**FEEDBACK REGARDING THE DRAFT SECTION 10 LISTS OF NDIS SUPPORTS**

**NATIONAL DISABILITY INSURANCE SCHEME AMENDMENT (GETTING THE NDIS BACK ON TRACK NO. 1) BILL 2024**

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Firstly, I believe the timeframe provided for responses to the Draft List of NDIS Supports is vastly inadequate. Providing a 10 working day period, in total, is insufficient to provide informed consultation and response from a wide representation of people with disabilities and the peak organisations who represent them.  This is particularly so, during a time period where there are so many co-existing and conflicting pieces of legislation, ie, the Response to the Disability Royal Commission, the Proposed NDIS Review and the NDIS Amendment Bill (Getting the NDIS Back on Track”).

I am, personally, finding that the participants with disabilities, who I represent through my advocacy work, are very confused by the differences in the separate pieces of legislative instruments and recommendation documents that are currently under discussion.  I believe that a minimum of an 8 week consultation period for such an important, and life altering proposed list of changes to current NDIS structures is necessary to enable appropriate co-design.

Additionally, your questions on your own survey is using language which is unclear to participants without any form of intellectual disability, let alone the participants who are faced with the challenges of navigating life with such a disability.

In your survey, the first question refers to the draft list of NDIS Supports you think should be included, and your second question refers to the Goods or Services on the exclusion list that you think shouldn’t be there.  However, the related documentation uses the titles “Supports” that are NDIS Supports, versus “Supports” that are not “NDIS Supports”, and does not include the terminology of “goods and services”.

 I can only assume that when you are referring to goods and services on the draft exclusion list that you are in fact referring to the document entitled “Supports that are not NDIS Supports”.  The continued use of inconsistent titles needs to be prevented in future so that we do not produce final documents with categories such as “Assistance with Daily Life” under Core funding, versus “Daily Activities” under Capacity Building funding, and then wonder why participants are confused by the difference between the two categories.  Clear and concise language is essential to enable understanding by all participants.

**SUPPORTS THAT NEED TO BE INCLUDED**

There is a list of 36 categories of NDIS supports and any carve outs to the descriptions, in addition to a list of 15 categories that are NOT NDIS supports.  My concerns are that these categories do not appear to directly correlate with prior lists of available supports, ie, the NDIS Pricing Arrangements.  Without detailed exploration of comparison between the new proposed lists and the old Pricing Arrangements, it is difficult to ascertain supports that may have been deleted. For instance, under the new NDIS Supports list, the only mention of Early Intervention Supports for early childhood is the provision *of a mix of therapies, and a key worker for the family.  Supports for all children 0-9 years with a developmental delay or disability and their families to achieve better outcomes regardless of diagnosis*. With reference to this description, there are no carve outs that are not NDIS supports.  On initial exploration, this appears to be a good outcome.  However, there is also no mention within the documentation of ANY supports for daily living, consumables, social and community participation supports etc, which are currently available under “Core” supports, regardless of the severity of disabilities. There are many, many families with severely disabled children under the age of 9, who NEED support workers to assist them to keep their children in their home environment, and not be forced into the excruciating decision of having to relinquish care of their much loved child, due to inability to cope within the home environment.  It is essential that more than just therapeutic support is available for children under the age of 9.

Is this list of NDIS supports fully inclusive?  If so, there are likely to be many more gaps, such as the above example, that would exist upon further exploration.

With further reference to the supports listed on the draft supports list my immediate concerns are as follows:

***Assistance to Access and Maintain Employment or Higher Education*** -

**Carve outs that are NOT NDIS Supports -**

* **Does not include learning and support needs of students;**
* **Work specific support;**
* **Funding or provision of employment services and programs.**

Without the above supports, participants that are currently accessing education and training, are actively engaged in a working environment or are currently engaged with employment services and programs, will no longer be able to pursue such activities. Has the Government considered that, not only would this vastly diminish the participant’s choice and control along with their social and economic participation, it would also not, in fact, result in any cost saving measures for the scheme?  If these participants are not engaged in such meaningful and productive activities, they would still require support during the said hours.  How is this a cost saving measure, and how is it in the best interests of the participant?

