

Submission on Draft Lists of NDIS Supports

23/08/2024



Introduction

The National and State/Territory Consumer Lived Experience Peaks are writing in response to the invitation to consult on draft lists identifying which supports will be defined as National Disability Insurance Scheme (NDIS) supports and which will be excluded from this definition. Our organisations are Peak bodies led by and representing the voices of people with lived experiences of mental health issues. We base our feedback on data recorded from the service provision streams of our constituent organisations, ongoing consultation with consumers of mental health services on joint priorities for an improved NDIS and mental health system in Australia, and consumer representation in relevant settings.

We are concerned that proposed changes to the definitions of NDIS supports will mean that the most vulnerable people in society will again be unable to receive the supports they need. We are disappointed that there is no evidence that mental health consumers were involved in decision-making around the development of these reforms to the NDIS. Due to the lack of time for meaningful consultation on the proposed changes, we are unable to answer the three questions put forward on the consultation website¹ and submit this document, with our recommendations, by way of providing feedback to this draft.

The National and State/Territory Consumer Lived Experience Peaks do not support introduction of this proposed transitional rule. However, if a transitional rule is to be implemented, it should not specify exclusions from NDIS. The list of exclusions significantly restricts flexibility, choice and control for NDIS participants, particularly participants with psychosocial disability.

Nevertheless, we make comment in this document on the inclusion and exclusion of certain supports in the draft lists which will affect NDIS participants with psychosocial disability if the transitional rule is passed into law. Our feedback on the lists is not exhaustive, and the brevity of our response compared to the in-depth discussion we would prefer to provide is a consequence of the limited time afforded to us to represent the views of our organisations and members, many of whom are NDIS participants.

¹ Australian Government Department of Social Services (2024). *Consultation on draft lists of NDIS supports – Discussion paper*. https://engage.dss.gov.au/consultation-on-draft-lists-of-ndis-supports/consultation-on-draft-lists-of-ndis-supports-discussion-paper/ (accessed 13/08/2024), p. 6.

Recommendations

1. Extend consultation to enable meaningful co-design.

The two-week window, even with the belated one-week extension, for consultation on changes that will impact thousands of Australians accessing needed supports through the NDIS is inadequate time for meaningful feedback. The easy read versions of the lists were published ten days after consultation opened, constraining participation of those who require easy read formats. The consultation does not reflect previous commitments made to co-design any changes to the NDIS, and does not adhere to the co-design approach principles, stated on the NDIS website, of being timely and inclusive:

"We will take the time needed to get changes right. We will transition to new arrangements in a careful and considered way over time. ...Reforms will be guided by good plans for implementation – developed in partnership with people with disability and the disability community."²

2. Ensure that "Reasonable and Necessary Supports" remain the fundamental core principle of the NDIS as per section 34 of the NDIS Act 2013 as an alternative to introducing restrictive lists of permitted and prohibited supports.

Funding arrangements should be informed by an understanding of participants' personal circumstances, and we are concerned that the proposed draft lists afford significantly less flexibility for funding plans to be tailored to personal circumstances than is currently the case.

3. If a transitional rule based upon these draft lists is to go ahead, remove the exclusions list (draft list of supports that are not NDIS supports) from the transitional rule to avoid further restricting flexibility, choice, and support options for participants.

Some supports that participants currently access through NDIS are, in these draft lists, no longer going to be considered NDIS supports. This will leave many participants unable to access the supports they need to participate in daily activities and to live socially connected, meaningful lives. Furthermore, having both an included and an excluded list with carve outs in both is confusing and

² NDIS. (2024). *Co-designing reform NDIS*. https://www.ndis.gov.au/community/making-ndis-stronger-together/co-designing-reform (accessed 13/08/2024)

against the stated aim of the lists in providing clarity to participants.³

4. Provide more information to explain what the lists cover, and delay implementation so that there is time to transition participants accessing supports to other providers and ensure full understanding of changes.

It is unclear whether the changes proposed in the draft lists apply to early intervention supports described under section 25 of the *NDIS Act 2013*. Information is not given about what might be offered under foundational supports and capacity building supports. It is because of these unknowns that people will fall through the cracks and not receive the supports they need. Participants require clear information about how this transitional rule is likely to impact existing NDIS-funded supports before the rule is implemented.

5. Map and communicate a clear pathway out of the transitional rule.

Transitional legislation is likely to be in effect for some time, as achieving agreement between States, Territories and Commonwealth will be a lengthy process. A clear timeline and implementation plan for co-design and development of the new rules, and exactly how long the transitional rule will be in effect, would ensure accountability to promises made about co-design of changes to NDIS legislation.

