**Submission - DSS Draft Lists of NDIS supports**

As a middle-aged person with multiple sclerosis and a participant I find the draft lists of NDIS supports deeply disappointing. Disabilities are complex and individual and supports must be tailored for the person with a disability. Excluded supports may be a support for one disabled person, and not for another. This is especially true for those of us that have a complex progressive degenerative condition where symptoms fluctuate. This list does not allow any flexibility and decreases innovation.

1. **Do you think the draft list of NDIS Supports covers the kinds of disability supports you think should be included?**

**If not, what changes would you suggest?**

Absolutely not.

I endorse the full submission by the Justice and Equity Centre to the Department of Social Services: Consultation on Draft Lists of NDIS supports (16 August 2024). In particular, the following recommendations:

1. **The transitional rules not impose new restrictions on the range of supports the NDIS will fund**

These transitional rules must not prevent the NDIS from funding supports it currently funds. Any new determinations to exclude supports from the NDIS should be left to the development of the NDIS Rules that will define ‘NDIS supports’, which will be subject to a full co-design process.

1. **Participants with approved funding for ‘reasonable and necessary’ supports not be prevented from spending that funding**

Proposed section 46 of the NDIS Bill should be amended to insert a grandfathering provision to allow NDIS amounts to be spent where a support has been found to be reasonable and necessary for a participant and funding for that support is already included in the participant’s plan.

1. **The transitional rules not impose blanket exclusions**

The transitional rules should not impose blanket exclusions for funding types of supports that may be necessary to address participants’ disability needs.

1. **The ‘substitution’ process creates a rights-based mechanism for participants**

The Government’s proposed substitution process should be reformulated to:

• not be dependent on prescribing supports in NDIS Rules (per proposed subsection 10(6)(a));

• not impose mandatory conditions (per proposed subsection 10(6)(d)) for a substitution to be approved and instead assess applications based on relevant factors;

• require the CEO to approve the substitution if relevant factors are met; and

• ensure participants have a right to seek review of the CEO’s determination not to approve a substitution.

1. **Categories of ‘NDIS supports’ be clarified**

The intended purpose, scope and description of categories of ‘NDIS supports’ should be clearer for participants to have clarity and certainty. Currently it lacks clarity or certainty. Given the potential consequences for participants if they were to (even inadvertently) spend their funding on ‘non-NDIS supports’ (ie changes to their plan management preferences, raising of debts, etc).

1. **Threshold requirements be avoided**

Threshold requirements for ‘NDIS supports’ should be avoided. If a threshold requirement is necessary, guidance must be provided so it is sufficiently clear to participants how the threshold will be evaluated and satisfied.

For example, the category of ‘Community Nursing Care’ provides certain types of care can be provided for ‘participants who have high care needs requiring a high level of skill’. In this example, it is unclear how it will be determined whether a participant has high care needs, or whether a high level of skill is required. If these requirements are met, the support can be funded; if they are not met, it is prohibited. The lack of clarity means a participant cannot be sure how to meet the conditions or whether the conditions are met in their case, and thus contributes to the chilling effects described above.

1. **References to ‘specialist’ and ‘disability-specific’ supports be removed**

References to ‘specialist’ and ‘disability-specific’ supports should be removed. Instead of requiring supports to be specialised in nature, the supports should address ‘disability-related needs’.

1. **Lists of ‘non-NDIS supports’ be removed**

The lists of ‘non-NDIS supports’ should be removed. Where the specification of ‘non-NDIS supports’ are needed, it should be included as a carve out to the relevant category of ‘NDIS support’ list and framed as narrowly as possible.

1. **Lists of ‘NDIS supports’ be grouped by subject matter**

Lists of ‘NDIS supports’ should be grouped solely by subject matter, such that all stipulations as to a type of support can be found together in the lists.

1. **Define categories of ‘NDIS supports’ and carve outs correctly**

Categories of ‘NDIS supports’ and any appropriate carve outs should be redrafted and defined correctly to avoid being misleading and legally inaccurate.

1. **Are there goods or services on the draft exclusion list that you think shouldn’t be there? If yes, list in order of importance.**

Yes.

