

22nd August 2024

Department of Social Services

Delivered via email/mail: NDISConsultations@dss.gov.au

Dear Department of Social Services,

Draft list for NDIS supports for the *National Disability Insurance Scheme (Getting the NDIS Back on Track No.1) Bill 2024*

Thank you for the opportunity to provide you with our feedback on the proposed transitional rules for the new “NDIS Supports” definition which would apply should the National Disability Insurance Scheme (Getting the NDIS Back on Track No.1) Bill 2024 (**NDIS Amendment Bill**) pass.

Like Medicare, the National Disability Insurance Scheme (NDIS) is an essential public service. It is transforming the lives of people with disability, their families and our communities. When people with disability access individualised disability supports, they enjoy independent, dignified lives that enrich our society.

Queensland Advocacy for Inclusion (QAI) and other members of the Queensland Independent Disability Advocacy Network (QIDAN) support people with disability to navigate their NDIS funding and, where necessary, to appeal NDIS decisions at the Administrative Appeals Tribunal (AAT). We see first-hand how decisions made by government either enhance a person with disability’s quality of life or go wrong and deny people with disability access to essential supports. It is with this experience that we write to you with our feedback on the draft lists of NDIS supports that have been released for consultation.

We have significant concerns with the content, clarity and structure of the current proposed rules for NDIS Supports. Whilst these are transitional it is important to ensure they are fit for purpose. They will apply until the final rules can be agreed between the Commonwealth, States and Territories. It is our view that the issues regarding the delineation of NDIS/Mainstream supports should not be changed for a transitional period, other than to include some clarity where required.

Our key concerns:

- The list confuses things a participant can and cannot use their NDIS funding for **and** the things which would be the responsibility of another service system. These are two different concepts. However, this list mixes it all up together and will be extremely confusing for participants, providers and the NDIA employees themselves. Participants continue to be stuck between service systems arguing about who is most appropriate to provide a support.

- The list of items participants cannot use their funding for is **overly prescriptive, will create confusion, is inconsistent and in many cases fails to understand the complexity of disability** and the potential for cost saving flexibility for participants. Many items are unclear and need more definition, for example what are “specialist products” are and why it is mentioned for some of the supports but not for others. If they refer to products that need to be prescribed by a specific specialist, it should be clarified. The same apply to some supports that “require specialist skills” – which skills are required, who the relevant expert.
- Further there is a real risk this prescriptive approach will **stifle innovative programs and practices** which can genuinely support participants to achieve their goals. This may even cause unintended consequences like the NDIA suspecting that participants are misusing their funds and consequently changing the management of their plans to NDIA managed with the intent of preventing further misuse.¹
- A key existing test in the current Support for Participant [Rules](#) as to what might constitute an every day item that **could be funded** because it is ancillary to another support funded or provided under the plan has been removed in this new list (see Rule 5.2(b)). However, it is our view that it should stay.

The risk in creating a hard list of supports that will not be funded is that it will include items that from a non-disabled person’s perspective could be seen as mainstream ‘luxury’ items, but which are in some circumstances, and for some individuals, an essential, cost effective, disability related support. The ability to consider these nuances is one of the core benefits of individualised support packages and in our view, the existing reasonable and necessary support criteria already manages sustainability and floodgates concerns. Our experience demonstrates that where apparent ‘every day’ items have been approved or agreed to in the Tribunal process, there have been significant reasons for that agreement or approval associated with a person’s disability (or ancillary to another support funded).

Some examples of how the list creates confusion and is mixing up concepts

All items which relate to the NDIS/Mainstream support system interface should be removed from the list entirely. That is, supports relating to health, mental health, child protection and family support, early childhood development, education, employment, housing and community infrastructure, transport, justice and aged care. They require significant and high-level inter-governmental negotiation between states and territories and the Commonwealth Government and are inappropriate to include in this list. They relate to broader reforms in the disability ecosystem and should not be captured by an arbitrary list without the requisite consultation and clarification.

¹ QIDAN advocates have been experiencing numerous cases where clients have their NDIS plan management changed to NDIA managed, without notice or consent. The NDIA justifies the changes are due to the existence of “unreasonable risk” linked to alleged fraud and / or misuse of funds. It is our view that issues related to fraud or misuse of funds should be treated differently (eg. NDIS Commission taking actions for example), and that the creation of a prescriptive list of supports will increase the number of cases where plan management is disputed.

Some of these supports have also not been adequately defined. Listing them will not lead to increased certainty or consistency but will likely have the opposite effect of forcing participants through protracted review and appeals processes in order to access certain supports.