6. Consider and design the transition process between the NDIS and State/Territory Governments and private sector providers to prevent currently funded supports the lists propose excluding from funding from becoming inaccessible.

Some of the excluded supports may not be available outside of the NDIS because there is no agreement from the States and Territories that they will fund these items, and some services no longer exist in the States and Territories as they are now provided through the NDIS. A lack of clear responsibility to supply the services mentioned on the lists makes accountability of services difficult and has been identified in the Productivity Commission report as a major issue with mental health services.⁴ This confusion could result in consumers using their funds for services that are not

³ Australian Government Department of Social Services (2024). Consultation on draft lists of NDIS Supports Discussion Paper. https://engage.dss.gov.au/consultation-on-draft-lists-of-ndis-supports/consultation-on-draft-lists-of-ndis-supports-discussion-paper/, (accessed 13/08/2024) p. 4.

⁴ Productivity Commission (2020). *Mental Health, Report no. 95* (https://www.pc.gov.au/inquiries/completed/mental-health/report/mental-health-volume2.pdf (accessed 13/08/2024).

acceptable and then being chased for fund misuse.

7. Consider draft lists as an opportunity to include more needed supports for NDIS participants who would be otherwise unable to access them.

The most vulnerable in our communities find it difficult to afford top level hospital private health insurance premiums that help cover the items excluded from the NDIS such as private psychiatry, mental health clinical supports (acute, rehabilitation) and non-PBS medications. Services provided through mainstream pathways often cannot meet needs; for example, access to psychologists through Medicare covers only a partial subsidy for up to 10 sessions per year with a Mental Health Care Plan, but people with psychosocial disability often require additional support to cover gap fees and access support more frequently. The ongoing exclusion of these services from the NDIS will result in more people trying to access already over-capacity public mental health services and could result in consumers needing to access crisis care services.

8. Amend the draft lists to offer regional and remote participants in thin market areas flexibility to access supports if there are no providers of supports on the inclusion lists in their areas.

Regional, rural and remote participants experience difficulties accessing NDIS-funded supports essential to their plans as there are often few or no providers available in their communities. If there are no providers of supports listed in the inclusion lists in their areas, these participants should be afforded the flexibility in their funding plans to access other supports to assist them.

9. Amend the draft lists to avoid excluding possibilities for co-commissioning which would leave some NDIS participants unable to access supports.

Exclusions of certain mainstream services noted on this list rule out the possibility of cocommissioning of services, which will disproportionately impact those in the thin markets in rural and regional areas where support options are extremely limited.

10. Give clear details about what the person in need of supports must provide to gain approval for funding to access items classified as "carve outs that may be considered 'NDIS supports' for certain participants."

Information about what participants need to provide when seeking approval for these items would

ensure fairness in application of the transitional rule. If clear information is not provided, the matter of who can access needed supports will rest on how well the person/their advocate can produce evidence and ad hoc decision-making dependent on who assesses an individual's application. This leads to inconsistent and unequal provision of supports.

Feedback on List of Included Supports

Overall, a section on disability-related mental health supports could be useful in the list of inclusions to specify key supports relevant to those accessing NDIS with psychosocial disability.

Therapeutic Supports: Psychosocial recovery supports should be included here.

Details about how decisions are made about what is evidence based need to be provided: are these based on formal evaluations such as clinical efficacy, cost effectiveness, or more rudimentary decisions?

Specialised Support Coordination: Include explicit mention of inclusion of support from a psychosocial recovery navigator, as suggested in the final report of the NDIS Review.⁵

Participation in Community, Social and Civic Activities: Include cost of participation in the activity itself, otherwise many NDIS participants will be unable to afford the costs of participating in community and social life.

Assistance to Access and Maintain Employment or higher education: Remove the carve out excluding "work-specific support related to recruitment processes, work arrangements or the working environment," which would prevent participants from accessing support in interviews or negotiating accommodations in the workplace when that participant does not receive Disability Employment Services support. Such supports are necessary to assist participants to "successfully obtain and/or retain employment in the open or supported labour market" per the item's description. It is unclear what supports are funded here if supports related to recruitment, work arrangements and environment are carved out, especially where participants are unable to access Disability Employment Services.

⁵ NDIS Review (2023). *Psychosocial supports*. https://www.ndisreview.gov.au/resources/fact-sheet/psychosocial-supports (accessed 15/08/2024).

Feedback on List of Excluded Supports

Mainstream – Mental Health: More details about what supports are included in carve outs that may be considered NDIS supports under Mainstream mental health would offer clarity for participants accessing NDIS for psychosocial disability.

