NDIS DRAFT LISTS OF SUPPORT
25 August 2024

To whom it may concern,

I have Spina Bifida and Psychosocial Disability. I am a wheelchair user and have been on the scheme for nearly 8 years.

Thankyou for providing us with the opportunity to consult on the proposed NDIS Draft Lists of Supports. Over the past year I have provided feedback to the NDIS Review and 2 Senate Inquiries in relation to the scheme and the proposed changes, I have also applied and been rejected for 4 Co-Design Opportunities. I feel right now, as I’m sure that many others in the Scheme do, Invisible. I hope the Department takes our submissions and consultation seriously and with true reflection and consideration. These are changes and decisions that will impact the quality of life for myself and many others, our ability to be independent, our ability to live alone, our ability to move safely in our homes, to eat properly, drink properly and maintain basic hygiene. These submission are important, WE are important and we also come fit with inbuilt problem solving born from years of navigating an inaccessible world. We have the solutions, we know our lives, please listen.

In relation to the proposed Draft lists and support lists:

Page 2: Assistance with Travel
It is unclear from the wording whether participants who are still able to use public transport can still claim transport expenses and costs when using a support worker. This is also unclear in the wording in the PACE plans. This wording says activity based transport with a support worker can only be claimed where the participant cannot travel independently or use public transport. So for example, a person with a Psychosocial Disability that can use transport engages a support worker to go to a Food Court to work on sensory processing, is the kilometre rate for transport in the worker vehicle able to be covered by the persons Social and Community Core funding? This wording says it can’t.

Activity based transport and provider travel should be a standalone sentence, without the qualification for unable to use public transport. OR Activity based transport should be added as a term to Page 8, Participation in Community, Social and Civic Activities.

Page 2: Assistive products for Household Tasks
Unlike some of the other submissions, I actually support the “specialist” qualification for this category. I understand why it is there and the category still supports modified items such as hand grabbers and hand dexterity attachments. However I know a lot of people will argue that everyday products can still be disability-specific. So for that reason I think there needs to be a carve out to enable to CEO to determine if an everyday item can be funded to assist a person in household tasks. For example I know many people with Spina Bifida who were funded lightweight stick vaccums. This enabled them to keep clean environments in-between weekly cleaning especially if they had pets or if they dropped something or smashed glass. But this support should ONLY be for people with a physical disability and only for those with sole responsibility for household cleaning (e.g. live alone with no informal supports).

Page 3: Assistive Products for Personal Care and Safety
I don’t agree with the “specialist” qualifier for this category. As someone who performs clean sterile catheterisation myself and deals with incontinence, this qualification is extremely limiting and concerning. There are many over the counter item used in the management of personal continence that are not considered “specialist” yet are vital to personal hygiene and even the ability to do the task safely and without risk of infection. You also need a lot of products when dealing with bowel incontinence and accidents. These products include baby/hygiene wipes, antibacterial hand wash, glycerin/lubricant, nappy bags, barrier cream (to protect skin). I currently receive a continence package that takes these incidental items into account and they have always been able to be claimed and funded by government Continence funding including the previous Enable NSW scheme before I transitioned to NDIS. It is unclear in the wording and the qualifier whether these items relating to personal continence would still be funded. If they aren’t, it is hundred of dollars a year out of pocket for me, for item that SOLELY relate to my Spina Bifida. It puts myself and others at risk of infection as well as just limiting our right to personal dignity.
I believe a standalone sentence stating, “products for management of continence” should be inserted into the category. This is similar to Page 8, Personal mobility Equipment, where it just states “products” to enable personal mobility.

OR you could add the qualifier, “dedicated products for continence management.” Dedicated means only for that purpose as opposed to “specialist” which means prescribed and not an over the counter item.

Page 4: Communication and Information Equipment

The opposite is true in this category, the word “specialist” should be added to this category. It opens the door for people to still buy items like ipads which we all agree is the reason we got into this mess in the first place. Or a qualifier needs to be added to the sentence that states these items can only be funded for those unable to communicate by other means solely and directly because of their disability.