Again, the submission by the Justice and Equity Centre to the Department of Social Services: Consultation on Draft Lists of NDIS supports (16 August 2024) provides some clarity about problems with the draft exclusions. In particular, they make the following recommendations:

1. **References to ‘specialist’ and ‘disability-specific’ supports be removed**

References to ‘specialist’ and ‘disability-specific’ supports should be removed. Instead of requiring supports to be specialised in nature, the supports should address ‘disability-related needs’.

1. **Lists of ‘non-NDIS supports’ be removed**

The lists of ‘non-NDIS supports’ should be removed. Where the specification of ‘non-NDIS supports’ are needed, it should be included as a carve out to the relevant category of ‘NDIS support’ list and framed as narrowly as possible.

1. **Lists of ‘NDIS supports’ be grouped by subject matter**

Lists of ‘NDIS supports’ should be grouped solely by subject matter, such that all stipulations as to a type of support can be found together in the lists.

The list of exclusions is rather large and unwieldy. This will cause confusion amongst NDIS delegates, local area coordinators, support coordinators, plan managers as well as participants and their families. The lists will cause confusion, increase red tape, will hinder the ability for the NDIS to meet the participant service guarantee.

1. **Do you have any further feedback or concerns with the draft NDIS support lists?**

Yes.

The timeframe for providing feedback of the draft NDIS supports lists has been very rushed and has not allowed sufficient time for the disability organisations, disability advocates, lawyers, participants and their families. This has neither been adequate nor optimal for co-design.

This quick timeframe has disadvantaged participants who have been providing written submissions to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, the Senate inquiry by the Community Affairs Legislation Committee into the National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Bill 2024 regarding the reforms put forward into the Getting the NDIS Back on Track No. 1) Bill 2024. Also, the Easy Read and Auslan versions were very slow to be released. The rushed timeframes and lack of easy read/Auslan versions has disadvantaged minority groups in the disability community such as those with intellectual disabilities; vision and hearing impaired; deaf blind persons as well as CALD and Indigenous groups.

The new NDIS supports outlined in Section 10(a) of the National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Bill 2024 moves away from the current focus on ‘reasonable and necessary support’ towards a more defined list of supports with further detail to be outlined in the NDIS Rules (as agreed with state and territory governments). This list is based on selected elements in the United Nations Convention on the Rights of Persons with Disabilities (CRPD). The CRPD is an important international human rights convention and should underpin all Australian legislation focused on Australians living with disability.

Disability Advocacy Network Australia notes in their submission to the draft rules that one carve out is that these supports are ‘solely and directly as a result of a disability need’. This is a very high bar to clear for a typical participant, as particular support needs are often hard to disentangle from those that are typically performed by people but are made more difficult as the result of a disability.

For example: an automatic vacuum, as described above, does not solely arise as the result of a disability. There is an ongoing need for all people to maintain a clean home, but a disability can in some instances make that task substantially more difficult or outright impossible.

MS Australia noted in their submission the definition about supports is highly restrictive, inconsistent and will limit what supports can be outlined in the NDIS rules. Further, they noted there is no allowance made for household goods and equipment such as vacuum cleaners, e-bikes, dishwashers and air conditioning. Access to these can be crucial for people living with multiple sclerosis and others with neurological conditions.

For example, many people living with MS suffers from temperature sensitivity and struggle to regulate their body temperature. Access to an air conditioner is the best way to manage this according to MS Australia.

As a person with multiple sclerosis, I find the exclusion of e-bikes and e-trikes extremely disappointing. I am unable to walk large distances, but an e-trike allows me to cover much longer distances to grocery shop, cafes and social groups. It has improved my cognitive ability, endurance and fitness as well as improved my mental health. The battery allows me to return home independently when I am unable to generate as much power in the legs due to neuromuscular fatigue related to multiple sclerosis.

