

23 August 2024

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

Delivered by email to NDISConsultations@dss.gov.au

Dear NDIS Consultations Team

Consultation on draft list of NDIS supports

PWDA appreciates the importance of commenting on the draft lists for the National Disability Insurance Scheme (NDIS) Supports related to section 10 to the *National Disability Insurance Scheme (Getting the NDIS Back on Track No. 1) Bill 2024* ('NDIS Amendment Bill').

People with Disability Australia (PWDA) is Australia's peak national cross-disability Disability Representative Organisation (DRO) and Disabled People's Organisation and is funded by the Australian Government to represent the 1 in 6 Australians with disability nationally. We want to stress the importance of people with disability having the key voice in this consultation.

Our community and organisation's position

PWDA is made up of, and led by, people with disability across Australia. Our Board are 100% people with disability with most of them also being NDIS participants. Both the PWDA Board and our national membership did not support the NDIS Amendment Bill, therefore we do not support the draft lists provided of NDIS supports that are the subject of this

consultation. In this response we outline the reasons why we do not support the draft lists and suggest alternative solutions.

"Taking away support especially when there are not suitable alternative options for support is setting disabled people up for poor life outcomes - poor wellbeing, increased poor health, increased risk of severe poverty and homelessness, increased risk of negative interaction with justice system, increased risk of suicide."

"I am so scared under this bill that I will be removed from NDIS. Without NDIS I will be dead. I cannot do anything physically by myself."

Alongside other national DROs, we expressed strong concerns about several aspects of the draft lists in a joint letter (see *Appendix B*) to Minister Shorten, including but not limited to the lack of engagement and consultation, the potentially significant impact on participants and how the draft lists will be implemented and reviewed.

In addition, we have strong concerns about participant access, the safety and inclusion of people with disability, how the proposed changes will impact choice and control, and how the proposed changes interact with other elements of the overarching framework the NDIS Amendment Bill will introduce.

There is little support for the draft lists in the disability community because of the potential implementation of the lists will reduce the safety and inclusion of people with disability and increase costs. Continued access to supports for people with disability is necessary and non-negotiable.

The Discussion Paper notes the draft lists "...[do] not change the types of supports that have always been appropriate to purchase with NDIS funding" (p.4). However, we are of the view that the drafts lists will not only change the types of supports that have been always appropriately funded through the NDIS but will also render an individual's whole circumstances irrelevant.

"It's ludicrous to not take a whole person approach. Every client needs to be well understood."

"You can't categorise people in groups if you are funding on a needs basis. You can't consider a disability in isolation from a person's health, supports, circumstances. Need a holistic approach."

A staggering 94% of our membership **believe** that the whole person, including all their conditions and impairments, the context and environment they are part of, and how all these interact, should be considered when accessing the NDIS. 88% of our members said if this did not occur, then it would make accessing supports harder.¹

Our reasons for our position

Placing disability supports on the line is enough reason to not support the draft lists. However, we note the following additional reasons why our Board and members do not support the draft lists:

1. The draft lists lack of clarity does not meet the needs of the disability community and will put people's lives at risk
2. The lack of clarity on how the proposed framework being introduced by the NDIS Amendment Bill will work, and how this will lead to confusion about what NDIS supports will be available and how the new rules will be used
3. Missing context and information in the draft lists make it unclear whether supports provided by the NDIS will consider the whole person and their needs holistically
4. We do not have detailed information on a low-barrier, timely or accessible exceptions and appeals process, especially when access to non-approved supports can be demonstrated to be value for money and reasonable and necessary
5. We have no information on the guardrails and safeguards to ensure people are not penalised, not subject to punitive measures, do not have unreviewed or

¹ People with Disability Australia, *NDIS Amendment Bill Consultation: July 2024 – Member Engagement Summary Report*, 31 July 2024, People with Disability Australia, Sydney, pp.12-13.

decontextualised debts raised, and are not forced to pay back debts when genuine mistakes are made and/or there are ambiguities in interpretations

