Submission – Inquiry into the NDIS participant experience in rural regional and remote Australia
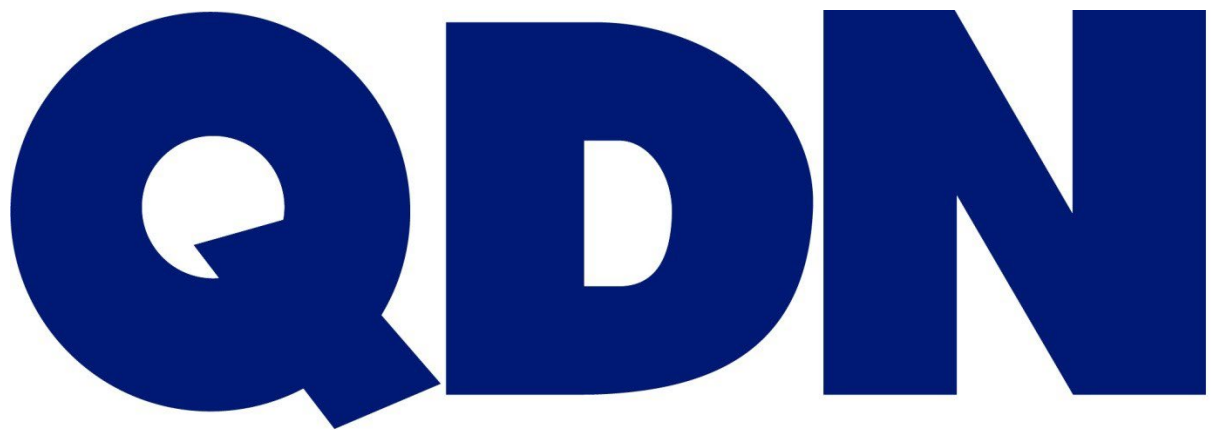
Submitted to the Joint Standing Committee on the National Disability Insurance Scheme

February 2024

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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.

We believe people with disability should always be at the table when decisions are made that directly impact their lives. QDN's systemic advocacy is focused on the rights and full social and economic inclusion of people with disability within their communities. Recent advocacy activities have focused on key areas identified by QDN members, 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.

Introduction

QDN acknowledges the QDN members and their families and carers living in rural, regional and remote Queensland who have contributed their experiences to inform this submission.

QDN welcomes the Inquiry into the NDIS participant experience in rural, regional and remote Australia. 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 who live in rural, remote, and regional areas experience significant challenges accessing the NDIS, implementing their plans, plan reviews, accessing services and supports, and the processes and culture of the NDIA.

It has been established that access to healthcare, aged care, and disability services poses an ongoing challenge[1], and as a result of low participant numbers, high provider costs, and workforce challenges, the development of the NDIS market in rural and remote areas of Queensland has been impeded[2]. It is important to note that people with disability who identify as Aboriginal and Torres Strait Islander, are Culturally and Linguistically Diverse, live in rural, remote and regional areas, or are on lower incomes experience additional disadvantages and barriers[2].

In this submission the following key issues are identified:

- Lack of readily available information
- Need for targeted outreach and support

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[1] https://www.statedevelopment.qld.gov.au/regions/queenslands-regions
[2] https://s3.treasury.qld.gov.au/files/NDIS-final-report-volume-1.pdf

- Inconsistent service quality
- Conflicts of interest
- Digital inclusion
- Workforce capacity
- Isolated from peers, communities and support groups
- Person-Centred Emergency Preparedness (P-CEP)
- Market challenges
- Long wait times
- Higher costs and price gouging
- Challenges with transport and travel
- Thin markets, including in Aboriginal and Torres Strait Islander communities that have limited community controlled or community-led organisations
- Lack of culturally appropriate services and cultural awareness

This Inquiry has been initiated at a time when significant changes and reforms are impacting all areas of the disability sector including outcomes of the DRC and NDIS Review. The NDIS is key to enabling people with disability to participate fully as citizens within Australian society and ensure people with disability can exercise their human rights and we anticipate these reforms will address many of the systemic issues faced by people with disability.

