Submission – Consultation on draft lists of NDIS supports 2024



Submitted to the Department of Social Services August 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 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 processes 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.

Introduction

QDN acknowledges the process of consultation to the Draft lists of NDIS supports 2024 relating to the National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Bill 2024. QDN acknowledges the need to reform NDIS processes and amend the legislative framework to support these changes and has made two submissions to the NDIS Bill inquiry.

During the very short timeframe for consultation on the draft lists, QDN engaged with 25 QDN peer leaders who are well connected with Queenslanders with disability in their communities. This submission is informed by their concerns and the work QDN and members have done over the past 10+ years around the NDIS and its design and formation prior.

QDN members have highlighted their concerns regarding the extremely short timeframes for the period to provide feedback especially considering the significant nature of these proposed changes and the impacts on NDIS participants and their supports. The short timeframe, lack of accessible versions and lack of awareness particularly for harder to reach cohorts has resulted in extreme stress, anxiety and confusion for people with disability.

Queenslanders with disability have experienced fatigue and impacts of a decade of change and reform and have expended energy and hard work to become informed customers of the NDIS system and ensure they effectively operate within its boundaries. Despite this, they are willing and committed to continuing to work and co-design the reforms needed to deliver a world-class disability service system in Australia that achieves the original goals and outcomes of the scheme.

QDN members have expressed concern that the concept of having detailed lists goes against the fundamental principles of choice and control and restricts people in their independence and inclusion. Over the last ten years QDN has heard many stories of innovative solutions to supports that have been refined over time to save money, time and create greater independence and inclusion of people with disability in their communities.

QDN members have expressed the impact that the recent media and stories on people with disability, and some members have talked about how they have felt like they are doing something wrong and this has fuelled negative public perceptions of people with disability.

Key concerns

Negotiation between States/Territories and the Commonwealth

QDN acknowledges that the lists of supports are intended to be transitional however there has not yet been appropriate consultation or agreement on the proposed Rules with States and Territories. QDN is concerned that without agreement with States/Territories the lists of supports will apply until the final Rules can be agreed on. The list in its current state is not fit for purpose and does not allow flexibility for people to live a life of choice and control. QDN is deeply concerned the draft lists will be used as the basis for negotiations between jurisdictions and become a legislative instrument.

Short consultation time

QDN members have raised concerns around the timeframe for consultation on the draft lists allowing only 14 days to respond and a lack of accessible versions including versions translated into other languages. Fundamental to informing these reforms is authentic codesign with people with disability, their families, and carers. 14 days is not enough time for the disability community to read, understand, engage, and provide feedback regarding the lists. QDN members have made it clear that this consultation is not co-design.

In addition, 14 days does not allow time to consult with harder to reach cohorts including First Nations peoples in remote communities, people experiencing homelessness, people with no internet access, people living in supported accommodation, forensic services or in the criminal justice system. These cohorts have unique needs that must be covered by the lists and there must be sufficient time for their voices to be heard in this consultation.

These lists have not been shared widely enough with the disability community. The Easy Read versions were only made available on 14 August 2024, half way through a very short

consultation period. QDN members have also pointed out that the Blind and low vision communities have not been provided with accessible information and is unlikely to in the timeframe provided.

Power given to the NDIA

QDN members have raised concerns about the level of power and authority that will be delegated to the NDIA over decision making and lack of rights for participants to review and appeal these decisions. No system operates without human error and mistakes and without appropriate safeguarding for participants and rights to appeal.

QDN members also raised concerns about the powers given to NDIA in the Bill amendments to give financial responsibility to individual participants for debt recovery and prosecution.

The draft lists are confusing

QDN members have provided feedback on the lists of NDIS supports and indicate that there is confusion about what they can and cannot use their funding for if the list in its current state comes into effect. There is also confusion about whether items not considered NDIS supports would be the responsibility of mainstream services, what this would look like, how people would access those services and if they will be in place in time to prevent more people falling through the gaps.

