# Submission – Consultation on draft lists of NDIS supports 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 welcomes consultation to the draft lists of NDIS supports 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.

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.

Lisa was talking about feeling like a criminal – like a fraudster – she mentioned media coverage has been really negative. Would be good to mention that here.

## Key concerns

* If they change the legislation – can I be audited for past activities before the legislation changed?

## Short consultation time

QDN members have raised concerns around the timeframe for consultation on the draft NDIS supports list allowing only 14 days to respond and a lack of accessible versions of the lists including versions translated into other languages. Fundamental to informing these reforms is authentic co-design 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 Draft NDIS 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 people 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 NDIS lists and there must be sufficient time for their voices to be heard in this consultation.

These lists have not been shared widely with disability community. The Easy Read versions were only made available on 14 August 2024, four days before consultation closed. 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.

## Foundational Supports Service System

Concerns have also 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 support 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 list is 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.

There needs to be evidence that public state-funded services such as health and education will provide services that are not included in the draft NDIS supports list. 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.

## The one size fits all approach does not work

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 consider the intersectional needs of someone with disability. The Draft NDIS supports lists reinforces this approach and is not conducive to the original tenants 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 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.

## Providing information and referrals

If the NDIS does not fund a support, the NDIA must 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’.

## Supports that are ‘NDIS supports’

QDN members have provided feedback on the list of NDIS supports and indicate that the following must be considered and these supports included.

* Assistive technologies such as noise cancelling headphones, ear defenders or stim tools must be included. There are also concerns if these items are included they may only be from specialist providers at a higher cost than they may be costed in mainstream retail outlets.
* People with disability in regional and remote Queensland have reported the lack of training services for assistance animals in their local area and the need to travel long distances for this service. Training and related travel to access training must be included under the Assistance Animals category.
* People with disability are disproportionately affected by emergencies, particularly people in regional and remote areas and are at increased risk in emergency situations due to the lack of accessible information, support and services. QDN recommends an additional category of NDIS supports called ‘Emergency and Disaster Preparedness’ to include funding to develop person-centred emergency plans, do emergency preparedness training and to purchase appropriate emergency kits.
* QDN members have expressed that the NDIS should fund supports for family members and care givers who care for a person with disability including training, respite care or psychological support.
* QDN members are calling for an increase of the transport contribution. Members have shared that if they use public transport, they are allocated a lower transport contribution in their budget. The choice to use public transport compared to a taxi service or private vehicle is weather dependent. For example, one QDN member cannot use public transport in his $50,000 electric wheelchair if it is raining due to risk of water damage. Whilst QDN acknowledges assistance with travel/transport arrangements is listed as an NDIS support, greater flexibility is required for participants to negotiate with the NDIA.
* Provider travel must be included in the list of supports. Currently, NDIS participants do not know how much they will be charged for provider travel until after the service is delivered and the invoice is provided. Some QDN members have shared they are unsure if their funding will cover the cost of provider travel and that if there is a shortfall in their budget they will miss out on a particular service. For example, one QDN member requires an Occupational Therapist (OT) assessment for a new electric wheelchair. He has been quoted 30 hours which includes provider travel. This cost itself could be up to $2,000 or $3,000. If this is not included in his plan, he could be using funds to pay for travel costs instead of actual services.
* Community participation should include arts and cultural activities.
* Housing support must include individual advocacy and associated costs to find and/or transition between different types of housing as needs change.

## Supports that are not ‘NDIS supports’

QDN members have provided feedback that the following supports should be considered to be NDIS supports.

### Day-to-day living costs

##### Accommodation and household related

**Standard household items** for example an additional bedside fridge/freezer for thermoregulation to store items such as cooling packs or vests to prevent seizures. This is particularly important for people living alone. Dishwashers are a necessity for people with vision impairment and dexterity issues. A Thermomix is much safer and accessible for people with a vision impairment or who are Blind to cook with and enables independence. Smaller household items such as accessible can openers or bottle openers are a necessity and specialised bedding like cooling sheets to maintain body temperature and reduce health risks.