For example, 'palliative care' has been listed as a support which should not be funded by the NDIS. This term is widely misunderstood and requires a much more nuanced understanding. For example, a person is likely to receive symptom management and allied health care and treatment through their local health service. They can access this at any stage of living with a terminal illness. While the person may be eligible to receive equipment on loan or community-based nursing support in the last few weeks of their life, this support is typically only for people who are actively dying. For people who require increased support at home due to reduced functional capacity as a result of living with a terminal illness, this support is most appropriately funded by the NDIS and yet is not adequately captured by the current draft list.

Action 2.6 of the NDIS Review recommends a multilateral schedule to a new Disability Intergovernmental Agreement to clarify distinct systems responsibilities and shared agreed responsibilities.² It is further recommended that only after the shared responsibilities are agreed on, the NDIA should update and republish NDIS operational guidance and NDIS Participant Support Rules. Without a clear agreement between the NDIA and the states and territories of which supports are funded by the NDIS and which are not, NDIS participants will continue to be refused supports that other mainstream systems believe are not their responsibilities.

Example 1 – Mainstream Transport

For example, on page 20 is the list of things that cannot be funded in the 'Mainstream - Transport' category it says:

Accessible public transport

Public transport fares

What this really means:

State Government and Local Governments are responsible for ensuring public transport is accessible for a person with a disability.

A person should not use their NDIS funds to pay for their own public transport fares. If the person must have a support worker, funded by the NDIS when accessing public transport, that fare could be paid for from NDIS funds (this would have been covered by the now removed 5.2(b)).

² Working together to deliver the NDIS: supporting analysis, pages 144-145.

Example 2 – Mainstream Housing and Community Infrastructure

On page 19 under Mainstream – Housing and Community Infrastructure it provides these items are not NDIS Supports:

The provision of accommodation for people in need of housing assistance, including routine tenancy support

Ensuring that appropriate and accessible housing is provided for people with disability, other than participants eligible for specialist disability accommodation (SDA)

Again, there is confusion about what this could mean. It could easily be interpreted as preventing support coordinators from working with participants to find appropriate housing outside SDA. This could not be the intention and isn't if read with page 1 which says the NDIS can fund the following:

Supports that guide, prompt, or assist a participant to undertake activities that ensure they obtain/retain appropriate accommodation.

This may include assisting a participant to apply for a rental tenancy or to undertake tenancy obligations in line with the participant's tenancy agreement.

Support coordinators (possibly to become navigators) often play a critical role in connecting and supporting participants to navigate housing options, including for example, getting tenancy advice from State Government funded organisations.

In addition to SDA, the NDIS also provides funding for 'Independent Living Options' (ILOs) these are intended to support participants to develop novel and flexible housing / support options. This funding would be prevented or refused under the items on page 19 notwithstanding the inclusion on page 1.

Under the same heading, 'postal services' are listed as an item which is not a NDIS support. We have difficulty understanding why this is listed at all. A 'carve out' is delivery fees for NDIS supports.

The delivery of items to our regional and remote participants is critical (whether by post or otherwise). Examples of things that need to be delivered include continence supports, shower chairs etc.

In our view the listing of postal services is unnecessary (and confusing) and the carve out unnecessary if the wording in rule 5.2(b) is included.

Example 3 – Mainstream School Education

On page 17 there are listed a number of items related to "Mainstream – School Education". This list again includes a mix of school services / fixed capital costs and smaller items which could be specific disability supports and needed by students both in and out of school.

Fixed / non-transportable aids in a schools sit next to aids and portable education aids and equipment like a modified computer, education software, braille textbooks. This type of specification should not be in a list which has not been negotiated and where participants have no guidance as to where these supports could be funded if they are over and above requirements for children without a disability.

The only 'carve out' is In-kind personal care in school (which if in-kind presumably is not funded) and Specialist School Transport (which is also confusing is that only for special schools or is that special vehicle required to transport a child in a mainstream school to out of school excursions?).

Example 4 – Mainstream – Child Protection and Family Support

At page 16 under 'Mainstream – Child Protection and Family Support' the following item is included:

Funding or providing out of home care or support to carers of children in out of home care where these supports are not additional to the needs of children of a similar age in similar out of home arrangements.

This is very unclear and should be deleted. NDIS supports for children with disability in out of home arrangements (including kinship arrangements) should not be disadvantaged in their NDIS supports because they live outside their parental home. The current criteria in section 34(1) is sufficient and provisions like this do not belong in the Rules and potential discriminate against children with disability in out of home care.

