DISABILITY MATTERS

NDIS: 2021 Year in Review and looking forward to 2022

Summary Report – January 2022

QDN
QUEENSLANDERS WITH DISABILITY NETWORK
NOTHING ABOUT US WITHOUT US

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 as the peak body for Queenslanders with disability 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, systems and services. This submission is informed by the lived experience of our members and supporters.

Introduction

On Monday, 13 December 2021, Queenslanders with Disability Network (QDN) hosted a members-only online event – *NDIS: Year in Review Forum* – to discuss the year that had been for the National Disability Insurance Almost 60 members with disability from across Queensland participated during the forum, which was held via Zoom.

Participants in the forum heard from QDN chair, Des Ryan and Every Australian Counts, Campaign Manager, Jean Cotchin, about the importance of having the voices of people with disability involved in NDIS policy debates and campaigns. Participants then moved into breakout rooms to give QDN members the opportunity to share what they were hearing in their local communities regarding the NDIS and solutions going forward

Feedback from participants highlighted a number of common experiences across the State that all have significant and serious impacts upon individuals with disability and their families including:

- plan funding being cut without explanation at reviews,
- a significant increase in the need for AAT appeals;
- and inconsistent communication from LACs and planners regarding funding decisions.

In addition to these three issues, this summary document captures the main NDIS issues identified by QDN members as well as ideas for local solutions and the number one message QDN members want candidates at the 2022 federal election to hear.

These priority issues include:

- NDIS plan review decisions and processes;
- Increase in AAT appeals
- Reduction of participant travel budgets in their plans
- Growing impacts on individual participants to take on range of responsibilities and roles with regards to managing their plans across self-management, plan management and agency managed without adequate support, training and capacity building
- Specific issues for people living in regional, rural and remote communities
- Impacts of price guide on participant budgets
- Inconsistency of supports coordination and limited skilled workforce to preform this role
- Local Area Coordination role shifting in scope and intention of their role and the gaps it has left

- Inconsistent communication and decision making around plans
- Support is needed to access NDIS for people who experience additional challenges and vulnerability and;
- Lack of power and authority for the NDIS Quality and Safeguards Commission to fulfil role

QDN once again calls on the Federal and State governments to work collaboratively to ensure the NDIS issues outlined in this summary report are addressed urgently and continue to work to ensure the scheme is delivering on its commitment of greater choice and control for Queenslanders with disability.

QDN members identified the following recommendations and actions to improve the implementation of the NDIS going forward into 2022:

- Improving shared access to data
- Implementing targeted strategies to assist with NDIS access
- Simplifying and demystifying NDIA language
- Increased access for individual and systemic advocacy
- Ongoing access to established peer support mechanisms for people with disability and their families to assist their navigation of the NDIS system
- Greater support and legal representation for NDIS participants in AAT Reviews that ensure equitable process
- Increased training for key staff in the NDIS workforce
- Greater transparency around decision making
- Building skills of people with disability to be informed and confident customers
- Consistent timeframes around consultations

QDN members are clear that it is only through listening to the lived experiences of people with disability and involving people from the beginning in the planning, design, implementation and evaluation processes that the NDIS can deliver on its promises of greater choice and control. This is an important key message Queenslanders with disability will be taking forward in the 2022 federal election.

Summary of breakout room discussions

During the *NDIS: Year in Review Forum*, QDN members were randomly divided into four breakout rooms to discuss three questions:

1. What is the number one NDIS issue facing you and people with disability in your local community?
2. What are your ideas for solutions going forward in 2022?
3. What's your one message to candidates in next year's Federal Election about the NDIS?

1. Priority issues with NDIS in Queensland

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. 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.

> ***"There is a lot of certainty when your plan comes up for review, uncertainty about who the LAC."***

Members feel frustrated with the s100 review process because no one they know has been able to secure a positive outcome – despite significant work and effort invested by people with disability, their families and advocates.

There was agreement amongst members that it felt like a forgone conclusion that their internal review would be rejected and they would be left with only one option – to go to the AAT. Members questioned the purpose of mandating the internal review process and forcing people with disability to "jump through extra hoops" if these reviews were taking up NDIA resources for a predetermined result, which was that people with disability were left to decide whether to go through with the AAT process.