The **cost of running household devices** that are required because of a person’s disability, for example, air conditioning for someone who cannot regulate their body temperature or a benchtop dishwasher for someone who uses a wheelchair can become expensive and not affordable. It is crucial that the NDIS funds the cost of electricity bills associated with the running of life-saving and altering equipment and devices. There are some state-based subsidies that only cover a very small portion of the cost.

**Electricity generators, solar panels, and batteries** are life saving during times of disaster or power disruption for people who rely on equipment to keep them alive, allow them to move around their homes or help them to eat or drink. One QDN member raised the point, “what if the power went out and I became stuck in my hoist mid air between my wheelchair and my bed?”. Without a battery or generator this would be a very dangerous situation. During disaster seasons, many parts of Australia lose power for days on end and participants need generators and batteries to power their equipment.

**Pool maintenance** such as skimming surface, emptying filters, filling a sample to take to the pool shop for chemical testing are all things that many people with disability need support to do and should be considered as NDIS supports. Under the proposed list it is unclear if these activities are permitted to be undertaken by a support worker. Maintaining a pool may be part of a rental contract and necessary for a person to maintain their housing.

The cost of **furniture removal** is something that should be funded as an NDIS support. One QDN member shared that before she acquired her disability, she would have loaded unwanted furniture into a trailer and taken it to the dump herself, however, she does not have the ability to do that anymore. She reports that participants engage their support workers to do this task, which is not good value for money compared to furniture removal services.

##### Finance and payments related

Insurance for accessible vehicles and mobility equipment is a cost that is not affordable for many people with disability. One QDN member shared the cost of insuring her vehicle. She purchased the vehicle for $60,000 and paid $70,000 for modifications to the vehicle to make it accessible. This means the vehicle needs to be insured for $130,000, a cost she cannot afford. Another member raised the question, “what if someone breaks into my house and steals my $50,000 wheelchair? I cannot afford the home and contents insurance; will the NDIS replace it? How long would that take? How long would I be stranded without a wheelchair?”.

##### Food, Beverage related

QDN members share that **fast food services and takeaway food** are often the only affordable option for food preparation and delivery for people with disability who live in regional, rural or remote areas. QDN members living in regional and remote areas do not have access to services that deliver food, leaving them with the option to order a meal from the only dining outlet in town and have it delivered. The cost of this might be $30-$40 compared to two hours of evening rate support work at $60 per hour, equalling $120 to prepare one meal. This is one of many examples where people with disability have designed cost-effective solutions that have the added benefit of connecting them with the local community.

##### Lifestyle related

**Internet services, mobile phones and associated phone plans** are critical to break down the digital divide for people with disability and assist in ensuring access to essential services and information, connecting to communities, advocating for themselves and accessing and using assistive technology (see also smart watches below). 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 and cannot afford to be connected digitally in an ongoing way. These barriers are increased for First Nations and culturally and linguistically diverse people with disability.

QDN is deeply concerned that **menstrual products** are not being considered as an NDIS support. There is a high risk of increased restrictive practices being enforced by service providers to repress or stop people's menstruation. In addition, menstrual products such as period underwear have provided lifechanging outcomes for women with disability, their families and carers. They are essential for women with disability experiencing mild incontinence or where other menstrual products are not appropriate for their needs. Period underwear can support people’s self-image and enable them to participate in activities like swimming and water sport. Period underwear is currently claimed under the NDIS and included in OT assessments for this reason.

**Sex work, sex toys** and sexual supports are critical to the wellbeing of people with disability. As recognised by the Federal Court in 2020[[1]](#footnote-2), these are reasonable and necessary supports that contribute to holistic health and quality of life. The NDIS must continue to recognise sex, sexuality, and relationships within the context of disability and ensure access to a range of safe sexual supports and services that meet the diverse needs of NDIS participants. Additionally, some people with disability require bespoke sex education which is crucial for ensuring people with disability can engage in safe and healthy sex lives. One example shared by a QDN member is the importance of sex education and therapy for people who have Autism and are gender fluid or transexual.

