

Submission on

The Draft Lists of Permitted and Prohibited 'NDIS Supports'

The Self Manager Hub submits this report to the Department of Social Services (DSS), National Disability Insurance Agency (NDIA) raising our serious concerns about the proposed draft lists of permitted and prohibited NDIS Supports.

The Self Manager Hub is the leading national peer-led organisation promoting and supporting the practice of self-management and self-direction in the National Disability Insurance Scheme (NDIS). We support and lead more than 15,000 self managers through social media, online groups, training and advocacy.

The Self Manager Hub believes that self-management is an essential component of a successful NDIS. Self-management provides flexibility so that people with disability can identify and use their funding on the supports that best meet their disability needs. This in turn drives innovation within the sector, reduces vulnerability and promotes community inclusion. We believe people with disability should be able to take our rightful place included in our communities as active and valued citizens.

We are concerned that the draft list of permitted and prohibited NDIS Supports will significantly limit the flexibility, choice and control people with disability have over their support. We have concerns in particular with the blanket bans on some supports that people with disability legitimately use to address their disability support needs - often at far more cost effective price. We believe the list demonstrates a lack of knowledge about the lives of people with disability and the myriad of ways we seek to meet our disability support needs.

The lists are complex, confusing and at times contradictory. These lists are inaccessible to many people with disability.

The timeframe for consultation has been too short for fulsome involvement of our members.

We are also concerned about the inclusion of the mainstream interfaces in the prohibited list when there remains significant gaps in the availability and accessibility of these supports.

You didn't ask us!

It is clear the permitted and prohibited support lists were drawn up with minimal (if any) consultation with people with disability who self manage NDIS plans and with minimal understanding of how we use our NDIS funding in ingenious ways to address our disability related support needs in ways that include us in community, and often reduce costs.

These lists are ableist by their very nature. They have been constructed by non-disabled people deciding what they think should and should not be a disability support without lived experience or understanding. The inclusion of period products as a “lifestyle choice” is indicative of the quality of information considered. These lists are an insidious erosion of choice and control, will increase costs and lead to worse outcomes.

The approved list of supports

The approved list of supports are all the disability specific goods and services, provided by disability organisations. Whilst we accept disability support has an important role to play, we do not believe this should be the main focus of the approved disability support list.

Many of us do use these disability specific supports; however, too often we need to wrangle with disability support providers so they may provide support that is flexible enough to meet our needs, and so we may have choice and control over who, how and when our supports are delivered.

Often disability specific services are not based on the evidence of best practice supporting a person with disability. Instead they are based on traditions of congregating and segregating people with disability from mainstream community. These disability specific services frequently operate contrary to the UNCRPD and Disability Royal Commission recommendations to end segregation.

If the stated objective to reduce costs of NDIS were true, we should see less of a focus on disability specific services. Pricing of many disability specific services has seen a dramatic increase in benchmark cost since the launch of the NDIS. The benchmark cost for basic hour of a disability support worker has increased by 59% in a little over 10 years. With the collective lobbying power of disability specific providers we can only predict that this trend will continue.

In short, the focus on approved disability specific supports will stifle innovation, lead to more forced congregation and segregation, increased vulnerability and poorer outcomes for people with disability. And it will cost more.

The prohibited list

If you had asked us, we would have told you that many items on the banned list are examples of the cost effective and innovative ways people with disability are meeting their disability related support needs.

These are just some examples from self managers

*** In all examples names have been changed.**

Day to day living costs

Rent

Connor has developed an individualised living arrangement. Connor shares his home with a supportive housemate. Although Connor pays rent, his housemate receives a rent subsidy paid through Connor's NDIS plan. Connor's housemate provides a supportive role, prompting Connor and gentle reminders, assisting with meals and healthy eating, providing companionship and the "being there" support overnight. Connor is thriving both at home and in the community.*

With rent on the banned list, it is hard to fathom how such individualised living arrangements can be maintained.