In the draft rules there is no clear definition of what constitutes a “specialised” product is. Will a product only be included if it is “specialized” or from “specialized providers? This is unclear. As Minister Shorten has repeatedly said providers apply a premium (wedding tax) when NDIS funding is mentioned. The same occurs when disability is mentioned. The cost will likely be greater if the product is specialized or from specialized providers. Below is an example from my own life as a person with multiple sclerosis:

For example, some people with a disability will find a mini chopper from Kmart cheaper and easier to manage. My occupational therapist recommended a JarKey Jar opener and CanKey Ring Pull opener purchased from Woolworths, Coles or Kmart as opposed to specialized providers such as Think Disability which has more expensive versions. These openers manage dexterity and hand strength issues and allow independence ultimately saving with disability support hours.

Similarly, the submission from the Justice and Equity Centre to the draft rules notes there is an “emphases on ‘specialist’ and ‘disability-specific’ supports at the expense of mainstream supports”. Many categories refer to ‘specialist’ or ‘disability-specific’ supports being able to be funded, while excluding ‘mainstream’ or ‘standard’ supports. This approach is concerning for several reasons.

* First, it is often unclear whether this would include the purchase of a standard support that is subsequently modified to make it appropriate for people with disability. This lack of clarity contributes to the issues raised above regarding blanket exclusions and slowing of participant engagement due to concerns about debts/rights to manage their plans.
* Second, the exclusion of mainstream supports that can be used for disability-specific purposes prevents people with disability from developing creative solutions, and utilising mainstream products in innovative and cost-effective ways to address their disability-related needs. Third, this approach entrenches segregation of people with disability, and perpetuates a view that NDIS participants live outside of mainstream community. This has longer-term exclusionary effects for people with disabilities and should be avoided.
* The Justice and Equity Centre therefore recommend the draft rules be amended to remove these distinctions. Instead of requiring the supports themselves to be specialised in nature, it would be more appropriate to require supports to address ‘disability-related needs’ in order to qualify as ‘NDIS supports’.

I fully concur with comments by Justice and Equity Centre submission to the draft rules in Section 6 – Categories of ‘NDIS supports’ – specific comments. In it they noted significant areas of concern including:

Assistance animals

Assistance in Coordinating or Managing Life Stages, Transitions and Supports

Assistance With Daily Life Tasks in a Group or Shared Living Arrangement

Assistance with Travel/Transport Arrangements

Assistive Equipment for Recreation

Assistive Products for Household Tasks

Assistive Products for Personal Care and Safety

Community Nursing Care

Customised Prosthetics (includes Orthotics)

Disability-Related Health Supports

Exercise Physiology & Personal Well-being Activities

Hearing Equipment

High Intensity Daily Personal Activities

Home Modification Design and Construction

Household tasks

Innovative Community Participation

Interpreting and Translation

Personal Mobility Equipment

Specialised Hearing Services

Specialised Support Coordination

Vehicle Modifications

Vision Equipment

In addition to the concerns noted by the Justice and Equity Centre, many advocates are concerned the broad framing of several categories may also capture important and necessary supports that may have to interface with the exceptions process, such as:

**Smart watches**

Smart Watches are an example of a personal items which can be viewed as a non-disability related support but can overlap with disability related needs. Disability related supports provided by smart watches can be of great assistance for those requiring help to manage medication, their schedules (foot and hygiene reminders, medical appointments), use communication tools, request aid, use as a torch, or to magnify items on a larger screen for those who are vison impaired. Also, to track seizures, gait or to track individuals who are a ‘flight risk’. Cheaper falls devices around the neck are easily forgotten and thus ineffective.

* These are helpful for those with mobility and balance issues, memory problems, and executive functions problems in conditions such as multiple sclerosis, Parkinson’s, brain tumours, acquired brain injuries etc.
* Without these devices, people may become more reliant on a support worker or require additional support from the health system, both of which have costs that quickly outstrip the original cost of the device.
* Paying for a smartwatch pays back in reduced worker costs, reduced health costs, and in greater independence.
* Advocates have regularly supported people to use these supports to overall reduce the funding they needed. Additionally, their ability to be purchased through Low-Cost Low Risk plan budgets already in many people’s plans means that the utility that they provide is not always clearly established with the Agency directly or at the AAT.

**Pool maintenance**

Things like skimming surface, emptying filter, filling up sample to take to shop for chemical testing are things most non-disabled people do themselves. But, if a person with a disability is unable to do this themselves because of an impairment related to their disability, these should be covered.

