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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. QDN operates a state-wide network of 2,000+ members and supporters who provide information, feedback and views based on their lived experience, which inform the organisation's systemic advocacy activities. QDN has worked with members around the NDIS for over 10 years since its introduction and has been actively involved in the design and formation prior. 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 – the NDIS and mainstream services that people with disability rely on every day, including health, housing, employment and transport.

QDN members have actively engaged to provide feedback, input and their lived experience at the Commonwealth level including the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (DRC), the National Disability Insurance Scheme (NDIS) Review and improving housing and support options for vulnerable people with disability. QDN commends systemic reform to the NDIS. While Queenslanders with disability acknowledge the positive impacts of the NDIS, they also acknowledge that there is a need to improve the implementation, performance and outcomes for people with disability as end users. Fundamental is the authentic consultation and meaningful engagement of people with disability, their families, providers and the broader sector. We believe people with disability should always be at the table when decisions are made that directly impact their lives.

QDN and the NDIS

To date, the NDIS in Queensland has had a significant impact on the lives of over 139,000 Queenslanders with disability. For many people it is the first time in their life they have accessed disability support. However, many Queenslanders with disability including QDN members continue to experience challenges with not only access to the Scheme, but also as participants across varying aspects of the Scheme resulting in poorer outcomes.

While QDN acknowledges the positive impacts the NDIS has brought for many people, there has been a lack of investment in consumer rights capacity building for people with disability as end users of the scheme. Building 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 is crucial to success. Along with 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.

Many people with disability have limited access to natural safeguards such as family relationships, peer support and community connections, particularly for those living in

closed environments, regional and remote areas or without a strong network of support. Greater investment is needed in peer support, community access, community visitor programs and advocacy to reduce risk and support people to navigate systems. QDN commends the work of the NDIS Review Panel and recommendations around addressing the gaps in oversight of providers, particularly when delivering high-risk supports.

QDN has undertaken engagement with our members to ensure the following feedback on the implementation and performance of the NDIS is informed by lived experience. This submission is also informed by Queensland's current human services policy and legislative environment, the DRC and NDIS Review recommendations. QDN acknowledges the diversity of people's disability, people's life experiences, decision making skills, abilities, formal and informal supports in people's lives and the need for safeguards.

Unregistered providers

QDN and its members recently engaged with the NDIS Provider and Worker Registration Taskforce in their consultation process through making submissions, attending roundtables and one on one meetings with the Taskforce. Throughout this process QDN members expressed the option to choose providers that best suit budget and goals regardless of registration has been crucial and life changing.

QDN has heard reports of the many benefits of using unregistered providers including:

- Quality supports from trusted providers
- More consistency in support staff, choice of workers and greater flexibility of shifts compared to experiences with registered agencies where different workers are sent to provide support
- Supporting local businesses for cleaning and gardening services and having greater choice in these services
- Cost savings in purchasing the same brand equipment and medical supplies, faster delivery and better service
- Better quality and cost savings in general across many service types.

Provider registration has not resulted in greater quality supports or prevented the abuse of people with disability. As recommended in the DRC Final Report (Recommendations 10.11, 10.25) stronger monitoring mechanisms need to be implemented including stronger compliance and enforcement activities for NDIS providers and increased face-to-face engagement with participants at greater risk of violence and abuse. Introducing independent reporting and monitoring mechanisms will also play a role in better outcomes for people with disability. Community Visitor Schemes should also be improved and nationally consistent (Recommendation 11.12).

QDN also recommends supported safeguarding to build the skills of people with disability to be informed and confident participants who understand how to assess risk, what to ask for if at risk and if required have access to supported decision-making when deciding on providers.

Worker Screening and Training

QDN members have raised the need for the NDIS workforce at all levels to have greater access to training and for ongoing professional development to be a requirement of their role. Training should include an understanding of the social model of disability, disability rights and the barriers and discrimination still faced by people with disability. The right training would reinforce quality service delivery.