Key issues

There is an urgent need for reforms to the delivery of the NDIS in rural, remote and regional areas in Queensland. Fundamental to informing these reforms is authentic co-design with people with disability, their families, and carers. QDN has undertaken engagement with our members to ensure our feedback to the Joint Standing Committee 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. The key issues that have been identified are outlined below.

1. The experience of the NDIS in rural, regional and remote Queensland

1.1 Lack of readily available information

There is a lack of readily available information that reflects the complexity of the NDIS[3], meaning many participants have difficulties or don't get the information they need to make informed decisions[3]. This is exacerbated for people with disability who live in rural, remote and regional communities and experience additional barriers to finding and receiving information. NDIS participants frequently express how difficult it is to navigate the NDIS and how challenging it is to find information[3].

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[3] https://www.ndisreview.gov.au/resources/reports/working-together-deliver-ndis/part-one-unified-system-support-people-disability-4

A QDN member shared that she found the lack of readily available information and the difficulty knowing where to find information scary, and she had to rely on people who had already applied for the NDIS to support her.

Research suggests that without an advocate or assistance to navigate the planning process, people with disability and their carers find it difficult to express their needs and goals during the planning process. This is often more difficult for people with an intellectual or cognitive disability, complex needs, Aboriginal and Torres Strait Islander people and people who speak English as a second language[4].

1.2 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.

1.3 Inconsistent service quality

The level of funding participants receive is widely believed to be related to the quality of the Planner or LAC, and that there are not as many quality Planners or LACs in rural or remote areas in Queensland[5]. This could be attributed to inconsistencies in the experience, education and knowledge of Planners and LAC[5] and/or insufficient service providers and professional supports in regional, rural and remote areas[4].

While most QDN members 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 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.

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[4] https://doi.org/10.1111/ajr.13020
[5] https://doi.org/10.22605/RRH5337

1.4 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 control[6].

1.5 Digital inclusion

The shortage of service and healthcare providers 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.

2. Availability, responsiveness and effectiveness

2.1 Workforce capacity

As mentioned in section 1, QDN members living in rural, remote and regional Queensland report workforce issues even in more densely populated regional centres. LAC and NDIA Partners do not have the resources, skills, staff, and capacity to provide the level of assistance that people with complex and intersecting needs require to access the NDIS.QDN members report concern around LAC workforce capacity including high staff turnover, poor staff skillset and the exclusion of allied health recommendations in plans. We know there is currently a national shortage of support workers[7] and the ratio of providers to participants in remote and very remote areas of Queensland is higher compared to participants in major cities[1].

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[6] https://www.nds.org.au/images/resources/Factsheet_-_Conflict_of_Interest.pdf
[7] https://apo.org.au/sites/default/files/resource-files/2022-03/apo-nid317209.pdf

The rural and remote disability workforce in Australia is struggling to keep up with the demand for quality services and supports for people with disability in an everchanging policy environment[4]. Being able to find housing in communities for the workforce is also a significant barrier and challenge. People with disability in regional areas with limited access to health services have been refused by GPs to complete an access form if they have previously been refused access to the NDIS. This speaks to broader misconceptions and lack of knowledge about NDIS processes in the mainstream health system. One regional QDN member expressed that the NDIA does not understand how all his disabilities and health conditions interact and change over time, nor the impact of this on his lifestyle.

Some QDN members expressed feelings that their planners don't understand their local context. One member shared that their planner was based in a different state to where they live and had no understanding of what supports were available in their community, suggesting services that were not available Queensland.