We have assisted clients' matters which Child Safety was mistakenly involved in, where the child's needs were disability related. In one particular case, a 15-year-old NDIS participant with Autism was referred to Child Safety because of his increased violence in the home environment (as a result of the disability). The parents entered a voluntary agreement with Child Safety, who assessed the parenting as exceptional, to arrange a temporary out-of-home care for the participant given the risks to the family. This was a temporary solution for the family and for the 15-year-old who did not have any other options, but in the long term, the NDIS should fund adequate supports for this young person, whose need for support and housing is solely required because of his disability.

Example 5 – Mainstream Mental Health

Under this section is listed "Treatment for drug and alcohol dependency, eating disorders, gambling and other addictions". Whilst we don't disagree that 'treatment' in this capacity is not a NDIS support, a list like this can easily be misinterpreted to mean a person with an eating disorder or drug and alcohol dependency cannot receive appropriate disability support through the NDIS. Disordered eating can be a feature of a disability, and which requires ongoing allied health support (eg speech pathology or psychological support to maintain eating).

The line between NDIS supports and other Government service systems which leaves people with disability at risk

Example 6 – Aged care

At page 21 aged care services are listed. The carve out is stated to be:

Supports for a NDIS participant under the age of 65 who chooses to live in residential aged care and purchase support from an aged care provider.

This is **legally incorrect**. Participants who enter aged care before their 65th birthday can continue to receive NDIS supports whilst living in an aged care facility after their 65th birthday. We have heard of disturbing trend of the NDIA refusing to fund supports (e.g. specialist AT) where they are still eligible for the NDIS. (ref section 29 of the [Act](#)). In addition, a clear action of the NDIS Review was:

– Action 2.11: The Australian Government should implement legislative change to allow participants once they turn 65 to receive supports in both the NDIS and the aged care system concurrently and clarify when aged care supports are reasonable and necessary.

Example 7 – Palliative Care

Palliative care is not described. We have heard of cases where NDIS Supports have been reduced significantly or not increased where a person's needs have changed because a person has a life limiting condition. This is wholly inappropriate and fails to understand the purpose and scope of palliative care provided by mainstream systems. An appropriate definition of the scope and purpose of palliative care is needed.

Example 8 – Disability Health Supports v Health

The division of responsibility between the State Health Systems and disability health supports is very complex and nuanced which is not properly captured in the disability health supports included as 'NDIS Supports' set out at page 5 and those that are not NDIS supports described as 'Mainstream Health Supports' at page 15 and then the carve outs.

The structure alone of these supports is cumbersome, and difficult to follow. NDIS Supports are described as:

Disability-related health supports where the supports are a regular part of the participant's daily life, and result from the participant's disability. This includes continence, dysphagia, respiratory, nutrition, diabetic management, epilepsy, podiatry and foot care, and wound and pressure care supports.

Supports for people with complex communication needs or challenging behaviours while accessing health services, including hospitals and in-patient facilities.

Issues:

- In the first paragraph the disability-related health supports are limited only to supports which result from a participant's disability. This would exclude, for example, for example a person with a severe to moderate intellectual disability being supported with their diabetes management or nutrition. Supporting a person with these needs through the NDIS is most appropriate and ensures they maintain their health (see for example, Please see example of Mazy and National Disability Insurance Agency [2018] AATA 3099 (9 August 2018).)
- This second paragraph implies that a person with a complex physical disability may not be able to go with support workers to access the GP or a hospital. Clients with disabilities where they don't have complex communication or behaviour will often need their formal support with them in a health setting to assist them with their complex physical needs. For example, if they are in a waiting room and need their support to go to the toilet then they will need their support workers – who have the skill and knowledge to assist.

We also have concerns about the exclusion of “diagnostic assessments and screening services” on the list of items that will not be funded. Frequently the NDIA requests very detailed information from allied health professionals about a participant’s treatment of functional capacity. A participant should not have to pay for these. The assessments are not covered by Medicare, and often times are not paid by the NDIA. We have had AAT matters where the NDIA provided a list of specific questions to the participant’s GP but refused to pay for that report. Without that information, the NDIA refused to fund the supports requested. The power imbalance is so clear, where the NDIA has the power to ask the questions but refuse to pay for the practitioner’s time to answer the same questions and as a result refuse the supports requested.

Comment on ‘everyday items’

We have developed a table at Annexure A which notes several supports that are contained in the current draft list which we consider should be in this category and which we consider are not appropriately captured by the ‘carve out’ provided.

Items such as smart watches, home modifications, access to sexual therapies and gym memberships *might* be appropriately funded in situations where all the reasonable and necessary criteria have been met. QAI and QIDAN are of the view that, at present, the six reasonable and necessary criteria in section 34(1) of the *National Disability Insurance Scheme Act 2013* (Cth) provides a principled framework for supports, which can and do allow flexibility to meet the needs of people with diverse disabilities and intersecting identities. This should not change.