6. The lack of a trial/pilot period to monitor and evaluate unintended and perverse consequences and outcomes created by the transitional arrangements, like the trial period at the start of the NDIS
7. The consultation on the draft lists has been inaccessible for many in the disability community, with the three-week timeframe and the late provision of Auslan and Easy English versions of the draft lists, being significant barriers to accessing and understanding the changes. The lack of accessibility directly impacts the community's ability to respond to this very important and potentially life impacting process. All people with disability should be afforded sufficient and equitable opportunity to have their say
8. The lack of information on how all the rules will work together and a lack of consideration of what might be missing, this includes a lack of understanding how transitional arrangements will work and how to prevent the legislation creating outcomes that do not disadvantage participants
9. Many non-approved supports currently identified in the draft lists promote the safety and community inclusion of people with disability and create natural safeguards
10. The lack of clarity on what supports will be available outside of the NDIS, most significantly the foundational supports that state and territories will provide
11. The current access to and the quality of supports are not the same across Australia, leading to national inconsistency in access and quality of non-NDIS supports
12. The lack of consideration for how the draft lists will impact access to supports for regional and remote areas, especially when limited providers have necessitated creative solutions being developed to meet the needs of participants

13. The lack of consideration for ensuring continuity of care, if supports are no longer provided by the NDIS and a person cannot access supports because of costs, and
14. Little information on how participants will transition to the new planning framework, including how changes will be communicated (noting many participants will not know changes are being proposed) and a clear timeframe for sequencing changes, especially finalising new rules.

What we would like to see instead of draft lists

In recent testimony provided by the National Disability Insurance Agency (NDIA) CEO to the Senate Community Affairs Legislation Committee on 6 August 2024, the CEO stated the following about the intention behind the lists:

“...we've done a terrible job, over the last decade, of being really clear with participants about what they can and cannot spend their budgets on. We've also been terrible in providing our staff with the right tools and the information to make really good decisions about 'reasonable and necessary’.”²

Our solution is for the lists to be replaced by clear guidance issued by the NDIA for each category of support in the draft lists and maintaining the current reasonable and necessary test for deciding on what supports the NDIS will provide. This solution has multiple benefits and improves:

- The quality of decision-making by providing robust advice to decision-makers on how they interpret correctly what is a reasonable and necessary support
- The NDIS participant experiences of NDIS planning and review processes, and
- The reduction of costs associated with resolving poor decision-making and seeking justice and recourse through the Administrative Review Tribunal.

² Commonwealth, *Public Hearing (6 August 2024)*, Senate Community Affairs Legislation Committee, <<https://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id%3A%22committees%2Fcommsen%2F28339%2F0000%22>> (accessed 14/8/2024)

In addition to releasing clear guidance, much needed focus needs to be placed on making sure the operational processes and tools used by those making decisions about NDIS supports, including Partners in Community, meet the needs of participants by:

- ensuring a robust and genuine co-design process with participants and other people with disability
- adopting a principles-based approach, and
- having the operational processes and tools made public and fully accessible.

Transparency of the communication and operational processes and tools used to implement clear guidelines will empower participants, supporters and individual advocates to apply and promote robust planning processes, reducing the need for reviews and appeals.

Adopting a principles-based approach can include the principles that already exist in the current NDIS legislation and should reflect precedents set by the Administrative Appeals Tribunal (AAT) and the Federal Court of Australia. To support this, we recommend a review of principles set by precedents in the AAT and Federal Court.

A principles-based approach will also better promote innovative and cost-effective solutions and supports that many participants have developed, to live their lives within their communities, while ensuring the quality and safety of those supports are maintained.

In line with the principles contained in the joint letter from national DROs to Minister Shorten on the consultation on the draft lists (see *Appendix B*), these principles include:

- Reasonable and necessary
- Be related to a person's disability
- Take into account what is provided by other government supports
- Represent value for money
- Do no harm
- Have clear exceptions process and reviews, and
- Promote inclusion in the community.

In addition, we propose the following additional principles:

1. **Participants must be better off overall:** Each decision should have an overall regard for improving the outcomes of the participant by ensuring participants are subject to a Better Off Overall Test (BOOT) in all decisions made about what supports they access through the NDIS
2. **All supports must support the realisation of the human rights of people with disability:** If it can be demonstrated a support promotes the realisation of a human right, as articulated in the *Convention on the Rights of Persons with Disabilities*, and the support and cannot be accessed elsewhere to the level of quality one could receive through the NDIS (due to location, thin markets, or other factor), then those supports should be provided.