For example, is it not better to have students actively engaged in a SLES program for two years after leaving school to develop skills to enable them to become active members of our workforce? The removal of such a support should not take place until alternate Foundational Supports are already in place in each State and Territory.

***Assistance with Daily Life Tasks in a Group or Shared Living Arrangements***

This section appears to be saying that STA and Respite can only be achieved in a shared living environment. Those words need to be changed to enable participants to have choice and control, and value for money, by self managing their STA Accommodation and Respite provision in an individual care model.

***Disability related health supports* -**

The description needs to include “Complex Bowel Management and Disability Specific Care” - for instance - hoisting techniques specific to individual disabilities and the life threatening condition of Autonomic Dysreflexia for high level spinal cord patients, while accessing health services, including hospitals and inpatient facilities.

***Exercise Physiology and Personal Wellbeing Activities-***

More detail is required.  The document states *physical wellbeing activities to promote and encourage physical wellbeing, including exercise*.  It is stated that there are no carve outs.

 I believe that more detail is required, as it is unclear as to whether this will only include exercise physiologists, or will it extend to personal trainers, dietitians, hydrotherapy etc?

Would it include services such as hypnotherapy, yoga, massage therapy etc.  I believe this is not proposed to be included, however with the title of “Personal Wellbeing Activities” and having no carve outs, this is the type of language that creates confusion.  Many of these activities can be lifestyle choices for one participant, however can potentially be considered reasonable and necessary support for another.

***Assistance with Travel/Transport Arrangements***

This needs to be clarified explicitly to explain what funding exactly is provided within the plan for travel purposes. For instance, if therapists/support workers are being allowed to charge both travel time and mileage to provide a service within a home environment, then that transport cost needs to be added to the funding in the participant’s plan.

***GOODS AND SERVICES EXCLUDED FROM FUNDING-***

I am referring to the Supports that are on the “Not NDIS Supports list”.

My primary concern with the above list is that living with disability is not “black and white”.  Whilst certain supports may be considered to not be appropriate NDIS supports for a middle class participant living in a major metropolitan area, the same support may very much be a vital support to a lower income participant living in a regional or remote community.  Similarly, supports that may be very important to a participant living with a major physical impairment, may not be reasonable and necessary for a participant living with another type of disability, for example a participant living with vision impairment.

Frequently, participants live with multiple disabilities, and what is and isn’t appropriate supports does need to be considered on an individual and whole person basis.  My specific examples from the lists are below:

**Accommodation and Household Related**

* **Standard Home Security and Maintenance costs, fencing, gates and building repairs** -

As one example of the individual consideration required regarding this category, is it not reasonable and necessary if you were a carpenter who always did your own home repairs prior to acquiring a spinal cord injury, which specifically prevents you from doing so ongoing, to be able to claim minor building repairs as a disability related expense?  Many, many other examples exist.

* **General furniture removal and services, and unwanted furniture pickup -**

Many participants with disabilities are simply unable to exercise the option afforded to their non-disabled counterparts of hiring a trailer and performing such services themselves. Is this not therefore a disability related expense?  Participants living in many regional councils are not provided with the option of curbside pickups and physically disabled participants are unable to move unwanted items to the curbside even if such service is available.

* **Pool… maintenance etc**
* It is recognised on the NDIS list of supports that house and yard maintenance is a reasonable and necessary inclusion. Similarly, participants who require such support should also be able to include the pool maintenance or spa maintenance service (excluding the chemicals that would be used and be an expense for any other person with a spa or pool). To consider these luxury items only is an irrelevant assumption, as many participants attempt to acquire said items to utilise for hydrotherapy and home exercise therapies, preventing decline and subsequently requiring further supports.
* **Electricity Generators, solar panels and batteries**
* It is a specific requirement under NDIS guidelines that all SDA homes built for participants requiring High Physical Supports must include the provision of an emergency power backup in the form of either battery storage or generators that will cover a minimum 2 hour period.  How can this separate part of NDIS guidelines exclude the provision of such a support?  With reference to batteries, are you proposing that you cannot purchase a battery, or spare battery, for your electric wheelchair, battery operated hoist or other items of approved assistive technology that require battery power for operation?  Again, this is not black and white, and for that reason cannot be automatically on a list of day to day living costs that are not covered by NDIS supports. Similarly, the next section that includes “bedding” is not black and white.  Participants with severe thermoregulation issues due to their disabilities, eg high level spinal cord injuries or advanced multiple sclerosis require specialty bedding - eg sheets with moisture wicking, cooling, absorbancy aids such as Kylies or Connis, even down to low friction fabrics to minimise friction when using slide sheets for supported positioning.  These are a necessity for those participants and should not be an additional cost burden due to their disabilities.

