24 August 2024

To the Consultation Team – Consultation on draft lists of NDIS Supports

I would like to urge you to reconsider a number of aspects of the draft NDIS supports lists (and the entire concept itself). Whilst I understand you are trying to achieve clarity and simplify what is and is not an NDIS support, in reality, people and the impact of their disabilities are infinitely complex. This attempt will not only result in more confusion (there are lots of contradictions in the document as it stands) but misunderstandings and people being denied vital services that are reasonable, necessary, dignity-enhancing and wholly disability-related.

Below I will describe several situations from my own experience with participants on the scheme (some of whom have complex needs) where the lists fails absolutely to determine what is an appropriate support. Some will be things that have already occurred and others reflections on likely future situations where a participant’s life would be detrimentally impacted if the list stands as it is.

Whilst I realise that ensuring all supports purchased are reasonable and necessary is vital, **there is currently no good summary data available regarding inappropriate supports that have actually been purchased by NDIS participants**. To date, most purchases have not been identified in detail by the NDIS, thus it is impossible for the NDIA to know whether or not they have been appropriate. This decision has been left to participants using the criteria provided by the NDIS and I would suggest in most cases these principles have been applied absolutely appropriately. **Before making whole-scale and limiting black-and-white definition changes, it would be prudent to actually understand what is occurring. It is also essential not to penalise all participants if certain cases of inappropriate spending are found – rather the NDIS should invest in further education, support and guidance for participants involved.**

I would suggest that rather than bringing in an ‘In and Out’ support list that was prescriptive (as opposed to being a guide with principles), that you **request participants submit simple supporting documentation for say, purchases over a set amount (possibly $100?) that are from a non-disability-specific provider**. This would enable the NDIA to have oversight and **gain data about what is being purchased and whether it is reasonable and necessary in the context**. This information could be lodged via PACE against the relevant invoice. It should have free-form fields for a participant to explain why the support was reasonable and necessary in their unique situation. Participants could be required to keep this information as justification should they be audited etc. and could possibly be reviewed routinely as part of the plan review cycle. Innovative and unusual supports should not be wiped of the table just because they are not needed by the majority of participants (or because the writers of the list were unable to imagine how vitally important and appropriate they could be to some).

I have attached a check-list provided by ‘The Growing Space’ that assists participants to determine whether or not a proposed support is reasonable and necessary and thus should be funded by the NDIS. This list is based on the NDIS Guide to Self Management (which is in turn based on the current rules), an excellent document that sadly now includes many suggestions of innovative supports that would be banned under the proposed list. Please consult this for further elaboration.

**Now to a few personal examples:**

The first presents huge potential issues for a participant I know well and is also an area where the information contained in the list as it stands is contradictory. One of this participant’s key NDIS goals is to go on a short holiday. Holidays are a normal part of the Australian experience and should not be denied a person just because they have a disability.

For the participant in question to travel for a short holiday, the cheapest and most practical mode of transport is by air. She has very specific accommodation requirements and dietary needs which means she needs to stay somewhere where her support workers can prepare all her own meals (she is unable to eat at restaurants or to consume take-away food) and there is a bath to meet her hygiene requirements. This greatly limits her accommodation choices. She also needs full 24-hour support from a worker throughout the trip. Whilst away she hopes to make a few visits to attractions, including one that can be very busy. As she does not cope with waiting (a key aspect of her disability), she will need to purchase as special express pass to make this visit possible.

**In this scenario, it is absolutely appropriate for the participant to pay:**

* Her own airfares (this is a regular cost for going on holiday)
* Her share of accommodation
* Her own food
* Her own tickets to attractions

However, because the participant has a significant disability and cannot travel without extensive assistance, **the following should be covered by the NDIS to enable the participant to reach her goals and participate in the community on the same basis as any other Australian**:

* The support worker airfares (when does a business executive or politician travelling entirely for work need to pay for their own airfares)?
* The support worker hours of labour
* The support worker accommodation (again, accommodation is covered or a per diem paid for any work trip) – In this situation, the support worker is required to provide 24-hour care and needs to stay with the participant. The participant will thus need to book a 2-bedroom rather than a 1-bedroom apartment or unit. The participant should be able to claim the additional cost (the difference between the accommodation she could have used if travelling without support and that which is required to accommodate both herself and her worker) as this is a cost directly related to her disability and would not have been incurred otherwise.
* The support worker entrance fee to attractions (where these cannot be covered by a scheme such as a ‘Companion Card’ – fewer places accept Companion Card than you might expect)
* The extra amount required to purchase the participant’s ‘fast pass’ as this is only required because of adjustments needed due to her disability (difference between this and a standard entry ticket)

Without the NDIS providing funds for these supports, it would be impossible for the participant to travel.