**Trampolines** are used by some people with physical disability as a way of building muscle tone. For some people, this may be the only option to exercise.

##### Clothing related

**Smart watches** are a vital piece of Assistive Technology for many people with sensory disability and provide features not available on other devices that support people to live independently. For those at risk of falls or seizures apps only available on smart watches are an effective technology to track movements that indicate risk and alert support workers or family members as opposed to medical alert watches which require action on behalf of the wearer. Smart watches are used by people with intellectual disability for reminders to take medication and undertake daily living activities such as showering, personal hygiene and drinking water leading to greater independence. Smart watches are also used via Bluetooth to answer calls easily and control smart devices in the home. QDN members report that the cost of smart watches is cheaper and lasts longer than other Assistive Technology that does not deliver on multiple functions in the way a smart watch does.

##### Pet related

Many people with disability require **pet grooming services** as they are physically not able to groom their pets including washing or trimming hair or claws.

### Not value for money/not effective or beneficial

##### Beauty services related

**Artificial nails** in specific circumstances and related to specific disabilities have been found to be disability related prosthetics. For example, for those with severe neuropathic pain because of their disability or brittle nails due to an autoimmune disease, artificial nails act as an orthosis to perform daily functions and in one case to type leading to greater employment opportunities.

Paying for a **hair salon** to wash hair prevents the need for the additional cost of a support worker who is not as experienced nor has appropriate equipment to wash hair in a comfortable and accessible way. For people with disability who can wash their body but not their hair, visiting a hair salon for this service maintains their dignity and independence, saves money compared to the cost of a support worker and creates greater connections in their local community.

In addition, people with significant physical disability must access a professional provider for services including waxing, trimming, or laser hair removal of pubic hair. Not only is this more cost effective in the long term but it reduces the risk of an unqualified support worker performing the task at home, including burns, cuts, or rashes. QDN members have shared that it is more dignifying to go to a professional provider rather than a support worker.

##### Alternative and complementary therapies

Broad sweeping statements declaring therapies are not value for money or beneficial are offensive and harmful. Hundreds and thousands of NDIS participants benefit from these therapies. To state they are not effective or not value for money is not consistent with the evidence base that exists. According to QDN members, the way these therapies have been grouped together in the list is inappropriate. For example, grouping tarot card reading with **yoga therapy**, a therapy proven to provide multiple benefits for many people with disability. One QDN member reported that **gaming therapy** is a beneficial therapeutic approach for people with ADHD or Autism.

A QDN member with physical disability who has been funded to receive **dry needling and acupuncture** for years, reports that this is one of the few therapies that helps his symptoms wholly related to his disability and does not consider this to be an alternative therapy.

QDN members believe that **wellness coaching** should be included as an NDIS Support.

### Mainstream – Health

**Pharmaceutical supports**, **nutritional supports, and Webster Packs** must be considered NDIS Supports. For people who are PEG-fed the state-funded systems do not cover the cost of what is considered an individual’s food cost. Disability-related pharmaceutical supports, for example, bowel and bladder medication and devices must be NDIS supports as they are often not affordable. Webster packs are another crucial support funded by the NDIS. Some people with disability cannot manage their own medication administration and webster packs help people with disability to do this.

Clarity is needed around **assistive technology and health**. For example, if a Blind person has Diabetes and cannot get an accessible pump funded through Medicare, it is crucial that person can get it funded by the NDIS. Additionally, there needs to be clarity about funding for NDIS participants with **Type 1 and Type 2 Diabetes**.

It is important that **CPAP machines and associated ongoing costs** including the cost of consumables are funded by the NDIS. One member said that her CPAP machine was covered by the NDIS and that if it wasn’t she would not have been eligible through Medicare due to her age and the fact she does not have a chronic lung condition, despite her sleep apnoea diagnosis and the fact that her CPAP machine has made a huge difference to her quality and life.

**Participants must be able to access NDIS supports whilst in hospital and access Hospital in the home services.** NDIS supports need to be used in all health services because support workers understand how to support a person eg how to lift, care needed etc. Not having these supports in health services increase risk of harm and injury.