The disability workforce shortage has meant that people who self-manage or are planmanaged have had to hire people who have never worked in the disability care sector before and have no qualifications. Many members who self-manage have developed their own training for support workers with no subsidy. QDN members suggest it would benefit both support workers and NDIS participants to have access to free training – in the style of a short course – that would cover off on the basics of disability support work.

Additionally, many members would like to be able to offer their support workers professional development but find it difficult to understand what training is practical, reputable and affordable. Offering quality training and professional development is an attraction and retention strategy to address the current national workforce shortage.

Training must be co-designed and facilitated by people with disability. Training and worker screening must be subsidised to reduce the cost for services providers and the risk those costs will be passed on to participants. People who self-manage should also be subsidised for the training they develop and facilitate for their support staff.

Accessibility and consistency

Some QDN members advise us the NDIS is not always accessible. There are many people with disability, particularly people with psychosocial disabilities that fall through the cracks and are not receiving the same level of access to the Scheme or utilisation of their plans due to systemic barriers. There are insufficient supports to assist people to apply for the NDIS. QDN members report they have struggled to access the NDIS, or have been supported poorly through planning and review, relying on unpaid labour from informal supports who have accessed the NDIS themselves or have experience working within the system and/or disability sector.

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. They can build no rapport with planners. 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. Members have also raised issues around record keeping. NDIS workers do not appear to have access to detailed records, again warranting repetition with every contact.

Lack of accessibility is particularly challenging for people with disability that may also have other intersectional identities, for example, First Nations and Culturally and Linguistically

Diverse people who may have further barriers to accessing information, culturally appropriate support, legal information and representation.

QDN recommends increased investment in independent advocacy, supported decision-making and investment in culturally safe support and advocacy at all stages of the NDIS process.

The one size fits all approach does not work

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 intersectional 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.

QDN sees a risk of negative impacts and challenges for people with disability including:

- Aboriginal and Torres Strait Islander people
- People from Culturally and Linguistically Diverse backgrounds
- People who live in rural, remote and regional areas
- People leaving the criminal justice system
- People experiencing homelessness
- People with psychosocial disability.

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-recognised.

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 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.

NDIS participants living in regional and remote Queensland

NDIS participants in very remote regions have limited access to support as the ratio of providers to participants is lower. In areas with thin markets participants are not able to choose a provider or change from one provider to another if they are unsatisfied with their current service provision. A one-size fits all approach is not appropriate for remote areas

and smaller regional towns where a health provider or Aboriginal Community Controlled Health Organisation may be the only provider to deliver health, aged care, community and disability support services.

Where the market has failed completely to deliver support to people with disability QDN recommends 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. This issue has failed to be resolved and people continue to fall through the cracks.

Many Aboriginal and Torres Strait Islander peoples in regional and remote communities provide support for relatives and community members. There are systemic barriers for Aboriginal and Torres Strait Islander peoples in registering as support workers or service providers such as lack of trust in Government systems including the disability worker screening process. This ongoing issue has not been resolved despite efforts at respectful engagement in communities to raise awareness, build capability and address workforce supply.

While most QDN members living in regional and remote areas engaged for this submission reported poor service quality from the NDIA, others were very happy with the level of dedication, person-centred service and knowledge of the local area revealing the inconsistency of service delivery in regional areas. NDIS participants have expressed concerns over inconsistencies in levels of funding regardless of diagnosis or need.

There is a need for continued place-based workforce strategies in regional, remote and rural areas and where thin markets exist to prioritise disability awareness training, quality standards in service delivery, cultural awareness training, and skills development and strategies.

Need for targeted outreach and support

We know that both participants and people applying for the NDIS experience challenges around support for decision-making, a lack of accessible information to inform decision-making, and lack of appropriate support for decision-making. This is enhanced in regional, rural, and remote areas, particularly in Aboriginal and Torres Strait Islander communities with a lack of services and culturally respectful services.