The one size fits all approach does not work

QDN members have expressed deep concern that the list is too prescriptive and would not provide for the flexibility required nor opportunities to continue to design solutions to supports that are cost effective, create greater choice and control, independence and touchpoints with local communities resulting in greater inclusion. There is concern people may be forced to purchase items from specialist providers at a much higher cost than they may be costed in mainstream retail outlets.

Feedback from QDN members frequently has been that the NDIS uses a "one size fits all approach" that is not person-centred or trauma-informed and does not consider the intersectional needs of someone with disability. The draft list reinforces this approach and is not conducive to the original tenets of the NDIS nor does it reflect a person-centred approach. People with disability have diverse life experiences, needs, goals, communication styles, strengths, abilities, and function differently in a diverse range of environments.

An intersectional approach is required.

Without a co-design process that considers the range of NDIS participants, QDN sees a risk of negative impacts and challenges for people with disability including:

- Aboriginal and Torres Strait Islander peoples
- 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 living in closed systems
- 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.

The criteria for reasonable and necessary supports in 34 (1) of the NDIS Act¹ provides the flexibility to meet the changing and intersecting identities of a diverse range of people with disability.

34 Reasonable and necessary supports

- (1) For the purposes of specifying, in a statement of participant supports, the general supports that will be provided, and the reasonable and necessary supports that will be funded, the CEO must be satisfied of all of the following in relation to the funding or provision of each such support:
 - (a) the support will assist the participant to pursue the goals, objectives and aspirations included in the participant's statement of goals and aspirations;
 - (b) the support will assist the participant to undertake activities, so as to facilitate the participant's social and economic participation;
 - (c) the support represents value for money in that the costs of the support are reasonable, relative to both the benefits achieved and the cost of alternative support;
 - (d) the support will be, or is likely to be, effective and beneficial for the participant, having regard to current good practice;
 - (e) the funding or provision of the support takes account of what it is reasonable to expect families, carers, informal networks and the community to provide;
 - (f) the support is most appropriately funded or provided through the National Disability Insurance Scheme, and is not more appropriately funded or provided

¹ Federal Register of Legislation - National Disability Insurance Scheme Act 2013

through other general systems of service delivery or support services offered by a person, agency or body, or systems of service delivery or support services offered:

- (i) as part of a universal service obligation; or
- (ii) in accordance with reasonable adjustments required under a law dealing with discrimination on the basis of disability.

Defined NDIS Supports, carve outs and non-NDIS supports

QDN members provided a range of feedback around the proposed 15 categories outlining supports that are not NDIS supports, and the considerations that need to be given to how these would be considered carve outs additions of specific supports. QDN members identified that there are many examples of supports that relate to their disability and day to day functioning that deliver appropriate, cost-effective options.

QDN members gave a range of diverse examples, and the following is not an exhaustive list of these but are provided as a sample of examples that show the need for consideration of the disability context and defined supports including:

- Menstrual products for girls and women with disability
- Technology related supports for digital accessibility
- Emergency preparedness and individual capacity building to have a plan for disasters and emergencies
- Assistive technology in specific circumstances
- Parents with disability.

There are a range of specifics described that require further definition and clarification and expansion. For example, there are people with disability who have a range of disability support needs who would not be 'classified as people with complex communication needs or challenging behaviour' who have critical disability supports needs when they are in hospitals that are not met or delivered by clinical staff.

Having a prescribed list of what NDIS funding can and can't be spent on without effective mechanisms for participants to be able to ask for review of decisions poses significant risks to people with disability being able to access the right supports, at the right time and in the right way for them.

The information provided does not clearly outline how 'carve outs' will be applied and how 'considerations' would be applied for certain participants in the application of reasonable and necessary and what people's rights are to review decisions.

The definitions of "not NDIS supports" and carve outs for mainstream services across the different portfolio areas need additional time for further consideration to work through specific implications for participants.