We consider that certainty for participants and Agency staff regarding these types of supports can be achieved through alternative ways, such as education and training for staff, capacity building support for participants and greater information sharing and awareness raising measures. Implementing a system to update operational guidelines to reflect decisions made by the AAT and Federal Court would also assist.

For example, the decision in Milburn³ noted that while funding for a gym membership would be considered discretionary spending for those who do not suffer from a disability, in that case it was attributable to the participant's support needs and therefore appropriate to fund through the participant's NDIS package. We have worked with participants who in order to access their exercise physiologist needed directly in connection with their disability must access a gym (and pay the gym membership) to access that gym.

Risks with proceeding with the current draft list

We envisage the following risks associated with the current draft list include:

- Further confusion in what can and can't be funded
- Restrictions on funding which:
 - Could destroy existing innovative programs,
 - Prevent and limit further innovation and flexibility that the NDIS Review was seeking, and
 - Remove choice and control of participants
- Hardwiring issues now before proper consultation between the Commonwealth, States and Territories and the disability community.

Our Recommendations:

1. For supports which should be funded by other service systems there should be no current changes to Schedule 1 in the current Support for Participant Rules until they have been properly negotiated by the States and Territories.⁴ This Schedule has applied since the inception of the Scheme and case law has developed around what is appropriate for the NDIS to fund and what should be funded by other service systems. It is far from perfect and needs proper work. This list does not do that. The proper consideration of service system delineation is required to ensure the recommendations from the NDIS Review are properly captured. All items which relate to other systems (eg. education, health, early childhood development, justice) need to be separated from other items and the text should reflect the current Schedule 1.
2. All items, services and therapies which may have a disability purpose or could be narrowly construed to limit genuine and innovative community participation programs should be removed (see our table at Annexure A for some examples) leaving only the most obvious items for example, alcohol, passports, cruises, gambling, weddings, funeral costs, legal costs, child support fees, donations and council rates.

³ Milburn and National Disability Insurance Agency [2018] AATA 4928 (20 December 2018)

⁴ Please note recommended Action 2.6 of the NDIS Review.

3. The text at 5.2(b) in the existing Rules should be included (or not removed) to ensure that items required which are ancillary to a NDIS support can be funded.
4. The NDIA provide better and consistent training to its employees, plan managers and support coordinators about the reasonable and necessary criteria.
5. Accessible information is available to participants on how to spend their NDIS funds.

Conclusion

We would like to conclude by highlighting that the short period for consultation has been completely inappropriate and inaccessible to many people with disability, despite being extended from two to three weeks. Despite repeatedly stating it will co-design reforms to the NDIS with the disability community, the government's continued approach of suddenly releasing proposals for reform with such little time in which to obtain feedback means that many people with disability who require time and support to process information and provide input are unable to meaningfully participate. That this point still needs to be made, ten years into the NDIS and following both the Disability Royal Commission and NDIS Review, is extremely disappointing and frustrating for many people in our sector. It does not constitute genuine co-design and will continue to result in policy and law reform that fails to meet the needs of the scheme's participants.

Implementation without genuine and robust co-design also risks removing choice and control from people with disability and could amount to removing the scheme's core value of providing individualised support packages that people with disability can use to cover the additional disability related expenses resulting from reasonable and necessary supports.

I hope this is of some assistance. Please do not hesitate to contact us if you would like to discuss any further.

Yours faithfully,



Matilda Alexander (Chief Executive Officer) and **Sian Thomas** (Principal Lawyer, NDIS Advocacy Practice) from Queensland Advocacy for Inclusion



Caitlin De Cocq Van Delwijnen (Principal Advocate) from Queensland Independent Disability Advocacy Network

ANNEXURE A: Sample of items which should not be on the list.

No	Page No.	Items listed as not a NDIS support	Comment
1.	2	Assistance to Access and Maintain Employment or higher education	<p>The carve states that learning, and work-specific support will not be considered a NDIS support.</p> <p>Many participants need assistance with education and employment as a primary goal, but their disability may prevent them from doing it successfully. We have had clients who needed assistance from a support worker to perform work tasks and it was deemed a reasonable and necessary support to be funded by the NDIA.</p>
2.	6	Home Modification Design and Construction	<p>The carve out states that design and subsequent changes or modifications to state or territory owned public housing will not be funded. In our experience, state owned public housing are only modified when the modifications are minor. NDIS participants who are not eligible for Specialist Disability Accommodation (SDA) may need home modifications beyond what public housing funds.</p> <p>However, there are participants who may need home modifications between what is considered minor and major. Some participants will be deemed ineligible for SDA but still need significant home modifications which won't be funded by the Department of Housing. We have had experience assisting a family living in social housing, which needed major modifications to support their 15-year-old child. The NDIA insisted that the Department of Housing should pay for the modifications (a cost of about \$400,000). After 2 years of AAT dispute, the young person was deemed eligible for SDA.</p>
3.	10	Motor vehicle	<p>Currently, the NDIS can fund the purchase of a motor vehicle where there are special circumstances. Vehicles which are suitable for modifications need to be new or near new. There are only a few models suitable and the price for those vehicles is prohibitive (\$50k) for most participants.</p>