There is an overwhelming need for supports coordination in plans for people who do not have the capacity to navigate plan implementation, particularly for their first plan. There is evidence to suggest that there is significant underutilisation of plans for vulnerable cohorts, and support to understand the plan and implement is vital to the success of the scheme.

Targeted outreach and ongoing support are required for potential and existing NDIS participants who live in rural, remote and regional Queensland. This should include

engagement, providing information and connection with mainstream and community services, and clear pathways of referral and support for access requests.

Conflicts of interest

There are often reports of exploitation of NDIS funds due to conflicts of interest occurring in regional areas of Queensland with limited options for service providers and thin markets. There have been reports of NDIS Coordinators who also work as Support Workers for participants, which poses a potential conflict of interest. Conflicts of interest like this can compromise the ability of participants to make informed decisions and can impact a person's ability to exercise choice and control¹.

Higher costs

NDIA-regulated price caps for some supports in remote and very remote areas of Queensland are forty to fifty per cent higher than the caps for the same supports in other areas. This is due to the increased costs of service delivery in these regions². It would therefore be expected that budgets are higher for participants in remote and very remote areas, however, budgets are slightly lower for participants in rural and remote areas³.

Long wait times

Long wait times have been reported by QDN members at every stage of the NDIS process, from access, to plan reviews, to request decisions, to Administrative Appeals Tribunal (AAT) decisions. During the January-March 2024 period QDN members have reported more backlogs than usual at the NDIA resulting in loss of funds for those waiting for their new plan post-review. One member who was unhappy with the outcome of their NDIS plan was told that due to the backlog at the AAT, it would be quicker to wait for their plan review 12 months later than to lodge a review application with the AAT.

QDN members particularly in regional areas also report they experience long wait times to see allied health professionals, as there are very limited options in their region and extremely long wait times for vital assistive technology and mobility equipment. One member has been waiting for almost five years for equipment she needs to move around. She feels she has no choice and control because she cannot go outside, stating, "I just spend my days looking at the walls". Another member reported they experience long wait times to have equipment serviced, as the provider only travels to their location when they have multiple jobs to complete. "Repairs take longer because of our location. We have to wait for there to be multiple jobs in the area before the repairer will travel". Members also report they are reduced to hiring mobility equipment and often must make the choice between accessing health services or hiring mobility equipment.

¹ https://www.nds.org.au/images/resources/Factsheet - Conflict of Interest.pdf

² NDIS-final-report-volume-1.pdf (treasury.qld.gov.au)

³ NDIS-final-report-volume-1.pdf (treasury.qld.gov.au)

Some members have provided feedback that if it was a car that required assistance and they were a member of RACQ, they could be provided with assistance and repairs to get back out on the road. Instead, they must wait months or even years.

Digital inclusion

The shortage of service and healthcare providers particularly in some rural, remote and regional parts of Queensland, mean people with disability have no option but to attend many appointments online. However, people with disability face barriers to digital inclusion. 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 which could enable them to interact with service systems including the NDIA. These barriers are increased for First Nations and Culturally and Linguistically Diverse people with disability.

QDN was funded to deliver a Digital Inclusion program from 1st of October 2021 to 31st of October 2022, which included 80 digital literacy workshops and the provision of 470 digital devices to people with disability. However, funding for this program has ceased. This program delivered devices, workshops and 1:1 peer support for people with disability to break down the digital divide and assist in ensuring access to essential services and information including the NDIS. A program such as this would reduce the digital barriers people with disability face when accessing services including the NDIS, connecting with community and advocating for themselves.

Improving shared access to data

QDN 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 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.

NDIA Reviews and AAT Appeals

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. If members were faced with the choice of taking their issues to the AAT, most were unable to access independent advocacy services and reported services were at or over capacity. Without independent advocacy support and guidance through the process, a number of members explained that they did 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.