Page 4: Daily Personal Activities

As stated above, a sentence needs to be added that states, “including provider travel,” to enable the person to know they can claim support worker kilometres to go shopping etc.

Page 5: Exercise Physiology and Personal Wellbeing

This currently states exercise can be claimed but doesn’t mention Dietician which is also covered by this category. It’s also not mentioned anywhere else in this document so should be added to this category of support.

Page 6: Household Tasks

House maintenance is mentioned as being funded in this category. Yet it also appears on page 11 as a not funded support. I do note the qualifier is different, page 6 says “essential household maintenance” and Page 11 states “general house maintenance.” This is terribly confusing and could risk a person making a claim and raising a debt if they thought house maintenance was covered and it really isn’t. For example I’ve hired a handyman to clean my inside and outside windows for before as I had mold from the humidity in summer and it was unsafe. In my eyes it is essential household maintenance that I can’t perform as I can’t raise my arms for prolonged periods of time or access even the tops of my indoor windows in my wheelchair. But is this general household maintenance? This is very unclear and confusing.

I think Page 6 should include handymen services in its description for essential maintenance and Page 11 in reference to non funded household maintenance should state extensive household maintenance, or include tradesmen such as plumbers or electricians as not being funded. BUT there should also be a qualifier for this handyman support on Page 6, this support should only be allowed where the person is both physically unable to do the task due to their disability and are responsible for the tasks. I cannot tell you how many parents I know who are claiming lawn mowing and cleaning from their kids plans. This is not what it is intended for, it is intended for adults who are responsible for maintaining their own properties, for this reason there needs to be a qualifier or this practice will continue to happen which is a waste of taxpayers money and takes away from persons such as myself who genuinely need the support.

Page 8: Participation in Community, Social and Civic Activities

As stated above, Provider travel and activity based transport need to be added here for those that use a worker vehicle.

Page 9: Therapeutic Supports

While I know this category refers to Occupational Therapy, Speech, Psychology, Physio etc many others in the Scheme don’t know this and it makes it incredibly confusing for people worried about a debt being raised against them for a wrong claim. I suggest listing them here. Please also add as the carve out as ‘not’ a support, Diagnostic Assessment. You mention this on Page 14 as a Health Support not to be funded but if you don’t mention it on Page 9 people will think they can claim all Therapy expenses from their plans and this includes assessments and reports. This needs to be made clear so people don’t incur a debt especially as these reports are very expensive.