Our expectations if draft lists are required

Despite our deep opposition to the NDIS Amendment Bill and the draft lists of NDIS supports, if the draft lists are implemented instead of our solution above, we strongly urge the following to occur:

1. **Introduce a pilot/trial period to support the robustness of transitional arrangements:** This would involve either delaying transitioning all NDIS participants onto the new planning framework and selecting a small number of low-risk participants for a pilot who can advise on necessary changes to the implementation of the transitional arrangements, including an interim buffer process to stop inappropriate and punitive penalisation of those who access NDIS supports in error.

Implementing a small-scale trial will ensure a more robust and effective transitional arrangements, as it will provide ample time for the disability community to manage expectations and fully understand the changes. In turn, this will support the development of a co-designed communication and education strategies for NDIA staff, participants and their supporters.

While we recognise that this will likely create operationalisation delays, taking this step will:

- Allow further and much needed scrutiny of the transitional arrangements, noting the subpar and inaccessible consultation on the draft lists
- Prevent unintended and perverse consequences and outcomes from implementing the transitional arrangements
- Allow for the promised and effective co-design of rules on key changes of the NDIS Amendment Bill (needs assessment and budget setting), and
- Begin conversations on what will constitute a foundational support with the states and territories.

During the trial period we also recommend and expect that people with disability and national DROs will co-produce an accessible low-barrier substitution/exception and appeals processes, which must be low-cost, timely and accessible to all.

The pilot/trial period is also a key opportunity to ensure the substitution/exception process works for people with disability. There needs to be significant consideration to ensure decision-making about what supports can be exempted is:

1. Clear and transparent
2. Sees a participant as a whole person, by considering their whole circumstances and their environment
3. Is timely and low-cost, and not involving impact-based reports/reporting processes, and
4. Has regards to any precedents set through the AAT and Federal Court, so supports that have been authorised in these forums should be exempted from the lists.

We note the NDIS Amendment Bill does incorporate a substitution/exception process,³ and that this process will need to be co-designed with people with disability, resulting in a time lag before an exception process is in place. There will be a period where the draft lists will be used without an exception process, and this needs to be accounted and planned for to prevent unintended consequences.

Therefore, this trial also supports the agency to create appropriate safeguards and/or additional guidance, ensures participants receive appropriate levels of support, and prevents unwarranted debt raising and/or punitive action taken against a participant while the exception process is being co-designed.

- 2. Co-produce a disability reform roadmap with the disability community and national DROs:** A co-produced roadmap will bring clarity to and improve the trust in Government to implement disability reforms. There are currently multiple vehicles of policy reform driving complex changes to the ecosystem of supports people with disability access to participate equally in society.

Government needs community buy-in for disability reforms and the disability community needs to trust proposed disability reforms go through robust consultations, and that there will be coordinated implementation. Unfortunately, to date this has not been the case, and it must be rectified.

“This bill will kill many people with disabilities and will have dire consequences for many more”.

“It’s hard to be a part of the solution, especially since you’ve been made to think you are the problem”.

"We need more transparency in decision-making processes so that participants can understand how decisions are made and ensure they are fair."

³ See Sheet SK188 revised, < https://www.aph.gov.au/Parliamentary_Business/Bills_Legislation/Bills_Search_Results/Result?bld=r7181> (accessed 22 August 2024)

Co-producing a roadmap is consistent with PWDA's **calls** to be equal partners in disability reform. The entirely inadequate consultation for the draft lists highlights the urgent need for the disability community and national DROs to be much more involved in consultation design.

"Disability supports must be co-designed and co-implemented with people with disability to ensure the system works."

"All decisions about disabled people should be made with our input. We are the experts about our needs and our lives."

"Codesign is vital at each step of decision making."

We recommend and expect the co-production of a disability reform roadmap will coordinate the implementation of, but not be limited to:

- The Government response to the Disability Royal Commission
- The forthcoming Government response to the NDIS Review
- The review of Australia's Disability Strategy, and
- The forthcoming Government response to the NDIS Provider and Worker Registration Taskforce.

