





704/88-90 George Street
Hornsby, NSW 2077

 02 9869 0866 / 1800 620 588
 www.family-advocacy.com

NDIS Consultations Team
Department of Social Services
GPO Box 9820
Canberra ACT 2601

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Delivered by email to NDISConsultations@dss.gov.au

Dear NDIS Consultations Team

Consultation on draft list of NDIS supports

Family Advocacy welcomes the opportunity to provide a submission to the NDIS Provider and Worker Registration Taskforce. We are a not for profit disability advocacy organisation that works across New South Wales (NSW) to advance and protect the rights and interests of people with developmental disability. We have been providing individual and systemic advocacy, and family advocacy development for over 30 years.

Family Advocacy endorses the submission made by [People with Disability Australia](#) on 23 August 2024. Further to the concerns and suggestions raised in this submission, Family Advocacy wishes to make the following points.

We are deeply committed to ensuring the NDIS effectively meets the needs of people with disability. We also appreciate the significant challenge around the need to strike the right balance in doing so and keeping the NDIS scheme sustainable. The discussion paper states this draft list “is intended to provide greater certainty” which we acknowledge is necessary. However, we believe this prescriptive draft list of NDIS supports with an IN and OUT list philosophically contradicts the intent of the NDIS which includes empowering individuals, promoting independence, facilitating greater inclusion in community and employment, providing tailored support, and ensuring equity and access whilst encouraging innovation and improvement.

As we hear from families who have children with disability, they are the ones who often bear the brunt of the unintended consequences of what are seemingly sensible ideas for reform. People who self-manage and plan-manage their NDIS supports have been able to use funding in creative ways to tailor supports are particularly affected by these changes. This draft IN and OUT list threatens the survival of self-directed supports as there is a real danger it will stifle individualised, innovative and cost-effective solutions that support choice, control and social inclusion. Also, thin markets will become even more thin, especially in regional, rural and remote areas. This contradicts the principles of the United Nations Convention on the Rights of Persons with Disability (UNCRPD), which emphasises the rights of individuals with disabilities to live independently and participate fully in society.

Personalisation is essential, whereby a person with disability at first instance, has the opportunity to be able to present information about what their needs are and a decision

maker is not constrained by a black and white list. The 'river of grey' will always exist in between, a by-product of the fact that disability is multifactorial and intersectional and affects people differently. We have so many examples of exceptions to the OUT list we can share but here are just a few.

Hairdresser – a young man who grew hair quickly but could not shave himself visited the Barber 2 times per week, which was much cheaper than hiring a support worker and allowed the young man to be out in his community forging relationships. In the end, the young man gained part-time paid employment with the Barber.

Smart watch – we know kids who go wandering so this is important for tracking them. For adults with cognitive disability or who are not verbal, the smart watch allows for the falls risk alert, plus location if there is a fall, and as such allows for more independence and peace of mind to the family member.

Massage – a lady with lymphodema requires massage to keep control of her weight so that she can independently transfer to her car without a hoist and can then drive. IF she does not receive the massage, she cannot transfer independently.

Education – we know young adults who have left school who are still needing literacy support to improve independence, order off a menu themselves, follow street signs, know what time to catch public transport, shopping, writing birthday cards and reading birthday cards. Sometimes this involves purchasing workbooks.

Parenting programs – even a general course can be of such valuable assistance for families whose child's behaviour may be expressing they are unregulated and cause disruption in a household. This can be much cheaper in the long run to have avoided potential risks with health and house damage.

Groceries – in the case where a young adult with complex needs requires 24/7 care, his support workers teach him how to cook and they eat the same food they have prepared together with the intention of social normality, which is one of his NDIS goals. Ordinarily, the support worker would be paid for a meal allowance so in this case, one could argue the shared meal is due to the person's disability and as such the support workers meal ought to be paid for by the NDIS as it is part of the person with disability's support.

Nails – a person with disability uses false nails as a prosthetic in order to be able to type for work. Without the nails, they cannot type due to pain and therefore cannot work.

Rent – many families we know, as proposed under ILO as a stipend, offer reduced rent for a flatmate in exchange for overnight supports or occasional day supports. This ends up costing a lot less than having support workers overnight.

It is worth mentioning that giving a person the general sense they have been seen and recognised by the scheme and its assessors goes a long way towards their trust in the scheme more broadly.

At Family Advocacy, we advocate that "people keep people safe". By allowing flexibility in individualised funding choices, it allows for the creation of a network of informal supports, increasing capability to make decisions and raise concerns and being part of community - key preventative factors to address violence, abuse neglect and exploitation of people with disabilities. This draft list takes away flexibility and thereby threatens the safety for a person with disability.

We hold significant concerns about this draft list and the impact it will have on families,

particularly unpaid carers, who will be the ones forced to supplement deficient support funding with unpaid care work, forced to reduce or quit their employment and forgo financial independence to support their loved ones because supports will be reduced by this inflexible draft list of NDIS supports.

In addition, there will be no doubt be an increased paperwork burden on our families if the NDIS comes back with a no and you need to prove you need a certain support, or then have to apply for a review. Our current reading of the NDIS Bill is that you can challenge the OUT list but there are quite a few hoops to jump through. As far as we understand it, the NDIS CEO can approve supports from the OUT list and to the IN list for an individual but only if it replaces other NDIS supports and is the same cost or cheaper and is as good or better for you and you get approval by an as yet undetermined process. This certainly does not provide certainty. It is absolutely essential that there be a right of reply and that this process be accessible, streamlined and time sensitive.

We have witnessed the innovation and good life outcomes as a result of self-directed supports and the use of community-based supports, both formal and informal. Any such prescriptive list of NDIS supports needs to safeguard this approach as these practices often showcase excellent examples of genuine participation in the community of people with disability. There is a risk, if not thought through well, that these benefits of innovation and long-term cost savings will be lost.

Another concern we wish to raise is at face value, this NDIS Supports list appears short sighted and the consultation a rushed response. People with disability, their families and representative organisations have not been sufficiently involved in this process, and their input is crucial. The original 2 weeks and then 3 weeks to respond was an extremely unreasonable timeframe to respond. Working families of children with disability need more than 3 weeks to respond to such a comprehensive draft list. We note the Easy Read version was not available until days before this submission was due, which is unfair. In addition, advocacy organisations such as ours who are already experiencing “capacity crunch” given the swathe of policy reform in the sector, require adequate time to consult with our network of families, compile their responses and relay them back. A much more considered timeframe is needed for genuine consultation and co-design.

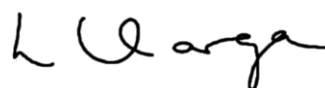
Further, throughout this process of NDIS reform, it is essential people are provided with increased access to individual advocacy to help navigate these changes, especially in regional and remote Australia where there is currently extremely limited access.

Working together with the disability community, we believe we can co-design and co-produce a pathway for the future of the NDIS that is person-centred and flexible that protects the fundamental human right of a person with disability to decide their supports, while improving the safety of people with disability and the sustainability of the scheme.

Yours Sincerely



Cecile Sullivan Elder
Executive Officer



Leanne Varga
Systemic Advocate and Campaigns Manager