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, 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.

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 millions of dollars being spent by the NDIA on defending cases at the AAT. Members are furious at media reports that the NDIA is hiring “top end of town” lawyers, from large law firms, to argue cases against people with a disability. Many members are angered by this power imbalance and felt that the money spent on “expensive lawyers” could be better utilised providing people with disability with the supports they need.

Reduction of travel budgets in participant plans

Members have experienced significant cuts in their travel allowances when it is time for their NDIS plan to be reviewed or they are having a change of circumstances review. The NDIA has not announced any formal changes to the funding of transport budgets, but it appears that unless participants are engaged in formal employment or “structured day programs” three days a week or more, the NDIA will only fund the lowest level of transport support. However, support workers continue to charge for travel if they run errands or take members to appointments, which are supports funded by the NDIA, so this cost is having to be taken from participants’ core budget, leaving them with less supports, particularly towards the end of their plans.

Members said cuts to transport budget also impact around need for continuation of the Transport Taxi Subsidy Scheme, set to expire in October 2022. The combination of less NDIS transport funding and the loss of the TSS would have significant negative impact for many members who rely on these supports to leave their homes and access basic services, like grocery shopping and doctors appointments.

Specific issues facing Queenslanders living in regional, remote and rural areas

QDN members from regional areas raised the lack of services in local communities which impacts on ‘competition’ to get the number of quotes to meet NDIA requirements. Members highlighted this means they are unable to get supports and/or Assistive Technology and if they do get the supports they need, it takes significantly longer than it does for participants living in city areas.

> ***“It takes 12 months to get approval for a new wheelchair and then you have to wait to get the new wheelchair. Make this process quicker and simpler.”***

Members from rural, regional and remote areas also explained that when there aren’t many service options it’s easy to go through them all quickly, making it hard for people to “just leave” if services aren’t delivering what people need. One member shared their experience that the only alternative to these unsatisfactory day service supports was to stay at home all day.

In remote, regional and rural areas with limited services, members are also concerned that if the current service provider isn't financially viable or can't find enough workers, they'll stop providing services. This leads to people in this area with no service options, meaning it's even harder to find staff and even longer delays for consumables and AT. Members are concerned that there are still no back up plans in place in remote areas if the one major provider leaves town.

In regional areas where the supply for support workers is low and demand has become high, QDN members commented that they are choosing to self-manage their plans to give them more options to find support workers. However, finding and managing support workers takes up a lot of times and requires specific skills that many members identify they need more support and training with.

> ***"We need more accessible housing particularly in regional and rural areas."***

Impacts of price guide on participant budgets

Members raised that they believed the price caps set out in the NDIS Price Guide were too high and that some providers were taking advantage of the current system by automatically charging the maximum amount regardless of their experience or skills. Given the current national disability worker shortage, members felt they had little options but agree to higher prices even though it meant that their budgets are being drained quickly. Despite members experiencing more providers charging at the maximum cap, the NDIA budgets appear to be calculated using a mixture of pricing levels under the price guide, so it is leaving participants without enough funding for the entire 12 months.

Supports coordination

Members at the webinar expressed almost universally agreed that the role of Support Coordinators remains a significant issue for participants moving forward requires greater oversight, monitoring and training.

Member 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. Members spoke about how capacity building was given little focus during the implementation of a person's first plan because most of the Coordinator's time was 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.

Members were also frustrated that the quality of supports coordination services varies widely and that 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.

Local area coordinators

The role of Local Area Coordinators was an issue that was continually raised throughout the forum. Members were frustrated that LACs' roles were not clearly defined and that they were increasingly becoming inaccessible and unresponsive to participants. As a result, participants were missing out on critical services they urgently need.

Additionally, members felt that many LACs had little to no understanding on disability inclusion, community, history and ongoing barriers to equality. Members suggested that 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.

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

> ***"Changes to LAC so they are more responsive. [I] send through an issue and it takes 3 months to get a response."***

Additional issues

In addition to the issues discussed above, members at the forum also raised the following priority issues for people with disability in their communities:

- **NDIS Quality and Safeguards Commission lack of needed powers and resources:** The NDIS Quality and Safeguards Commission needs more resources and powers to enable it to undertake the volume of work to monitor, safeguard and provider oversite of registered providers including ensuring participants are safe and guidelines are followed
- **Inconsistent Information:** Participants reported the challenges they experience each time they contact the NDIA that there is a different person on the other end, who provides inconsistent information
- **Access to scheme:** 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 within the NDIS.