Taking this very important step will provide sufficient opportunity for the disability community to consult people with disability on the complexity of proposed changes, provide considered and valuable feedback to Government on proposed changes, ensure feedback of people with disability is reflected in decisions made so changes meet the needs of people with disability, and finally communicate decisions in ways that are accessible for people with disability especially decisions that go against what the disability community advocated for.

3. **Ensure all existing supports and plans in the previous planning framework are honoured:** This is especially important for participants that are currently are accessing supports that are key to their safety, quality of life and inclusion in society.

Taking this step will also ensure that necessary and tailored communications will be developed and implemented with impacted participants, as there are participants that

are not fully aware and/or understand that changes to their supports are coming or how they will be impacted.

- 4. Rolling any participants to foundational supports must only occur when effective and available:** All participants should not lose access to key supports that 'may' be covered as part of foundational supports in their state or territory, prior to them being available, and are proven to be effective, equally accessible by all, and are of the same or higher quality than supports that would otherwise be accessed through the NDIS.

Developing consistency in the quality and access of foundational supports must be a priority during the transition, ensuring no-one is actively disadvantaged while these broader supports are designed, developed and implemented.

Through ensuring that NDIS participants have consistent access to flexible, effective and necessary supports, until there are equally accessible, effective and high-quality foundational supports will impact participants positively. Taking this approach reduces the pressure on foundational supports, and ensures people with disability who do not meet NDIS criteria have access to effective and high-quality foundational supports, ensuring all people with disability have access to supports they need.

- 5. All future consultations and processes must be accessible:** It is unacceptable that the accessible versions of the draft lists were not available until late in the consultation period. Having inaccessible consultations and processes results in entire cohorts being unable to engage with proposed changes, and the practice goes against the Department's own **Good Practice Guidelines for Engaging with People with Disability** and the Government's accessibility obligation under Article 9 of the *Convention on the Rights of Persons with Disabilities on the Rights of Persons with Disabilities*.

“For anyone with a history of trauma or abuse? This process is neither safe nor accessible.”

Our expectation of accessibility must be met, and we note that our expectation for a co-produced disability reform roadmap (see above) must also be considered as an

accessibility measure: having a clear path forward maximises the participation of people with disability.

Lastly, in response to the following questions posed in the Discussion Paper, we provide our feedback in *Appendix A*:

1. Do you think the draft list of NDIS Supports covers the kinds of disability supports you think should be included?
2. Are there goods or services on the draft exclusion list that you think shouldn't be there?

Thank you for the opportunity to provide this response. If you would like to discuss our submission, please contact my Senior Manager of Policy, Mx Giancarlo de Vera via email at giancarlod@pwd.org.au or on 0413 135 731.

Yours sincerely,



Megan Spindler-Smith
Acting Chief Executive Officer
People with Disability Australia

Appendix A

Supports that should be included	Supports that should not be excluded
<ul style="list-style-type: none">• Short-term accommodation• Respite	<ul style="list-style-type: none">• Sex work and sex toys• Menstrual products• Cosmetic treatments and wigs• Prescription glasses• Fast food services and takeaway food• Batteries, generators and electricity costs• Computer hardware• Smart phones and smart watches• Alternative and complementary therapies like acupuncture and deep tissue massage• Teaching aids or supports related to educational attainment• Specialised/adaptive clothing• Home modifications• Vehicles• Work-specific aids and equipment required to find and perform a job• Gardening and lawn mowing

Appendix B

19 August 2024

The Honourable Bill Shorten MP

Minister for the National Disability Insurance Scheme, Minister for Government Services
Parliament House
CANBERRA ACT 2600

By email: Bill.Shorten.MP@aph.gov.au

CC: Ms Rebecca Falkingham, Ms Corrie McKenzie, Ms Sarah Hawke

Dear Minister Shorten,

Joint letter from national Disability Representative Organisations on the Consultation on draft lists of NDIS Supports for NDIS Amendment (Getting the NDIS Back on Track No. 1) Bill 2024

The national Disability Representative Organisations (DROs) are writing to express our strong concerns about several aspects of the proposed NDIS Supports lists:

- Lack of engagement and consultation
- Impacts on people with disability
- Implementation and review

Primarily, we want to propose an alternative to these lists, which is to use a principles-based approach, that allows people with disability and their families to continue to utilise a range of innovative and cost-effective support solutions to live their lives in the community.