Non NDIS Supports

Day-to-day living costs

* Bedding is listed as a day-to-day expense. While I understand general bedding is a normal expense there is a large variety of bedding that is disability specific. I have bought a number of items over the years that relate solely and directly to my Spina Bifida that are deemed reasonable and necessary bedding items. This includes waterproof mattress protectors for incontinence. Positioning U-Shaped pillow as I spend 16 hours a day in bed and cannot lie flat, mattress overlay due to my Sciatic nerve compression (and being bed bound 16hours per day, it’s also less cost than funding a full new mattress for Participants). There are also various Gel memory foam pillows and overlays that assist with thermoregulation especially for those with neurological disorders or Spinal Cord injuries. I have a specialist contour memory foam pillow due to congenital malformation in my neck which is also related to the Spina bifida. Without it I sleep poorly and my health outcomes decrease with lack of sleep. There should be a carve out for specialist bedding for those with Physical Disability, continence needs or Spinal Cord injuries for these reasons.
* Car insurance – I know participants who have raised premiums solely and directly due to their disability. For example needing to have multiple support workers insured as drivers, or for portable home contents such as wheelchairs or smartdrives insured (my portable contents insurance is $16,000 due to my chair and smartdrive and costs an extra $10 a month although I don’t claim it from my plan myself, I know others who do). Modified vehicles also cost more to buy and insure. Participants should be able to claim the difference between a normal vehicle and modified or additional expense incurred solely due to their disability
* Food and Beverage – it is unclear in the wording whether Meal services are still able to be claimed. It is not mentioned in Page 11, and Meal Preparation and Delivery is stated on Page 6 under household tasks but Meal Service is not mentioned as either allowed or not allowed. This needs to be clarified as a carve out, “Prepared meal services, where the meal Preparation and delivery costs only can be claimed not ingredients”
* Menstrual Products – Like many people I don’t agree with these being on the out list. There are many people with an intellectual disability who cannot manage periods, this is a human right and risks forced birth control or forced sterilisation to deal with periods.
In my case however, I use a long overnight pad as a bowel incontinence pad. Bowel incontinence pads don’t exist and I don’t want to be forced by this government to have to use an adult pull up. That is degrading and unfair. A long overnight pad reaches past the bottom and catches small solid bowel accidents. This provides me both dignity and discretion. Please don’t take this away.
* Travel related – it is still unclear what can or cannot be funded for Short Term Accomodation. “Holidays” have never been allowed, yet people still claimed them as STA. There is no mention of STA in this document. You need to add one, and it needs to be clear that Short term Accomodation is for respite purpose only (away from the persons usual care team) or for capacity building only. I believe there needs to be an outcomes based approach to STA, with providers clearly providing to the agency expected and then realised outcomes (activities participated in and progress made etc), backed up by documentation filled out during the persons STA which includes a therapeutic team. This will stop the one stop shop holiday STAs. This document does nothing to stop the STA abuse.
* The document also makes it unclear whether parking expenses can be claimed when using a worker vehicle. I have been worried about claiming this myself as I don’t want a debt or be labelled misuse of funds, but there are many parking expenses I incur solely from being in a worker vehicle or solely from being on an outing with a worker or capacity building outing.
* Carve outs – gym services – there are many people claiming personal training. This document doesn’t say whether this can or cannot be claimed only that the entry and membership costs cannot be claimed. This needs to be clarified.

Not value for Money

* Like many people, I don’t agree with hair services not being able to be claimed. I have a mobile hairdresser come and wash and dry my hair in my home with a mobile height adjustable basin. I have a tethered spinal cord and upper back spinal kyphosis related to my Spina Bifida and I cannot lift my arms for too long and have severe pain and fatigue. I also cannot bend my neck forward over a sink. I am otherwise independent with daily washing and grooming using my bathroom home mods and adaptive equipment. If hair washing is removed it would be an additional cost for a worker to transport me to the hairdresser, both hours and kilometres, as we are unable to do it over my sink due to my tethered cord and I do not wish to be naked with my male support workers. This will costs around $150 for time and kilometres. The mobile hairdresser costs me $50. I don’t agree that that isn’t value for money as I’m sure many people will point out.
* You have also not clarified whether Chiropractic can or can’t be claimed. I expected it to be on Page 14 as an alternative therapy, I know many people with Spina Bifida who find chiropractic beneficial and know of some AAT case where this was included as a Therapeutic support. I believe as they maintain AHPRA registration it should still be allowed to be claimed under therapeutic supports.

I don’t personally engage with other services mentioned in the out list such as housing, supported employment etc so cannot comment on those supports.

I do want to quickly mention that I know the government has allowed participants the ability apply to the CEO/delegate to fund a support listed as not approved on this list. This however creates a logistical nightmare both for the agency and for participants. Will we need it in writing in our plans? Will we need to do a plan variation to add it to the plan? Do we just ask our LAC? Do we just claim it and apply for approval at the point of compliance risking a debt? There are many questions. But if we all need to put in a plan variation to fund pads, wipes, hair dressing and mattress protectors, the agency is going to have a backlog of 500,000 participants to deal with, all requesting variations to include supports that they currently rely upon each and every day to live a meaningful, safe and independent life. It is in this context I ask you to truly consider the submissions including my own and amending the lists. We are not asking for additional money, these are supports that have been integral everyday supports for many of us since the day the scheme started.

I thankyou for reading this submission and I hope you consider the points made.

Kind regards