN's Digital Inclusion Program, which provide access to digital devices as well as digital literacy for people with disability, as this is crucial to ensure equity of access. Feedback from our members has been to improve the NDIS digital access is increasing accessibility of the NDIS website through simplifying language and content as well as more inclusive information accessible to people requiring screen-reading technologies and learning disabilities such as dyslexia.

"There is a wide assumption being made that people prefer to engage their services online, a lot of people from my communities don't have the confidence to use technology... some don't have computers or money to be able to own and operate computers and/or devices and feel ashamed that they can't afford technology and aren't hardwired with the skills to use it, which is a real barrier than can prevent First Nations, Culturally and Linguistically Diverse and ageing people from seeking out and engaging in support." QDN member.

Language Barriers

QDN Members often report lack of simple, clear and straightforward information coming from the NDIS, overly bureaucratic language and unnecessary acronyms used and have even described a "secret language" that people with disability need to be aware of to access and navigate the scheme as well as receive particular outcomes.

Members have expressed that often people with disability rely on the support and advocacy of peers who have navigated the NDIS and understand the language the NDIS responds to. This can make it confusing for people with disability to both understand and access the scheme in first place. These language barriers can be further compounded for people with intellectual and learning disabilities, people who are non-verbal, people who are illiterate, people who identify as Aboriginal and Torres Strait Islander and from Culturally and Linguistically Diverse Backgrounds.

"You don't know what you're asking or what you need, you don't know all the right terminology or

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[20] Thomas, J, Barraket, J, Wilson, C, Ewing, S, MacDonald, T, Tucker, J & Rennie, E, 2017, Measuring Australia's Digital Divide: The Australian Digital Inclusion Index 2017, RMIT University, Melbourne, for Telstra. DOI: www.dx.doi.org/10.4225/50/596473db69505

acronyms...it just needs to be simplified." (QDN member)

Communication with the NDIA

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. 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." (QDN member)

"Call centre contacts, planners and LACs ask me the same stuff over and over again. It's poor record-keeping." (QDN Member)

There is a disconnect between the relatively lengthy and often vulnerable self-disclosure characteristics 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. Decision-makers, on the other hand, are distant and unaccountable. Participants do not receive detailed feedback on reasoning behind funding decisions.

Lack of consistency

Lack of consistency has been raised by our members, who state they often do not have just one planner who they are able to work with throughout the NDIS process, and therefore have no opportunity to build relationship and understanding. Participants must repeat their story many times. Participants feel the quality of their plan has varied depending on the skills, experience and empathy of the planner.

"I feel that there's so little connection between LACs who end up doing your plan review and yourself,.. I had a review in January of 2022..but the person in the review, I'd never met before, I'd never talked to before, and here I was, I had to say my whole life and explain how so many things were so important to me in the space of an hour...there has to be a rapport building of some kind. We need to have the power to say that's not what I said in my review.. And that happens by draft plans and we need to be able to talk to those who do the review, like...they can't just disappear into thin air after they've had that initial meeting with you or phone conversation with you." (QDN member)."

One of our members reports the call-centre, too, is inconsistent. Some workers say one thing, and others saying another, often without hesitation or any attempt to source a sure answer.
A member once had to go through ten different call-centre staff about Scheme funding for accessible equipment. This matter, he reports, is now with the AAT, and to transcribe the legal information into an accessible screen reader format will cost the NDIS approximately $1400. This money, let alone the cost for the NDIA to engage counsel, would have covered the costs of the equipment.

"The NDIS call-centre is staffed by two different types of employees: full-time government and casual labour-hire through the SERCO Group. The SERCO staff are not as well trained as the full-time government employees, in fact I'm not even sure some of them have been trained." (QDN Member)

Lack of accessibility is particularly challenging for people with disability that may also have other intersectional identities, for example, First Nations and Culturally Linguistically Diverse people who may have further barriers to accessing information, culturally appropriate support, and may have additional barriers to accessing legal information and representation.