There is a need to specify whether it is the profession of the person providing the paid service, or the location in which they provide the service (i.e. medical offices) that renders a support clinical in "Supports related to mental health that are clinical in nature, including acute, ambulatory and continuing care, rehabilitation."

Carve outs should be specified for the following items:

- Support from a psychologist for people with psychosocial disability, as existing mainstream
 access options do not cover full fees, leaving individuals to pay a gap fee many cannot afford,
 and offer an insufficient number of subsidised sessions for many participants with
 psychosocial disability.
- Accessing non-clinical psychosocial support within a clinical environment. There are often
 group, peer, art therapy and other psychosocial recovery supports provided by non-clinical
 professionals that are offered through mental health clinics, facilities and residential
 environments that, if these are excluded from NDIS funding, will leave participants who
 cannot afford private access fees without access to these support options.
- Access to specialists, such as (but not limited to) Occupational Therapists and Speech
 Therapists, who may sometimes be working in a clinical environment or classed as having
 clinical expertise, but who provide psychosocial recovery support.
- Music and creative arts therapies, which can provide psychosocial support, and encourage community participation.⁶

Not value for money/not effective or beneficial: Include details about how decisions are made

⁶ Jensen A., and Bonde, L. (2018). The use of arts interventions for mental health and wellbeing in health settings. *Perspectives in Public Health*, *138*(4), 209-214, https://doi.org/10.1177/1757913918772602.

about what is and is not value for money or beneficial, and for which groups. Participants with psychosocial disability could be disproportionality impacted by exclusions on this list, especially if feedback from participants themselves and evidence about what best supports their needs has not been considered. Similarly, participants who are from Culturally and Linguistically Diverse backgrounds are already affected by the exclusion of culturally relevant therapies Western biomedical models do not class as "beneficial" from funding, and these additional restrictions are not in line with the Government's previous commitment to improve NDIS access for Culturally and Linguistically Diverse communities. Additionally, some supports have promising or emerging evidence bases that, if excluded now, may mean that supports found in the future to be beneficial are excluded.

This section of the list should be revised with consultation with diverse communities to form a stronger understanding about what supports NDIS participants find to be effective and beneficial. We note for the purposes of this constrained consultation several items that affect participants with psychosocial disability:

- Wellness and coaching related supports should not be excluded. We are particularly concerned that psychosocial recovery coaching could be excluded under this list. Excluding Life/wellness/career coach/cultural coaching removes access to key supports for NDIS participants with psychosocial disability. Excluding cultural coaching and wilderness therapy could result in fewer culturally appropriate supports for Aboriginal and/or Torres Strait Islander NDIS participants.
- Carve outs should be noted for participants with psychosocial disability to access meditation and yoga, given the benefits of these activities for mental health.⁸

Day-to-day living costs:

The following items should be removed from exclusion:

Sex work, sex toys and sexual aids, and access to sex therapists, educators and family

⁷ NDIA (2024). *Cultural and Linguistic Diversity (CALD) Strategy 2024-2028*. https://www.ndis.gov.au/about-us/strategies/cultural-and-linguistic-diversity-strategy.

⁸ Vancampfort et al. (2021). The efficacy of meditation-based mind-body interventions for mental disorders: A metareview of 17 meta-analyses of randomized controlled trials. *Journal of Psychiatric Research*, 134, 181-191, https://doi.org/10.1016/j.jpsychires.2020.12.048.

planners should be removed from exclusion and should be classed as funded supports. Supports for sexual expression functioning and relationship building are essential to the wellbeing of people with disability, who are a group whose sexual needs and expression are often stigmatised or denied. In 2020, the federal court upheld the right of a person with disability to use their NDIS funding to access a sex worker, and we oppose the reversal of this court decision. We support the statements and recommendations in the *Joint Statement: Ten Organisations Call for People with Disability's Access to NDIS Funded Sexuality Services to be Protected:*

"The exclusion of sexuality and sex work services from the NDIS would undermine the fundamental human rights and the choice, control and access of people with disability to essential supports that enable full participation in all aspects of life, including sexual expression, health, reproduction and relationships." ¹⁰

- Smart watches and phones can support independence and recovery for those experiencing anxiety, agoraphobia and other mental health challenges and should not be on the list of exclusions.
- Hair and personal care services, as these are essential to support participants with daily
 personal-care tasks or with participation in social and community life. Seeing a professional
 for these services is more cost-effective and more appropriate than engaging a support
 worker. If they are not removed, then carve outs should be specified.