These principles can include those that already exist in the NDIS Legislation and have significant precedent within Administrative Appeal Tribunal and Federal Court decisions. These principles include individualised and whole-of-person decision making. These principles need to be codesigned by people with lived experience of disability.

We cannot support these proposed lists being in place, particularly without serious engagement with people with disability, families, supporters and kin. Our organisations believe these lists in their current form will cause significant harm to people with disability, and are completely out of step with the spirit and intent of the NDIS.

The key principles we believe must be included for NDIS supports are:⁴

- Reasonable and necessary
- Be related to a person's disability
- Take into account what is provided by other government supports

⁴ These principles are based on some of the existing rules: <https://www.ndis.gov.au/understanding/supports-funded-ndis/reasonable-and-necessary-supports>.

- Represent value for money

Additionally, any changes must:

- Do no harm
- Have clear exceptions process and reviews
- Promote inclusion in the community

When the NDIS Review final report was released, our organisations said that ‘continued access to support for people with disability is necessary and non-negotiable. Any changes to how support is provided, either inside or outside the Scheme, must not lead to any gaps in the support we receive.’ We restated this categorically when the NDIS Bill was first introduced.

The primary purpose of the lists is purportedly to provide clarity for participants, nominees, providers and the disability community and enable people with disability to make informed choices when selecting their supports. The Discussion Paper goes so far as to state the transitional rule “does not change the types of supports that have always been appropriate to purchase with NDIS funding.” This is misleading as these lists patently change the nature of supports and create inherent uncertainty in the way they are drafted.

The proposed NDIS Supports lists and carve outs are highly problematic, ill thought through and rely on outdated registration groups for providers, rather than what people with disability require or currently utilise. The drafting contains many contradictions, is extremely confusing and limit many supports that have been funded previously. It is also clear in many instances that there has been no consideration of the intersectional issues that impact the disability community, for example the intersection of disability with poverty, criminal justice, and child protection.

In particular, the proposed lists will have an inevitable and disproportionate effect on the ability of First Nations people with disability to effectively utilise the NDIS. Even under the current arrangements, it is already evident that First Nations persons are not accessing the NDIS at comparable rates and are not receiving the types of supports that they need, especially in rural and remote areas. If these rigid lists are implemented, First Nations people will be burdened with the need to fight even harder, just to be approved for basic supports that are clearly reasonable and necessary.

While there is a need for transitional rules to be put in place should the NDIS Bill pass, this is the wrong way to go about it. Instead, we need an approach that preserves the definitions of supports as currently understood - principles of existing reasonable and necessary supports - while the work takes place on building a clearer system.

Our concerns with the proposed lists include:

- Timeline of engagement
- Lack of accessibility
- Limited community inclusion and consultation
- Increased costs
- Decreased access to the community
- Lack of clarity about exceptions or clear review process
- Implementation within NDIA (National Disability Insurance Agency)

- Lack of connection with other reforms
Timeline for development of final NDIS Support rules

Lack of engagement and consultation

Timeline of engagement

The 13 days of public consultation on the lists of NDIS Supports is profoundly inadequate for something that will affect the lives of over 650,000 Australians with disability and their families. These changes will upend lives, work, school and much more and need much more careful co-design and co-production.

DROs have a range of views about the length of further consultation that these lists require. The vast majority of DROs hold the view that more time is required for meaningful consultation. The time needed varied from 4 to 12 weeks, with only one organisation suggesting no extra time is needed. Most organisations believe that much longer is required to properly examine what is proposed and ensure wide engagement with diverse communities.

Lack of accessibility

It is unacceptable that the NDIS Supports lists were not available in Easy Read or Auslan formats until 5 days before the consultation closing. This excludes a wide range of people with disability from having access to the information about what is proposed. This is contrary to Australia's Disability Strategy, the NDIS Act itself and the Convention on the Rights of Persons with Disability. Presenting information in accessible formats is necessary for all government consultations. The lack of accessible communications is particularly concerning for this consultation that has major implications for communities who require not only accessible formats, but also support and time to understand the complexities of the proposed transitional rule.