- **Advocacy:** Participants reported that they experience challenges in accessing individual advocacy if they need it due to long waiting lists and high demand on that system.

2. Solutions

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.

Members believed that there is a better way forward and that 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.

> ***"Having to reprove our disability again at reviews is expensive and its hard keep proving your disability at every review."***

Implementing targeted strategies to assist with NDIS access

Members raised the ongoing need to fund targeted strategies to support marginalised groups, particularly people with psychosocial disability, to access the NDIS, for example, the Community Connector Program and QDN's Targeted Outreach program.

The Community Connector program previously worked with four specific groups to assist them to access the NDIS, including: Aboriginal and Torres Strait Islander communities, Culturally and Linguistically Diverse communities, people experiencing psychosocial disabilities; and Ageing parents or carers of people with disability.

As trusted community members, Community Connectors played a critical role in reaching out to people with disability in harder-to-reach communities, increasing awareness of the NDIS and providing support for people to access the Scheme. Some members at the webinar, were deeply disappointed that the Community Connector Program is no longer funded by the federal government.

Another strategy that members raised as a solution for improving access to the NDIS is the Targeted Outreached Program run by QDN. The Targeted Outreach Project (TOP) is helping eligible Queenslanders with disability join the NDIS by working with organisations, services and groups on the ground in local communities to help people with user friendly information about the NDIS. The TOP team then links people with disability to regional Assessment and Referral teams who can provide free assistance to help fill out forms, talk to doctors and specialists and process the paperwork.The TOP is specifically working to get more people from the following groups accessing the NDIS, including:

- people in regional, rural and remote communities
- Aboriginal and Torres Strait Islander people
- people from Culturally and Linguistically Diverse (CALD) backgrounds
- school leavers
- adult prisoners
- adults on community service orders
- children in youth detention
- children attending special school
- people living in hostels, supported accommodation, caravan parks, social housing, community housing or experiencing homelessness
- People with disability who are not in the groups above but would like to have further information and assistance with NDIS access.

Members at the webinar expressed strong support for targeted strategies that work with people with disability to assist with accessing the NDIS. This is particularly the case for specific groups of people with disability who have experienced additional barriers to inclusion and acceptance in their local communities.

Simplifying and demystifying NDIA language

Implementing simple accessible communication strategies like ensuring participants are not bombarded by unnecessary acronyms and overly bureaucratic language, which currently prevents them from fully utilising their plan.

Increased access for individual and systemic advocacy

Increasing funding for individual advocacy to meet the increased demand due to the increase in AAT appeals. Participants and their families are now spending an excessive amount of hours a week managing, reviewing or appealing their NDIS plans and many report feeling like they are “drowning” without any professional advocacy support. Increasing funding for individual advocacy levels out the playing field and ensures that people with disability are not forced to use their supports – informal and formal – to appeal NDIA decisions, but can instead focus on their overall goals and greater inclusion in the community.

> ***“NDIS is still on a medical model, this is not the only way we should be addressing NDIS. Conditions that are episodic conditions need to be recognised, as they can’t live with just having a few good days a month.”***

Ongoing access to peer support

Participant highlighted the importance of peer support in their navigation of the NDIS from access, plan implementation and plan review stages, indicating the importance of this as an ongoing way that NDIS participants can share information and build their skills and capacity that needs to be

Training for key staff in the NDIS workforce

Throughout the webinar, members raised the need for the NDIS workforce to have greater access to training and for ongoing professional development to be a requirement of their role.

As previously mentioned, members strongly believed that LACs, planners and Support Coordinators should all be required to undergo a minimum level of training before beginning in their roles. In particular, generally speaking, members experiences were that staff in these roles would benefit from a greater understanding about the social model of disability, disability rights and the barriers and discrimination still faced by people with disability. With the right training in these areas, staff would be able to better respond to the needs of NDIS participants and improve their communication with people with disability.