Carve outs should be specified for the following items:

- Clothing and menstrual products, where participants with sensory issues need specific, specialised clothing or menstrual products as a part of daily living and personal care needs.
 Menstrual products should not be classed as "lifestyle" items, as they are essential to daily living for many people.
- Holidays, where they can be used to facilitate respite. Holiday options and accommodation

⁹ National Disability Insurance Agency v WRMF [2020] FCAFC 79 (2020).

https://www.judgments.fedcourt.gov.au/judgments/Judgments/fca/full/2020/2020fcafc0079 (accessed 23/08/2024).

10 Joint Statement: Ten Organisations Call for People with Disability's Access to NDIS Funded Sexuality Services to be
Protected (2024).

https://www.touchingbase.org/ndis-and-sex-work/joint-statement-ten-organisations-call-for-people-with-disabilitys-access-to-ndis-funded-sexuality-services-to-be-protected/ (accessed 21/08/2024).

can currently be used to provide respite for families/carers, in making possible the respite by providing a place participants want to go. The participant may not want to leave the house or have someone live with them whilst the family has the respite, and therefore a carve out needs to be specified.

Standard household items such as dishwashers, where they are required to support some
participants with daily living and personal care support needs resulting from their disability
or psychosocial disability. Funding these items is more cost-effective than engaging a support
worker to carry out tasks such as dishwashing.

Mainstream - Health:

Carve outs should be specified for the following items:

- Sleep consultant services for participants with psychosocial disability, given the cooccurrence of insomnia and mental health challenges of 40-50%.¹¹
- Non-clinical support for chronic pain for participants with psychosocial disability, because
 chronic pain and mental health challenges often co-occur, with a significant proportion of
 Australians experiencing mental health challenges also experiencing long term chronic
 pain.¹² Decline experienced in one of these areas can have adverse effects leading to decline
 in the other.
- Equipment or assistive technology prescribed as a result of clinical care, treatment or management from a medical practitioner delivered in the context of clinical care, where participants require these items on an ongoing basis after the episode of care.

Mainstream – Aged Care: A carve out is needed for psychosocial supports for people living in aged care facilities who access NDIS for psychosocial disability.

¹² Australian Institute of Health and Welfare (2024). *Physical health of people with mental illness*. https://www.aihw.gov.au/reports/mental-health/physical-health-of-people-with-mental-illness (accessed 21/08/2024).

¹¹ Fornaro, M., et al. (2024). Insomnia and related mental health conditions: Essential neurobiological underpinnings towards reduced polypharmacy utilization rates, *Sleep Medicine*, *113*, 198-214, https://doi.org/10.1016/j.sleep.2023.11.033.

Mainstream – Housing and Community Infrastructure: Carve outs should be included to enable participants in Specialist Disability Accommodation and Supported Independent Living arrangements to access appropriate crisis housing and short- or medium-term accommodation if they are evicted. There is a risk of participants having no choice but to sleep rough if they are not provided with this support.

Mainstream – Child Protection and Family Support: Family therapy, parenting programs, dating and relationship services, and marriage and relationship counselling should not be on the list of exclusions. Support options that enable people with psychosocial disability to participate in relationships, including romantic relationships, and to engage with their families, are an essential part of building capacity and providing support for social and community participation.¹³

Mainstream – Justice:

The following items should not be excluded from funding or should be specified in carve outs:

- Specific identified supports enabling access to NDIS funding immediately upon release, such
 as specialist support coordination and navigation, pre-sentencing psychiatric reports to
 support access to NDIS items upon release, and psychosocial recovery coaching. There is also
 a broader need for amended legislation to specify when a person is to be no longer labelled
 an 'offender.'
- Suitable short- or medium-term accommodation for NDIS participants who require specialist
 disability accommodation or supported independent living arrangements upon release from
 prison but for whom long-term accommodation has not yet been sourced. Without this
 support, participants are often released into homelessness.
- NDIS supports to meet the access and daily living needs of participants who are in custody
 awaiting decisions about trial, for instance, those individuals classed as mentally impaired
 accused being held in secure mental health facilities, who are otherwise denied not only
 their liberty, but access to items essential for their health and wellbeing.

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¹³ Meltzer, A. and Davy, L. (2019). Opportunities to enhance relational wellbeing through the National Disability Insurance Scheme: Implications from research on relationships and a content analysis of NDIS documentation. *Aust J Publ Admin*, *78*, 250–264, https://doi.org/10.1111/1467-8500.12373.

The National and State/Territory Consumer Lived Experience Peaks urge DSS to undertake authentic co-design engaging communities and NDIS participants who will be most impacted by proposed changes before any rules are put into place, transitional or otherwise.