**Here is the contradiction**:

On page 2 of the 2024-08-02-draft-ndis-support-lists it states that ‘Assistance with Travel/Transport Arrangements’ **is** an NDIS support at all times (this would include assistance whilst flying where essential) but then on page 12 (the pages do not actually have numbers, unfortunately) it states that airfares **are not** NDIS supports.

It is vital to clarify that airfares for the participant and their family (plus other travel-related costs for the participant that would also apply to a general member of the population) are not claimable, but **all additional costs related to disability support whilst travelling (airfares for support worker, support worker entrance tickets and accommodation etc.) should absolutely be claimable when they are essential for the participation of the participant.**

**Now examples of items or services listed in the OUT list but which may fully meet the NDIS reasonable and necessary criteria in some cases**:

* Business development costs/business skills development costs - when they form part of developing a microenterprise to provide unique, valued employment and community participation for the participant (but where the enterprise is not likely to be a real income for the person)
* Groceries - where they are purchased for a support worker who is required to cook/eat with the participant on excursions/respite (if they have no option to provide their own food) or to provide skill development sessions
* Mobile phone accessories – a tough cover for participant who regularly throws their phone when in meltdown
* Tickets to events when purchased for support worker to attend with client (many places do not offer companion card free entry)
* Menstrual products - where cycles are disturbed by disability-related factors and thus greater than usual quantities are required (participant should be able to claim the difference between standard usage and what is needed as a result of their disability)
* Trampolines - where they satisfy a disability-related movement need and that cannot be appropriately met in other ways (much cheaper and more socially appropriate than disability-specific alternatives). This should be prescribed officially by an OT etc.
* Smart watches – where they increase safety in the community, allow independent movement, and/or reduce the financial and psychological cost of care in the case of an incident occurring
* Holiday accommodation, airfares, meals and activities - costs relevant to accompanying support staff only (this would usually only directly apply to self-managing participants as these costs would be fully integrated in the quote for a total package service from a large provider – plus a lot more as extra 'overheads' would be added to make the organisation a profit)
* Tickets to theme parks etc. - only for support workers (not participants), except in the case where the participant requires a special access pass due to their disability (for example, is unable to wait in lines or cope with crowds). Here the difference between the standard cost and that of the special fast-pass should be a permissible claim (as per the example above).
* Hair washing at salon - where it maintains dignity and is the cheapest, most effective option for self-care - This is one we have seen personally when a participant was unable to tolerate the sensations of having their hair washed in the bath or shower for a period of time – for just $5 the local salon offered to provide a salon wash to help overcome these extreme sensory aversions and after a number of months the participant was again able to cope in the home environment. Without this support she would have faced scalp health issues, huge self-esteem issues and potential peer rejection etc. The service offered the added benefit of a regular outing into the community and opportunity to develop conversational skills with the hairdresser, both of value in and of themselves and part of the participant’s goals.
* Gaming therapy – not sure what is intended here, but it is vital not to exclude social programmes or evidence-informed therapeutic activities that are based around a gaming theme as this is a passion that connects many people with disabilities with their non-disabled peers and can open amazing doors for growth and connection
* Sleep consultant services – where severe sleep disruption is a key element of a person’s disability, this could be a carve-out in certain cases

Again, I would urge you to abandon the current proposed list of ‘In and Out’ supports and **instead instigate a process for participants to provide documented evidence around the choices they make and how they adhere to the vital principles of ‘reasonable and necessary’**.

At the very least, I would urge you to postpone bringing in any list until such time as you have actual data on what supports have been used by participants (and why) and thus what may be appropriate in special cases. In all situations, there must be a simple and quick mechanism for individual cases to be considered/approved and for any decision to be reviewable.

All Australians are trusted to complete their own tax returns, guided by information provided by the ATO. Whilst obviously at times people make errors, the system we have supports honest self-reporting and also investigates and prosecutes the limited number of cases of fraud that occur. On balance it works. People with disabilities must also be trusted to make appropriate decisions about what constitutes a reasonable and necessary support in their unique context, guided by principles and examples provided by the NDIS. Records should be kept to clearly link decisions to check-lists and audits can be randomly conducted. The intent of the NDIS includes treating people with disability with respect, allowing them self-determination and facilitating their ability to maintain dignity and participate with other Australians on an equal footing. Please do not destroy this world-leading system and replace it with an inflexible and hastily drafted ‘In and Out’ list.

Kind regards,

A concerned member of the community, mother to a participant and support worker for two participants

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