Alternative home and living arrangements such as the SIL group home will undoubtedly cost more and result in poorer outcomes for Connor.

Furniture removal

Ella was evicted from her SIL group home when her needs changed and could no longer be supported by her provider. She returned to parents' home. Ella used her self managed funding for a removalist to bring her furniture to her parents' home as her reason for moving was directly related to her support needs.*

Ella could have used a support worker to pack up and transport her belongings but the removalist was half the price and more competent at furniture removal.

Not value for money/not effective or beneficial

Beauty Services related:

Amina has Down syndrome. She is able to manage her personal care needs independently however, despite many attempts at capacity building, she is unable to effectively wash her hair by*

herself. The NDIA will pay for two hours a week for a support worker to come to her house and join her in the shower to wash her hair. Instead Amina and her mother negotiated with the local hairdresser for a twice weekly hair wash. Amina can walk to the hair salon by herself, she is a regular at the salon and is building her community connections, she is less vulnerable having this need met in the community, and all for one third of the NDIS allocated price.

Luca is a man with physical disability and unable to cut his nails. He uses his NDIS funds at the local beauticians to have his nails cut. This cost a quarter of the cost of a support worker. He also attends the local barber for a shave as he is unable to undertake this grooming himself. Again the cost is significantly less than using a support worker who may or may not have the necessary skills required.*

Yoga therapy

Kamal attends yoga classes to build his physical skills and independence. He is funded for exercise physiology (EP). His EP liaises with his yoga teacher to help them ensure the yoga practice brings the most benefit to Kamal. He attends a mainstream community class twice a week, with a programme adapted to meet his disability needs. There has been exceptional improvement in Kamal's mobility and independence. He has not had a fall in several months. Previously he would fall almost every week. This support is cost effective, brings about good outcomes and is inclusive.*

Smart watch

Laurina has an intellectual disability. Previously she would require a support worker to accompany her when she was in the community. With intensive travel training and the use of a smart watch, Laurina can make her own way to familiar locations in the community. The smart watch enables her to contact her family to tell them she has arrived at her destination and let them know when she is leaving. The smart watch was paid for with NDIS funds and cost less than a day's cost for a support worker.*

These are just some examples of the ways people with disability have tailored their support to meet their disability needs. There are many, many more examples which are also on the prohibited list.

While we can see the government has made some concessions to the exclusion list, enabling a bureaucratic process to have some supports allowed in certain circumstances. However, we believe the problem is inherent in the lists and these new measures will do little to help.

People with disability know ourselves best and we know the best ways to address our disability needs. We need to be able to use our NDIS funds as creatively as possible. This does not mean we are asking for additional funding. We are just wanting the flexibility to use our NDIS funds to best meet our needs.

The Self Manager Hub recommendations

- Withdraw the draft list for Permitted and Prohibited 'NDIS Support'. The lists are complicated, confusing and contradictory in parts. They are also inaccessible to many participants and the timeframe for consultation has been too short for meaningful consultation.
- Reimplement the principles of "Reasonable and Necessary" (NDIS Act 2013) in the transitional Rules. Approved disability supports can be defined as:
 - Supports must be related to a person's disability
 - Must not include day-to-day living costs not related to your disability support needs eg groceries
 - Should represent value for money
 - Must be likely to be effective and work for the participant, and
 - Should take into account support given to you by other government services, your family, carers, networks, and the community
- A commitment to the full codesign of all legislative instruments associated with NDIS. this includes reasonable time periods for codesign and consultation and that information is accessible for all.
- Mainstream interfaces should be set out separately to the list of NDIS supports. Mainstream supports should only be excluded when the services are currently available and accessible to people with disability in their respective state or territory/

The Self Manager Hub would welcome the opportunity to work with the government in codesign of supports under the NDIS and welcome any opportunity for further discussion.

Kind regards,

Linda Hughes

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Representing the Self Manager Hub Board and membership.

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