2.2 Isolated from peers, communities and support groups

People with disability do not always have access to a network of people or informal supports they can call on, nor are they connected to their community[8]. This isolation can be increased for people with disability who live in rural, remote and regional areas due to geographic distance, barriers to connecting online, and barriers to participating in their local communities. Support Coordinators and LACs have a role to play in connecting NDIS participants with their local communities however reports indicate this is not prioritised. Community-based peer supports programs such as QDN's peer support groups play a role in addressing this gap however investment is needed to expand foundations supports as evidenced by the NDIS Review which includes providing people with digital capacity to connect online.

2.3 Person-Centred Emergency Preparedness (P-CEP)

People with disability are disproportionately affected by emergencies, particularly people in regional and remote areas[9] and are at increased risk in emergency situations due to the lack of accessible information, support and services[9]. Examples include inaccessible early warning systems, infrastructure that prevents escape for people with mobility issues, and being separated from assistive technology and people who support them[10][11].

One QDN member said that she is at high risk during disasters in their community because her support workers must leave to look after their own family and home, leaving her without support. "We're in a region with this very real threat that the NDIA doesn't recognise. When I was sandbagging my home recently, I had to ring around providers to get a support worker to assist me." Many people with disability who live in regional, rural and remote areas of Queensland rely on unregistered providers who are not required to have

[8] https://doi.org/10.1002/ajs4.245
[9] https://knowledge.aidr.org.au/resources/ajem-october-2023-having-a-seat-at-the-table-disability-and-disasters/
[10] https://nema.gov.au/disability-inclusive-disaster-preparation
[11] https://collaborating4inclusion.org/wp-content/uploads/2019/11/DIDRR_Framework_document_FINAL.pdf

emergency plans, and many are sole traders who do not have the staff to continue delivering services during disasters or emergencies.

Business continuity planning undertaken by service providers is typically untested and often not fit for purpose. A business continuity plan (BCP) might be drafted by a senior manager working in an office by themselves, as opposed to one that is developed in consultation with frontline workers and considers their staff's emergency planning for their own families and households. This leads to situations where managers are relying on staff to be present in disasters to continue to provide an ongoing service (e.g. staffing a SIL property) without a sound understanding of their staff's availability in disaster, (e.g. staff may be unavailable to work because they are required to care for children or elderly parents during the disaster). BCP planning that is conducted with frontline staff is known as 'user-driver planning'. There is also little in the way of legislated duty of care that makes service providers responsible for the safety and wellbeing of their participants during disaster. Equally, at present, there is no lead agency for disability listed in jurisdictional disaster management plans.

3. Choice and control

3.1 Market challenges

NDIS participants in very remote regions have limited access to support as the ratio of providers to participants is higher[1]. 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[2].

One QDN member stated there is only one Occupational Therapist in their region and they charge higher fees compared to other regions. Members report that in remote, regional and rural areas with fewer providers, providers don't feel the pressure to provide quality service as there is no competition. One member said, "where do you go for support when you have such a limited choice anyway? We're a little bit forgotten. There's no drive to understand the needs and requirements of people with disability".

Some QDN members also express fear around changing service providers, and some don't understand that it is an option. One member stated, "because we're forced to choose from a smaller pool of people, when I want to change my support worker or coordinator, I feel conflicted because my brother uses that coordinator, and I fear raising this or complaining in in a small region because of the consequences for him".

QDN members have expressed that if they need more support hours one week, it's not possible; there is no flexibility due to the lack of workers where they live. One member said he told his planner he needed less hours of support, but this was not changed. He stated he could have used his budget to pay for his Occupational Therapist instead. He feels he needs to use the support hours despite not needing them, to avoid losing the funding in his plan.

3.2 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-February 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.

Issues of timing impact people with disability in regional, rural and remote areas more due to the lack of services and wait times to get assessment for assistive equipment as well as shipments of equipment. Scheme planners are not able to make final decisions about participants' plans and 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. It also takes far longer to gather evidence for plans due to long wait times and a lack of local services[12].

QDN members 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.

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.

3.3 Higher costs and price gouging

NDIA-regulated price caps for some supports in remote and very remote areas 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 regions[2]. 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 areas[2].