Limited community inclusion and consultation

DROs have not been able to have meaningful consultation with our communities about these lists, and what they may mean for people with disability and their families due to the timeframe and lack of accessibility. For those who have had short consultations with members or their communities, feedback has been fiercely opposed to these lists, angry about not being able to properly engage, and concern about the implications.

Impacts on people with disability

Increased costs

Many of the supports listed will increase the costs of the NDIS. These include the removal of mainstream supports that people with disability and families use that are often much more cost effective than disability specific supports. People with disability have used NDIS funds in a variety of innovative ways to stretch their budgets further. These lists remove and undermine that innovation, and revert to expensive, disability only support types.

Decreased access to the community

In parallel with the increased costs, the rising use of support workers will decrease community access and inclusion. If only disability specific supports are allowed, people with disability may be forced further into segregated settings. Impacts around segregation and lack of inclusion in the community are likely to disproportionately impact communities already facing challenges to accessing supports, such as those living in regional, rural and remote communities.

Lack of clarity about exceptions or clear review process

We have grave concerns about the lack of detail or clarity about exceptions or clear review process for any NDIS Supports or carve outs that need to be changed. It is unacceptable not to have review and exceptions policy detail available for DROs and people with disability to provide feedback on.

We note that there is currently a Government amendment in the Senate that would allow people to apply for an exemption to the definition where another support would be cheaper. This is not enough; it will put a heavy onus on people with disability in an already complex scheme, and will not fix these fundamentally flawed lists.

Implementation and review

Implementation within NDIA (National Disability Insurance Agency)

DROs are very concerned about how these lists will be implemented by the NDIA, which currently is experiencing significant delays across the organisation. Access, plans and reviews are all taking months, which is causing heartache and harm for people with disability and families. We do not see how adding such harsh lists will be of any assistance to the current crisis in the Agency. The implementation of the transitional rule would need to be scaffolded by both significant training for staff about its application when resourcing is already a major challenge for the Agency.

Lack of connection with other reforms

The NDIS Review, the Disability Royal Commission, the review of Australia's Disability Strategy and the Registration Taskforce have all proposed a wide range of changes to policy and practice for people with disability and their families. Many of the proposals in these NDIS Support lists are contrary to the recommendations of other reforms. It is also problematic that the timelines for all these reforms, particularly Foundational Supports, are unclear and plans for consultation have not been communicated transparently to people with disability and their representative organisations.

Timeline for development of NDIS Supports final rules

We are strongly concerned that these NDIS Supports lists will be in place for an extended period of time, despite being not fit for purpose. DROs want to see a deadline for the

delivery of the co-designed and co-produced final rules for NDIS Supports, such as six months from the passing of the legislation.

Our key asks

Based on the concerns noted above, we strongly urge the Government to:

1. Adopt a principles-based approach: The proposed lists will have a negative impact on people with disability. A principle-based approach will allow people with disability and their families to continue using innovative and cost-effective solutions to live their lives within their communities.
2. Provide an extension for consultation: People with disability and DROs need time to meaningfully engage with their members and communities, and to fully examine the extent of both benefits and risks of the lists. The list needs the expertise of people with disability at the forefront and centre of their development and implementation.
3. Provide clarity and assurances on exceptions and reviewable decisions: Policies pertaining to exceptions and reviewable decisions must both be firstly developed in consultation with people with disability, and secondly made available in accessible formats. While we oppose the lists, ensuring people with disability can contest decisions will be crucial if the lists are implemented.

Signed by:

- Australian Autism Alliance
- Australian Federation of Disability Organisations
- Children and Young People with Disability Australia
- Community Mental Health Australia
- Disability Advocacy Network Australia
- Down Syndrome Australia
- First Peoples Disability Network Australia
- Inclusion Australia
- National Ethnic Disability Alliance
- People with Disability Australia
- Physical Disability Australia
- Women With Disabilities Australia
- Every Australian Counts
- Deafness Forum Australia
- Autism Aspergers Advocacy Australia
- National Mental Health Consumer and Carer Forum