Approach towards participants

Feedback from members frequently has been that the NDIS uses a "one size fits all approach" that is not person-centred or trauma-informed and does consider the individual needs of someone with disability. People with disability have diverse life experiences, needs, goals, communication styles, strengths, abilities, and function differently in a diverse range of environments. Members report greater feelings of safety with peers, and so that they often draw on this support more than that of formal supports when navigating the NDIS. Without greater staff accountability, people with disability won't feel safe accessing and participating in the scheme,

" I don't believe that's going to happen (people with disability feeling safe) until staff members and those making the decisions are held accountable for when they don't uphold principles of equality, respect and co-design. The onus is all on people with disability to be honest and thorough in their reports...when it comes to those who make decisions...if staff are rude and disrespectful there is no accountability." (QDN Member)

Members report a lack of information and exploration around how funds in their plans can be used as well as a lack of explanation around the different levels of support coordination that can be accessed. This can be due to a lack of understanding on the part of LAC's, planners and support coordinators about different NDIS services and funding options.

Many NDIS participants' plans funds remain the same despite providers charging more for services due to wage increases of NDIS staff, which can create affordability issues.

"It would be good to know how you've been funded, what is coming from where, how it has been decided...(it) would be good to see the back of house of the decision-making process...(it) would be helpful to know I've funded for 'x' amount for various services, so I can work on getting more evidence for certain supports." (QDN member)

People with disability have voiced the importance of evidence from medical and support specialists that really understand them and their disability. Often, the person with the best understanding of a person's support needs is not the person whose evidence is most valued by the NDIA.

More disability-specific services for diverse cohorts are required to support and empower more marginalised people with disability and provide culturally appropriate responses as well as continued training for mainstream NDIS staff around diverse groups of people with disability, such as those mentioned above.

"I'm talking about First Nations people with disabilities issues, we need to look at the First Nations Strategy, partnerships with First Nations people, the National Disability Insurance Agency needs to work with First Nations people with disabilities to ensure that our co-design... to ensure that it is implemented and codesign a new First Nations Strategy and Action plan. For example, we will need to work together to ensure the strategy is culturally appropriate, supports self-determination, meaningful and

measurable, reflects the meaning and goals of First Nations people with disability and to advise and keep on track the First Nations advisory council, we would need to work with them to create to ensure that the First Nations Strategy, the First nations Advisory Council members are first nations people who have lived experience of disability and understand the issues and challenges in the communities." (QDN member)

The NDIA has a 'power-over' dynamic with participants instead of a participant-led/participant-centred model. Members have reported concerns about funding cuts to their plans, denial of requests for essential items or plan components, wait-times for decisions, and the 'uphill battle' escalating decision reviews to the AAT.

"On 29th June, I submitted a request to go from self-managed to plan-managed (NDIS states this should be resolved in 21 days). After numerous phone calls, lodging a complaint and then a support worker contacting NDIS on my behalf, it was finally resolved on 16th September. It created a lot of anxiety for me, which then affected my neurological symptoms. A part of the reason for putting in this simple request was to free up cognitive space to prepare a much more significant request for plan review." (QDN Member)

QDN members overwhelmingly expressed concerns that the proposed process will lead to people with disability once again relying on standardised testing and funding packages to meet their basic, everyday needs. The NDIS was established to replace standardised models as it was widely acknowledged that this approach led to inadequate and inappropriate support for people with disability, and in many cases, no support at all. People with disability do not want to go back to the old system.

"We cannot 'box' people with disability into neat categories. A 'one size fits all' approach does not work, and this was one of the reasons why the NDIS was released to begin with. Participants need individualised, tailored assessment and planning to ensure their function and needs are appropriately assessed." (QDN Supporter and Occupational therapist working with people living with psychosocial disability)

QDN has undertaken significant work in Queensland supporting people with disability experiencing additional marginalisation. Our experience is that successful outcomes for people with disability from these cohorts require trauma-informed, person-centred, individualised support to navigate complex government systems and ensure they have access to quality, safe and inclusive services, both NDIS and mainstream. For these groups of people, focussed and extensive support is required to gather the information needed to access the Scheme and reap the full benefits it can bring, including improved educational and employment outcomes, access to health and housing services, and opportunities for social inclusion.

While acknowledging the positive impacts of the NDIS on the lives of over 120,000 Queenslanders with disabilities, QDN highlights the ongoing difficulties faced by many individuals in participating in the scheme. Through our members, projects and advocacy work, we have identified a range of systemic issues and barriers and emphasise the need for authentic consultation, meaningful engagement and codesign with people with disabilities, their families, providers, and the broader sector to ensure that the NDIS meets the needs of its end users.