**Finance and Payments Related**

* **Travel Insurance, Life Insurance…Home and Contents Insurance, Car Insurance…**

It needs to be clarified if participants are expected to increase their household contents insurance to cover the inclusion of NDIS provided items of assistive technology.  For example, adjustable beds, lift chairs, electric wheelchairs, hoists, shower chairs, etc, that are kept within the participant’s home. If a participant’s home were destroyed by fire or severe weather event, it needs to be clarified, in writing, if the NDIS proposes that they would immediately replace on as “as new” replacement value, all previously provided disability related items in a participants home.  If not specified, then the additional costs of increasing a participant’s household contents insurance to cover those items should be covered by the NDIS.  Similarly, clarification is required on whether the additional cost of insuring accessibility related car modifications is a cost which is covered by the NDIS, or a written guarantee provided that should a vehicle be written off, or rendered unusable for purpose, then the NDIS will immediately replace on as “as new” replacement value, which includes those necessary modifications, and in addition to the wheelchair that is likely to have been in the vehicle at the time of accident.

***Food and Beverage***

* ***Fast Food Services and Takeaway Food***
* Again, this cannot be black and white. If a participant is eligible for assistance with meal preparation in their NDIS plan, and they happen to live in a small rural town with only one pub in town with whom they have developed an agreement for them to provide a hot cooked meal, 7 days a week, is it not reasonable and necessary for the preparation and delivery component of that meal to be claimed?  Many rural and remote areas are precluded from the options of meal delivery services, and sometimes of even availability of local support workers to provide this service. Meals on Wheels and other options are not available to them. I believe an appropriate separation of the cost of such a service is reasonable for the meal preparation and delivery component (less the cost of ingredients) of this support.
* ***Lifestyle Related***
* Many of the items specified in this section may be a reasonable and necessary inclusion for people living with the challenges of some disabilities. Modified gaming consoles to enable usage by those with fine  motor or vision impairments, modified items of sporting equipment, musical instruments, sex toys and general play equipment may be very necessary and very much related to the needs created by some disabilities.
* ***Travel Related***
* Utilising the inclusion of cruises and holiday packages may, in fact, be the most accessible and economical available provision for the overnight accommodation, meals and activities component of many participants short term accommodation (STA).  If utilising these already packaged options and just adding the support worker costs is cheaper than the NDIS Pricing Arrangements rate, then why should these options not be made available?
* Choice and control can only exist outside of an external requirement that STA or Respite may only occur in a group setting. The underpinning goals of the NDIS was for individual participants to be working towards their own individual goals.  Such individualisation is hard to provide within the requirement of a group only setting.

***CARVE OUTS THAT MAY BE CONSIDERED “NDIS SUPPORTS” FOR CERTAIN PARTICIPANTS***

If a participant is only accessing a gym, community pool or recreational club to access services specifically related to their disability support needs (ie working with an exercise physiologist or a personal trainer), then surely the cost of membership or entry to such a facility should be considered as an ancillary cost to a funded support?

***Not Value for Money/Not Effective or Beneficial***

* ***Wellness and Coaching Related***
* General Massage, Life/Wellness/Career Coaches, and qualified therapists that utilise gaming within their engagement tools can very much be needed and necessary for many different types of disabilities.  One hour a week spent with a highly experienced life coach may, in fact, reduce the support worker need for many participants living with acquired brain injuries, executive functioning challenges and/or autism.
* ***Beauty Services Related***
* Hair and Beauty Services, including nail salons: These may, in fact, provide the most economical option for participants who are unable to maintain regular hairwashing and nail trims independently.  Mosts support workers and companies who provide support workers have a 2 hour minimum shift requirement.  This would mean that a participant who only requires nail trimming would be paying approximately $130-$140 for the support worker shift, versus $20-$40 for the same service provided in a nail salon, or $80-90 provided by a podiatrist (and they exclusively tend to feet).