**Supports incorporated for rehabilitation services, OT, speech, people recovering from surgeries and managing deteriorating**

Palliative care

People with disability and life-limiting conditions are experiencing reduced access to services to say at home and maintain independence. Services such as those available on the NDIS including personal care, meal preparation, domestic assistance, respite and social supports can support people to stay at home and out of the hospital system. The NDIA and other government agencies across all jurisdictions must work together on a solution to ensure people get the supports they need towards the end of their life.

### Mainstream – Mental Health

QDN members are strongly advocating for the NDIS to fund mental health therapies including Cognitive Behavioural Therapy (CBT), trauma informed care, and other support for mental health related to a person’s disability. One member explained that even though she does not have a diagnosed psychological disability, she experiences depression and anxiety as a result of her physical disability.

QDN members would like the NDIS to fund supports for ongoing psychosocial recovery, which should be informed by a recovery model.

### Mainstream – Child Protection and Family Support

**Specialised equipment** to support parents with disability must be funded as an NDIS support.

### Mainstream – Early Childhood Development

Alison has some points re this from session, she is drafting her response so would be good to check in with her

### Mainstream – School Education

##### Aids and equipment for educational purposes

To enable equal access to education, aids and equipment for educational purposes including modified computer hardware, education software and Braille textbooks must be funded as NDIS Supports. QDN is aware that children in school and adults at TAFE or university are often excluded as educational institutions do not provide information in ways that are appropriate or accessible for students with disability. For example, students who are Blind or have a vision impairment are taught using audio (for example, text to voice) and are not learning literacy, cannot read or write, spelling, grammar, punctuation. The NDIA must work with governments across all durations to fill these gaps.

Schools are not obligated to provide students with **orientation and mobility** support, this must be funded as an NDIS support.

### Mainstream – Higher Education and Vocational Education and Training

Many people with disability who study at TAFE and University receive support from the NDIS. Whilst the educational institution may be responsible for supports provided in the classroom, they are not responsible for providing assistance for activities like eating or going to the bathroom. This support must be funded by the NDIS, as taking this off the list of funded supports would force people with disability to unenroll from their studies.

Universities are supposed to provide a support person to help students with disability navigate the campus, however, some QDN members report that their university says no one is available and to get this support through the NDIS, even though this is not correct. This is especially problematic for people who are studying unique degrees. What ends up happening is that participants use a support worker to do the role of someone who should be getting funded by the university, which becomes a serious issue during auditing processes. This same member reported that his university refused to convert a graph into an accessible format for him to read, insisting that he use his NDIS funding to have in converted, despite him telling the university that this is a fraudulent activity.

### Mainstream – Employment

**Specialist disability employment providers** who use an evidence-based, person-centred model to support people with disability in finding and retaining employment should be included. QDN has heard reports of Disability Employment Services (DES) declining NDIS participants as clients due to the nature of their disability or providing volunteer-based work only or work that is not suitable or appropriate.

**Supports that occur during work** – the Draft List suggests that employment supports that the NDIS currently funds would be more appropriately funded elsewhere in the system, for example, Job Access. However, many people with disability do not work enough hours in the week to be eligible for Job Access. This would force many people out of work. If a person with disability loses their job because they are no longer funded to receive supports at work, the NDIS becomes responsible for providing support to that person anyway.

### Mainstream – Housing and Community Infrastructure

According to the draft list – **SDA** is a group activity – this means people who require 1-one-1 support will not be eligible anymore. It would be triggering for people who need 1-one-1 – traumatising for some people.

### Mainstream – Transport

### Mainstream – Justice

### Mainstream – Aged Care

## Recommendations

The feedback collated for 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. Supports should be holistic, based on a person-centred assessment and underpinned by a Human Rights based approach and framework.

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.

## 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 look forward to further consultation and engagement regarding these lists.

1. [National Disability Insurance Agency v WRMF [2020] FCAFC 79 (fedcourt.gov.au)](https://www.judgments.fedcourt.gov.au/judgments/Judgments/fca/full/2020/2020fcafc0079) [↑](#footnote-ref-2)