Additionally, many members were struggling with the current disability workforce shortage and were either self or plan managing in order to be able to hire staff more flexibly. However, this meant that NDIS participants were often hiring people who had never worked in the disability care sector before and had no qualifications. Members suggested that it would benefit both support workers and NDIS participants to have access to 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 both practical, reputable and affordable. Members felt that being able to offer disability support workers more training and professional development would be a way of enticing more people to work in disability care and be one solution to address the current national shortage of disability support workers.

Greater transparency around decision making

Members believe that more information should be made available in user-friendly, accessible way about the “financial sustainability” issues with the NDIA, so that participants can engage in an honest and open discussion about the future of the NDIS. People with disability and their families have a strong vested interest in seeing a funded and successful NDIS now and into the future, however, without all the information they don’t feel they can have a productive debate about the future of the scheme.

Greater transparency includes more publicly available information about financial assumptions and also information about how the NDIA makes decisions about what things represent ‘value for money,’ when it decides not to fund supports. Understanding what information is used to make these decisions would assist participants understand and communication at each stage of the plan development with the participant and their family/decision makers would lead to better outcomes and avoid lengthy reviews and appeals to begin with.

Building skills of people with disability to be informed and confident customers

Many members believed many of the current issues stemmed from the lack of targeted training and support to build the capacity of people with disability as empowered customers in the NDIS market. Particularly in Queensland, for many NDIS participants, this is the first time in their lives they are receiving any disability supports or funding and for all people with disability it is the first time they are given choice and control over how their funding is spent. However, as first-time consumers, many members felt their needed to be greater focus and investment in targeted strategies that help participants navigate the NDIS and feel confident in their decisions as customers. For many people with disability, peer support plays a key role in providing this knowledge in an accessible and practical way. However, many members felt that peer support programs were not given the respect they deserve by the NDIS. Additionally, many members wanted to see people with disability leading the conversation about new and innovative ways of building people's confidence in using their NDIS funds.

Consistent timeframes around consultations

Members believed that all information about proposed changes to the NDIS should be published in a clear, accessible way, with plenty of time for meaningful, genuine consultation with people with disability. Some members called for a minimum consultation period if the document in question involves changes to the NDIS, to ensure people with disability can have their say.

2. Messages to candidates in the 2022 Federal Election

Finally, members were asked to consider the one message they would send to candidates running in next year's Federal Election about the NDIS.

Firstly, members wanted candidates to understand that it starts with respect. Politicians and senior leaders at the NDIA need to respect people with disability, educate themselves on the issues facing people with disability and start to take action to address these barriers urgently.

> ***"We contribute to the economy and are not a burden."***

Secondly, members wanted candidates to understand that when it came to discussing policies impacting people with disability this motto always applied – 'nothing about us, without us'. Politicians and senior public servants need to ensure that when they make decisions that impact people with disability they include, involve and talk directly with people with disability, engaging them in each step on the planning, design, delivery and evaluation process.

> ***"Fund it and fix it. Stand up and give us a fair go. The NDIS needs to be fair and reasonable for all going forward"***

Finally, there was a long discussion about the need to change the current messaging around the NDIS. Members strongly believed that the NDIS should not just be discussed simply as a cost, but also for as an economic benefit, which was highlighted by the Productivity Commission when it designed the scheme. 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 across Queensland and not to mention 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.

> ***“We are all people first, we are not asking for special treatment just equal treatment.”***

Members at the webinar widely acknowledged that the NDIS is an important scheme and whilst there are areas of improvement to deliver a quality scheme, they wanted all candidates at the federal election 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.

> ***“These issues NDIS will change my vote, so what you say about the NDIS in the campaign influence our votes.”***

Conclusion

In conclusion, the message from the *NDIS: Year in Review Forum* was clear, Queenslanders with disability want to be respected, listened to and understood for the benefits they bring to their local communities. It has been a very busy year for the NDIS, and significant changes made and other proposed. However, QDN members stated that it is critical for the NDIS to stay on track, true to the core principles of choice and control for people with disability.

To get the NDIS moving forward again, QDN members are calling on federal election candidates to listen to the NDIS experts – people with disability – and take our issues seriously at next year’s election. QDN members also reminded candidates that there are 900,000 Queenslanders with disability who are passionate about protecting the NDIS – and they vote!

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