* Pools, pool heating and maintenance: the AAT has found the installation of a hydrotherapy pool is a reasonable and necessary support, would come at a ‘much lower’ cost than any proposed alternatives,’ and would have a large number of significant benefits. Spires and NDIA [2023] AATA 1230, [87]-[91].
* It is unclear if a support worker is permitted to do these activities under proposed list.
* Maintaining a pool can be part of a rental contract and necessary for a PWD to maintain their current housing.

**Fencing**

May be a valid use where person with a disability lacks the intellectual capacity to determine unsafe situations and run away frequently. Secure fencing would keep them safe where you wouldn’t otherwise need fencing.

**Assistive technologies like noise cancelling headphones / ear defenders or stim tools**

Unclear if currently included in the list.

* Used in neurological conditions such as multiple sclerosis and others where the brain becomes overloaded from stimuli resulting in falls risk, lack of reasoning ability, memory issues, and an inability to participate in social and community activities.
* Are these only included if that are “specialised” or from “specialised providers”? If they are specialised or from specialised providers the cost will likely be greater than buying from normal retailers such as JB Hi-Fi.

**Sex workers and sex toys**

May be entirely valid supports and both have been funded where appropriate up to now. The blanket exclusion of sex work does not take account of the many reasons people with disability may seek this support. This includes to address sexual pain, to support healing after sexual abuse and trauma, or to experience sexual physical touch. Additionally, the Full Federal Court has found sex work to be a reasonable and necessary support, and in line with the ‘values, objectives, purposes and guiding principles with which this legislative scheme is replete’ in particular in forming part of the spectrum of social interaction between individuals and community. NDIA v WRMF [2020] FCAFC 79, [141]-[143].

The Justice and Equity Center in their submission supports the Joint Statement: Ten Organisations Call for People with Disability’s Access to NDIS Funded Sexuality Services to be Protected and its call for the Government to engage with the disability community in developing a framework for NDIS funded sex work and sexuality services that reflects the needs and rights of people with disability.

On the Growing Space Facebook page there is a scenario discussed of a person with a physical and intellectual disability where attending to sexual functional needs avoids aggressive outbursts in a group home against other participants and workers.

**Period underwear and products**

Period underwear and products are not lifestyle products.

Used by huge numbers of disabled people for perfectly disability related reasons. Period underwear and products can also be used for continence issues.

Some may require a tampon applicator or modified period underwear for disability specific reasons.

**False nails**

There are cases that have AAT rulings where false nails in specific circumstances and relating to specific disabilities have been found to be disability related prosthetics.

**Hair and beauty services**

Used by PWD with neurological conditions, upper back muscle weakness, arm and hand weakness, lack of hand dexterity and fine motor skills. Many disabled people are unable to care for their hair themselves and go to their local hairdresser to have their hair washed as for $40. This is done quickly, safely, with specialised equipment. The alternative is done at home with a support worker for a minimum of 2 hours + $120+ plus purchase of equipment like mobile basin and hose.

Many people with disabilities are unable to safely care for their body and pubic hair (eg. shaving legs, arm pits and bikini line). For many, this inability means either going to a dedicated hair removal salon 3-4 times a year for waxing / laser / IPL. Or alternatively, in less than desirable situation where these tasks are performed by a support worker where the PWD is naked and exposed during the task. When such tasks are performed in home environments by support workers there are causal links to abuse, sexual assault and violence. If the task is performed by a trained professional in a purpose-built professional setting it does not carry nearly the same risk of harm.

**Household Goods**

In the Disability Advocacy Network Australia (DANA) submission to the Community Affairs Committee of Getting the NDIS Back on Track No. 1, Bill 2024 [Provisions], pp17-20 they argued that too broadly limiting how NDIS funds could be spent would impact flexibility, choice and control and ultimately mean more money would be spent on supports than are necessary. The example provided in the submission was that of household goods, which can address and mitigate disability support needs and reduce the reliance on support workers to do the same tasks. It’s disappointing to see this included in the draft list of outs.