Price gouging

QDN members often share stories about the extreme price difference between the price of mainstream services and services purchased through their NDIS plans. One member shared an experience of paying an Occupational Therapist \$2,000 for the administration component of a minor modification to his bathroom. Another member said that a wheelchair he needed to purchase cost \$15,000 through the NDIS but the same one online cost \$5,000. Another member feels that because the need outweighs the supply, "providers have the power to charge ridiculous prices". She emphasised that she will never stop needing the supports she pays for, and that price gouging needs to be brought under control. QDN acknowledges NDIS Review recommendation 11 to reform pricing and payment frameworks to address these issues.

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.

Recommendations

The following recommendations are based on the work QDN has undertaken on the NDIS over the past 10 plus years, QDN members insights and current disability reforms and are underpinned by a human Rights based approach and framework, co-design principles, person-centred principles, and the UNCRPD.

- 1. Implementation of Disability Royal Commission Final Report Recommendations 10.11, 10.25 and 11.12 to ensure stronger compliance and monitoring mechanisms in the NDIS and improvement of Community Visitor Programs.
- 2. Supported safeguarding to build the skills of people with disability to be informed and confident participants who understand how to assess risk, what to ask for if at risk and have access to supported decision-making when deciding on providers. Transparency and information sharing is a critical part of skilling participants, particularly in the context of self-managed plans.
- 3. Investment in peer support groups including those operated through QDN to build NDIS participant social connection, confidence and capacity in having a voice around the issues that impact them.
- 4. Deliver increased investment in independent advocacy and pathways to advocacy and supported decision making at all stages of the NDIS process. The NDIA and disability-specific and mainstream advocacy organisations should work together to maximise access to dedicated, independent advocacy to support individuals experiencing challenges and barriers in accessing and maintaining the NDIS.
- 5. Implement actions in Recommendation 3 of the NDIS Review to provide a fairer and more consistent participant pathway. These actions would address many of the issues experienced by participants provided they are led and co-designed by people with disability including representation from remote, rural, and regional Queensland.
- 6. Set up a provider of last resort scheme recommended in the Disability Royal Commission to ensure there is a safety net of service provision and support where markets have failed in regional and remote areas to safeguard against abuse, neglect and exploitation.
- 7. Implement NDIS Review recommendation 14 to improve access to supports for First Nations participants across Australia and for all participants in remote communities through alternative commissioning arrangements. The commissioning approach should be led and co-designed by Aboriginal and Torres Strait Islander people with disability including representation from those living in remote communities.
- 8. 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.
- 9. Workforce strategies should prioritise disability awareness training, quality standards in service delivery, cultural awareness training, skills development and

- strategies to attract, recruit and retain quality staff including incentives for working in remote and rural areas.
- 10. Investment in a Digital Inclusion program that enables people with disability to be able to access digital devices and digital literacy training. This will enable people access to essential services, the NDIA and community organisations, facilitate communication and social connection, and expand their vocational, educational and employment opportunities.
- 11. Co-design a data sharing process with people with disability to ensure efficiencies across agencies in sharing, accessing and storing data resulting in better experiences for participants in providing evidence.
- 12. Provide targeted, tailored and ongoing engagement to deliver outreach to potential and existing NDIS participants. This needs to include engagement, providing information and connection with both mainstream and community services about the NDIS, how to identify clients that would be eligible for the NDIS, and clear pathways of referral and support for access requests. The model also needs to include engagement and employment of people with disability, with lived experience of the NDIS to provide peer support, share information about the benefits and types of disability supports it can provide for people. Once access has been approved, they need specialised support to ensure that plans are activated to their potential and an ongoing case management to support with any issues and safeguard the delivery of supports and navigate the complex environments.

Conclusion

QDN thanks the Joint Standing Committee on the National Disability Insurance Scheme for the opportunity to submit this response. QDN looks forward to continuing to bring the voices of Queenslanders with disability to the Committee.