***MAINSTREAM HEALTH***

* ***Non-prescription medicines***
* Non-prescription medications are often required by participants with direct correlation to their disability needs.  For example, a participant with a high level spinal cord injury and upper motor neuron bowel often requires the use of enemas and stool softeners, such as movicol, as part of their complex bowel regime. These are just one example of non-prescription medicines that directly correlate to a person’s disability needs. There are many more.
* ***Health Retreats***
* Again, I believe that an economical package of accommodation, meals and activities (plus support worker costs) should be able to be provided at a health retreat to cater to a participant’s goals around health and wellbeing, if it enables them to build capacity and develop coping strategies when dealing with the additional stresses that come from living with a disability.  This should be within their choice as an acceptable STA destination if it can be provided within the current NDIS price guidelines.

***CARVE OUTS THAT MAY BE CONSIDERED “NDIS SUPPORTS” FOR CERTAIN PARTICIPANTS***

**It is vital to ensure that if supports that fall under these categories are to be funded jointly with the States and Territories, that the provision of such services (or foundational supports) have already been agreed to and are in place within the mainstream systems.  NDIS should not be denying any participant a support under the justification that it can be provided by the health system or any other system, if, in fact, such a support is not easily or readily accessible.**

***MAINSTREAM MENTAL HEALTH***

Again, I believe that the NDIS  needs to decide and make it clear whether they are, or are not, including psychosocial supports under the umbrella of NDIS. If it is to be an included diagnosed disability then, like mainstream health supports, I believe that any exclusions can only take place when, and if, “alternative foundational supports” are in place, and readily available for people who live with these vastly life altering challenges.  If the foundational supports are not in place, and you are including psychosocial disabilities under the umbrella of the NDIS, then you must include full supports, as is provided for any other disability.

***MAINSTREAM CHILD PROTECTION AND FAMILY SUPPORTS***

If an NDIS participant is excluded from out of school hours care and vacation care programs due to their disability needs, then an allowance for support during these periods must be an allowed NDIS support.

Investing in family therapies, parenting programs, relationship counselling or other family supports is essential to enable parents and siblings to develop the coping strategies needed to maintain family units wherever possible.  It is a proven statistic that the separation/divorce rate of relationships that involve the additional care burden of having a child with a disability is much higher than the mean. ([*https://www.aihw.gov.au/getmedia/a792fd34-61db-4f62-91f8-9aa8e41f8207/cda.pdf.aspx%3Finline%3Dtrue*](https://www.google.com/url?q=https://www.aihw.gov.au/getmedia/a792fd34-61db-4f62-91f8-9aa8e41f8207/cda.pdf.aspx%253Finline%253Dtrue&sa=D&source=editors&ust=1723702835452231&usg=AOvVaw1RBNhf5WDlbEB_-gsFqE1p)*; page 43).*  The provision of such supports is particularly vital when minimal core supports are being provided under the guide of “parental responsibility”, when the actual care needs by far exceeds those of a typical developing child without a disability of the same age.  It is needed, for not only the psychological support needs of the parents and siblings, but also to contribute towards the safety of the participants themselves.

***MAINSTREAM EDUCATION***

As stated previously, if children are excluded from out of school hours care or, in fact, from mainstream education programs, due to their disability (behavioural) needs, then disability supports to enable the provision of homeschooling or early childhood education should be a reasonable provision to ensure every child’s right to an education is being upheld.

***MAINSTREAM EMPLOYMENT***

Once again, most supports on the “Not NDIS Supports” list are reliant upon substantial foundational supports provided by the states and territories already being in place.  It is imperative that such supports have had the time to be developed effectively and be fully operational prior to any existing NDIS funding being withdrawn from participants.

The same needs to be said with regard to the withdrawing of any existing supports with regards to any housing and community infrastructure. Likewise, mainstream transport exclusions, mainstream justice exclusion, mainstream aged care exclusions, etc