Similarly, MS Australia in their submission stated it was disappointing to see no allowance for household goods and equipment such as vacuum cleaners, e-bikes, dishwashers and air conditioning. Access to these can be crucial for people living with MS. For example, many people living with MS suffers from temperature sensitivity and struggle to regulate their body temperature. Access to an air conditioner is the best way to manage this.

As a person with multiple sclerosis one of the most problematic symptoms is extreme fatigue which limits our ability to undertake personal cares, daily household cleaning, maintenance and participation in family, social and community activities. Disability symptoms make the task substantially more difficult or outright impossible.

* Light weight or automatic vacuum cleaners allow independent maintenance of a clean home with less reliance on support workers. (DANA and MS Australia)
* E-trikes can be used instead of a wheelchair allowing grocery shopping to occur, visits to cafes, exercise and maintenance of physical and mental health. This allows independence and often results in less use of support workers.
* Dishwashers are often a necessity not an everyday item for people with visual impairment, dexterity issues and for those who use wheelchairs.

According to DANA, one carve out suggested in the draft rules is that these supports are ‘solely and directly as a result of a disability need’. This is a very high bar to clear for a typical participant, as particular support needs are often hard to disentangle from those that are typically performed by people but are made more difficult as the result of a disability. An example of the automatic vacuum, as described above, does not solely arise as the result of a disability. There is an ongoing need for all people to maintain a clean home, but a disability can in some instances make that task substantially more difficult or outright impossible.

The Growing Space Facebook page discuss a scenario where the use of a washing machine is not an everyday item. In the scenario a participant with a physical disability involving faecal and urinary incontinence. Faecal incontinence occurs overnight, every night at their place. There are also 2-3 changes of school uniforms during the day. The participant’s laundry is very soiled. So, a 2nd commercial washing machine so as not to contaminate the whole family’s laundry. This is reasonable and necessary, cheaper than the alternative of a laundry service and allows the participant to attend school in non-smelly clean clothes throughout the school day.

**STA**

Currently the only respite care on the list is STA/respite provided in group homes. Group homes are not suitable for everyone. The Disability Royal Commission showed that PWD are often subjected to violence, abuse and neglect in these settings either from staff or other PWD whose behaviours may pose a risk to others.

* For some group homes are extremely noisy leading to sensory overload triggering a “fight or flight” response. This is true for those with trauma, neurological illnesses, and those with sensory difficulties like autism.
* Group homes used for respite are unlikely to provide the PWD a chance to build capacity or work on goals during their respite.

**Specialised driving instruction**

The support lacks clarity.

Specialised driving instruction unless it is in a modified vehicle or with adaptive equipment is highly restrictive and will disadvantage some participants who currently use services that are not in modified or adapted vehicles.

**Travel**

Currently unclear if those who can travel independently in a taxi but not drive or take public transport are still eligible for funding.

Or for those who can travel independently in some circumstances (ie short, local trips), but not others (longer or unfamiliar trips) are eligible.

**Psychology and counselling**

Under therapy, there is a description of occupational therapy and speech therapy but no mention of psychology and counselling.

Many PWD require psychology and counselling to adjust to their injuries and impairments.

In progressive illness, psychologists are helpful in keeping PWD motivated, physically and emotionally healthy and engaged in the community. Lack of supports in this area will lead to increasing burden/costs to NDIS and health system, social isolation, depression, and suicide.

**Business development costs, business skills development costs** - this will stop Participants with social and economic participation goals related to developing a micro business like my brother.

**Career coach** - this will also stop Participants with social and economic participation goals. Why restrict purchasing a service from a more experienced mentor with your disability or functional limitation in pathways and planning that will help a Participant maintain work?

**Marriage and relationship counselling**

Those caring for a personal with multiple sclerosis face greater carer burden, potentially leading to relationship difficulties and breakdowns according to MS Australia

As these relationship difficulties are the direct result of disability and impairments, marriage and relationship counselling should be considered a valid inclusion in some situations.

**Individualised Living Options** Paying rent and/or utilities for a housemate in exchange for support. This is currently how some participants live in an independent living situation.

It’s unclear in the arrangements if this will be excluded.

The NDIS already funds this kind of support. Some people have specific funding called Individualised Living Options.

Thank you for accepting my submission.