Given the timeframes for consideration, QDN believes that further engagement is needed to be able to properly work through the consequences and implications across the diversity of people's disability needs.

People with disability need to understand what the process will be for decision making about 'carve outs' and there needs to be a clear process for requests to review decisions.

Foundational Supports Service System

Concerns have been raised around defining NDIS supports at this stage without a strong and robust foundational supports service system, and equitable, inclusive and accessible mainstream services that meet the needs of people with disability, no matter where they live or their life experiences.

QDN acknowledges the importance of this foundational supports service system and the impact it will have on the hundreds of thousands of Queenslanders with disability who currently are not able to access basic disability supports to meet their fundamental needs. This means that there is no safety net in place and therefore no safeguards if the draft lists are implemented without clear timeframes, guidelines and implementation plans with States and Territories to ensure people with disability will not be worse off and will not continue to fall through the cracks and gaps.

It is critical that mainstream state services such as health and education will provide services that are not included in the draft lists. There is a high risk that people will fall through the gaps until a foundational supports service system is developed and there is greater clarity around filling gaps not covered by the NDIS.

Providing information and referrals

If the NDIS does not fund a support, it is critical that the NDIA provide referrals to people with disability with information about where they can get that support. This was one of the original tenets of the NDIS and is not currently happening leaving people with disability with no support or information, contributing to the notion of the NDIS being an 'oasis in the desert'. The original function of Local Area Coordination has never been delivered as it was intended as part of the architecture and design of the scheme. People report that they are provided 'lists' of where to go for supports that do not exist. QDN acknowledges that the NDIS Review has talked about the role and function of 'navigator' which in principle reflects the more hands-on approach and support that people need to find and access services and supports. It is critical that this is delivered and that referrals can be made to 'actual services and supports' that exist in the community otherwise people are again left falling through the gaps. An 'interim' system of NDIS supports list without addressing the fundamentals of what is required in other parts of the system leaves people further vulnerable to significant risks and lack of access to critical supports.

Recommendations

Feedback QDN collated to inform this submission in a short timeframe is indicative of the complexity of individual supports essential for people with disability to live a life of choice and control. QDN engaged with 25 members during the short consultation period and heard

many examples of the disadvantage people would face without the right supports in place before new legislative instruments are introduced. Supports should be holistic, based on a person-centred assessment and underpinned by a Human Rights based approach and framework.

Recommendation 1 – Whist acknowledging that an additional 5 working days have been given, this is not adequate and QDN recommends extending the consultation period for the draft lists of NDIS supports to engage in genuine co-design and consultation with the disability community including engagement strategies targeting harder to reach cohorts.

Recommendation 2 – All information and communications relating to NDIS reform must be provided in all accessible formats to ensure a diverse range of people with disability understand and are able to respond to consultation and co-design processes. This includes ensuring people are supported where needed to take part in these processes.

Recommendation 3 – Until there is negotiation and agreement with States and Territories regarding supports funded by other service systems, there should be no change to Schedule 1 of the NDIS (Supports for Participants) Rules 2013. Whilst QDN acknowledges there is work to be done on Schedule 1 to reflect the NDIS Review and engage in co-design, the draft NDIS lists are not fit for purpose in delineating what is an NDIS support and items that relate to other service systems.

Recommendation 4 – A prescribed list of NDIS supports must be accompanied by effective mechanisms developed in consultation with the disability community for participants to request a review of decisions. This process must be communicated clearly in all accessible formats to participants including their rights to a review.

Recommendation 5 – A workforce development strategy must be developed for NDIA staff to include ongoing training and education on how NDIS funds can be spent and information and referral for other support systems to reduce confusion and anxiety for participants.

Conclusion

QDN thanks the Department of Social Services for the opportunity to provide this submission to the consultation on draft lists of NDIS supports. QDN and its members continue to be engaged and provide feedback regarding NDIS reforms.