No	Page No.	Items listed as not a NDIS support	Comment
			<p>The Tribunal has on at least one occasion approved a car and on one occasion refused a car by applying the reasonable and necessary criteria.</p> <p>In very special circumstances, including where there are no public transport options and the participant cannot travel on public transport due to their disability and taxis are not available in the area and when combined with other particular circumstances of the persons disability, we have had vehicles funded.</p> <p>The cost savings for the NDIS can be significant when compared to hiring special disability vehicles on a long-term basis.</p> <p>(Note, we consider, there is scope for the NDIA to register security interests on these types of items so that the participant cannot sell them without the Agency's consent).</p>
4.	11	Home Security	<p>Home security cameras can provide substantial cost-effective support to allow a person with limited mobility to see who is at the front door and permit them access from their bed.</p> <p>Special security lock boxes are also often necessary to manage the flow of support workers coming in and out of a participant's home.</p> <p>The Deaf community use cameras to see outside their home or at the door where they do not have hearing. This is very different from a person who can hear if there are people walking around their yard or at the door.</p>
5.	11	Moving services	<p>If a participant is being required to move by the Agency because of a funding change (we are currently seeing this occurring for participants) then it is inappropriate for a participant to have to bear that cost of moving their belongings.</p>
6.	11	Pools service	<p>Some participants have a disability requirement for regular hydrotherapy and have installed their own special purpose facility at home. But for their disability</p>

No	Page No.	Items listed as not a NDIS support	Comment
			this wouldn't be required. Where there is a disability purpose for the pool which significantly reduces the need for allied health support the cost of maintaining the pool could if the reasonable and necessary criteria are met be able to be recovered through the NDIS.
7.	11	Standard household items – Linen	QAI has assisted a client at the AAT whose disability caused her to pick her skin and rub and scratch. Through extensive trials the use of silk sheets was found to significantly reduce the harm caused by these behaviours. Due to the nature of her disability these sheets needed to be replaced very regularly (bi-monthly). The need for silk sheets was a critical disability support which significantly reduces harm to our client.
8.	12	Internet service	For clients who require communication through video conferencing (eg Deaf clients) they require significantly more data to allow them to communicate. This is over and above what would be required day to day.
9.	12	Smart Watches	Smart watches with an inbuilt falls detector and alarm systems are a significant support that can substantially reduce a person's need for person to person support.
10.	12	Sex work and sex toys	For a small proportion people with disability engaging in any sexual activity is not physically possible without support or special modifications.
11.	14	Alternative and complementary therapies – eg Life coach	<p>The exclusion of therapies that are "out of the ordinary" will prevent NDIS participants from accessing supports that are truly reasonable and necessary for them. These exclusions have a very narrow approach and disregard cultural needs.</p> <p>In our experience, if the reasonable and necessary criteria is met (which include a requirement that the therapy is effective and beneficial having regard to current practice), these supports should be funded.</p> <p>A description of 'life coach' who is skilled in supporting a person to set goals, build confidence and</p>

No	Page No.	Items listed as not a NDIS support	Comment
			strategies to meet those goals may be more appropriate than a 'psychosocial recovery coach' for some participants. Particularly those who have not benefited from psychology or psychosocial recovery. (Not the language of psychosocial recovery is not accessible for some participants.)
12.	14	Alternative therapies (eg Gaming therapy) / Dating apps	The NDIS has resulted in the development of social and recreation activities for young people tailored to their disability needs. Setting a ban on items like gaming therapy or dating services could result some participants being told they cannot use their NDIS funds for social group programs if there is a gaming component (eg dungeons and dragons) or a meet up (in a safe environment) component.
13.	14	Nail salons	Accessing a nail salon on a regular basis for foot maintenance (between podiatry appointments) could be significantly more cost effective for clients with limited mobility than reliance on support workers or increased podiatry.
14.	14	Hair washing	A weekly hair wash at a hairdresser is a great option for people with limited hand and shoulder use and more cost effective than requiring a support worker in the home for the purpose of hair washing.