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

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[12] https://www.ndis.gov.au/media/4802/download

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.

3.4 Challenges with transport and travel

People with disability who live in remote areas often are required to travel great distances to attend health services or receive specialised health care[13]. NDIS participants who live in regional, remote and rural areas report that their NDIS packages are not big or flexible enough to include travel, so they are not able to go to appointments in-person unless they cover the travel costs themselves, which is not an option for many. One member said, "I've exhausted the available orthotists in my area and needed to access the services from other states, but the LAC told me that they'll only fund for local services". Another member had to travel to a Brisbane hospital and needed two support workers and a hired wheelchair to do the trip. They had to pick and choose what support they received because their plan is not big enough or flexible enough for these types of costs. One member explained that whilst she hasn't had to travel long distances to access services, she's had to get long-distance services as she isn't able to visit people face-to-face. "I haven't had to travel but my brain has. There's a level of comfort talking face-to-face". She explained that it is overwhelming not being directly part of the process and difficult to get what you need with so many back and forth emails. She said it would be so much easier if she lived in the same area where the services were located.

4. Experience of Aboriginal and Torres Strait Islander people, people from Culturally and Linguistically Diverse backgrounds, and people on low incomes

Aboriginal and Torres Strait Islander people with disability

In 2018, 24 per cent of the Aboriginal and Torres Strait Islander population had disability, around 139,700 people[14]. As of 2015, 30 per cent of Queensland's Aboriginal and Torres Strait Islander population lived in major cities, 51 per cent in regional areas, 7 per cent in remote areas and 12 per cent in very remote areas[15]. We know that the prevalence of disability is high among Aboriginal and Torres Strait Islander people, however according to the NDIA[16] participation in the NDIS remains lower than projected. Aboriginal and Torres Strait Islander people who live in rural and remote areas are less likely to benefit from the NDIS[4]. A large proportion of Aboriginal and Torres Strait Islander people with disability have

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[13] https://www.aihw.gov.au/reports/workforce/health-workforce#rural
[14] https://www.indigenoushpf.gov.au/measures/1-14-disability
[15] https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/4714.0~2014-15~Main%20Features~Summary%20results%20for%20States%20and%20Territories~10002

[16] https://data.ndis.gov.au/media/1945/download?attachment

their access requests cancelled because their forms are not being returned, or because the NDIA was unable to contact them[16].

Culturally and Linguistically Diverse people with disability

Queenslanders with disability from Culturally and Linguistically Diverse backgrounds are less engaged with the NDIS; they experience language and cultural barriers and challenges accessing information and services, identifying supports, understanding their rights and exercising choice and control[17][16]. Some cultures hold beliefs, stigma and shame about disability which can prevent people from seeking support.

Disadvantage in rural, remote and regional Queensland

Regional, remote and rural Queensland is diverse and people with disability who live in rural and remote areas can experience intersectional disadvantage; some rural or remote communities experience lower incomes, lower levels of education and employment, higher levels of poverty and homelessness, higher cost of living, poorer housing, and poorer health outcomes[18]. Many people in rural and remote Australia experience this social disadvantage which puts them at higher risk of mental illness and alcohol, tobacco and drug misuse[18]. Geographic isolation impacts people's capacity to apply for the NDIS and the greater the geographic isolation, the less access there is to support services, experts or specialists[8].

The lack of affordability to have assessments, diagnoses and treatments to get access to the NDIS is a barrier and puts people with disability at a disadvantage. The expense of consultations, collecting evidence, and obtaining reports are barriers to accessing the NDIS[8]. One member described her situation as a vicious cycle; as she is on a low income, she cannot afford to pay for a diagnosis, to access the NDIS.

4.1 Thin markets, including in Aboriginal and Torres Strait Islander communities that have limited community controlled or community-led organisations

For Aboriginal and Torres Strait Islander people with disability living in remote communities in Queensland, NDIS support is under resourced due to thin markets. While efforts have been made by the Queensland Government Assessment and Referral Team to support people through the NDIS application process and through the NDIS First Nations Business Development Program to increase the number of culturally appropriate services in these communities, there are still many people being left behind. Even for those who are on the NDIS, there is a significant underspend of plans due to the lack of available services and understanding of what is in their plans.

QDN welcomes NDIS Review recommendation 14 regarding alternative commissioning arrangements to provide critical services to these communities. Australia's First Nations people hold the key to closing this gap and an alternative commissioning approach must be led and co-designed by Aboriginal and Torres Strait Islander people with disability.

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[17] https://eccv.org.au/wp-content/uploads/2019/07/ECCV-NDIS-Policy-Issues-Paper_final_27062019.pdf
[18] https://www.ndis.gov.au/media/201/download?attachment

4.2 Lack of culturally appropriate services and cultural awareness

There is a lack of culturally appropriate services in rural and remote areas which impacts people's choice and control in relation to supports and deterring them from applying for access to the NDIS[8]. Many disability services do not consider the cultural needs of participants, nor do they communicate in a culturally appropriate manner[14].

Investment in business development programs for both First Nations and Culturally and Linguistically Diverse people to become NDIS providers or to grow their NDIS business would result in more culturally appropriate services.

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. The recommendations are underpinned by the following principles and frameworks:

- Human Rights based approach and framework.
- Co-design principles to ensure the planning, design, delivery and evaluation of policy, services and products are co-designed by and for people with disability.
- Person-centred principles.
- The United Nations Convention on the Rights of Persons with Disability (UNCRPD).

1. A fairer and more consistent approach

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 outlined in this submission provided they are led and co-designed by people with disability including representation from remote, rural, and regional Queensland.

2. Ongoing targeted outreach

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.

3. Individual advocacy

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 work together to maximise access to dedicated, independent advocacy to support individuals experiencing challenges and barriers in accessing and maintaining the NDIS.

4. Support place-based workforce strategies

Continue to support place-based workforce strategies in regional, remote and rural areas and where thin markets exist. Where these strategies are not working, review impact and outcomes to identify different models of service delivery that ensure equity of access to supports.

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.

5. Digital inclusion

Investment in QDN's 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.

6. Peer support

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.

7. Person-Centred Emergency Preparedness (P-CEP)

Investment in Person-Centred Emergency Preparedness (P-CEP) projects across rural, remote, and regional Queensland. The P-CEP framework supports disability inclusive disaster risk reduction by making sure people with disability are at the centre of emergency management. Projects should be delivered collaboratively by disabled people's organisations (DPOs), community services and disability support organisations, emergency personnel, and local government. QDN also recommends implementing surge workforce planning for NDIS providers, including incentives or requirements to collaborate with other providers, requiring service providers to take greater responsibilities for safety and wellbeing of participants in emergencies.

8. Address the lack of transport options

Targeted and innovative approaches for rural, regional, and remote communities to build participant capabilities, market, and services, with considerations and services built in to address lack of transport and significant geographical distances in rural, remote and regional areas of Queensland.

9. Culturally appropriate services

Investment in business development programs to support First Nations and Culturally and Linguistically Diverse people to become NDIS providers or to grow their NDIS business with incentives for operating in rural, regional, and remote areas.

10. Alternative commissioning

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.

Conclusion

QDN thanks the Joint Standing Committee for the opportunity to provide this submission to Inquiry into the NDIS participant experience in rural, regional and remote Australia. There is a need for overall improvement of the processes and structure of the NDIS and more effective engagement for people with disability who live in rural, remote, and regional areas. There is no one single type of rural or remote place meaning there is not one type of service model or delivery that will work for all rural and remote communities. Targeted approaches are required in rural, remote and regional parts of Queensland that do not have a large enough population to allow disability providers to operate[1]. If people with disability have access to care and support in their own communities, they can maintain connections with their communities, have increased independence and improved social and economic participation.