

22 August 2024

NDIS Consultations

GPO Box 9820, Canberra ACT 2601

By email - NDISConsultations@dss.gov.au

Dear NDIS Consultations team,

Amaze submission to consultation on draft lists of NDIS Supports

Amaze works to build acceptance and understanding of autism in communities, educational settings, organisations and businesses, and wider society. Informed by evidence, experts and lived experience, we influence policy change for Autistic people and provide independent, credible information and resources to individuals, families, professionals, government, and the wider community. We are closely connected with the community through our national Autism Connect helpline, peer support networks and capacity building initiatives.

We are concerned that the legislative framework proposed under section 10 of the *NDIS Amendment (Getting the NDIS Back on Track No. 1) Bill* ("NDIS Amendment Bill"), and draft NDIS Supports lists ("draft lists") grossly fails to balance the interests of clarifying NDIS Supports with the priorities of ensuring participants can access flexible, individualized, whole of person and cost-effective supports. In particular, we are concerned that the draft lists provide a prescriptive list of eligible and ineligible supports with little flexibility to meet the individual goals and support needs of participants, or empower participants to choose more cost-effective solutions. We are also very concerned about your lack of co-design, or at the very least meaningful consultation to ensure NDIS reforms and these drafts lists meet the needs of all stakeholders, including Autistic people and their families and carers. We recommend:

1. Review and strengthen section 10 of the NDIS Amendment Bill to include principles for NDIS Supports and/or parameters for NDIS Supports rules.
2. If NDIS Supports lists are to be adopted, review and amend the draft lists to:
 - enable an individualized, whole of person and flexible approach to be taken to determining NDIS supports.
 - ensure participants can access funding for day to day, and capacity building costs that relate (instead of "solely and directly relate") to their disability support needs.
 - provide flexibility for participants to access the day to day living assistance, and capacity building supports they need "to achieve their goals" (replacing "to live as autonomously as possible" throughout the list).
 - enable participants to purchase cost-effective mainstream (rather than specialised) products and services, where they have been deemed safe and equally capable of meeting a participant's support needs.
 - address the aspects of the lists requiring review identified in Appendix 1 to this submission, including exclusions relating to disability specific childcare services, sleep consultants, eating disorders treatments and school refusal.
3. As an addendum to the draft lists, provide a table identifying who (another funding system, employers, participants etc.) is responsible for supports that are not NDIS supports.
4. Table a Co-design Framework with the NDIS Amendment Bill to apply to the design and implementation of all law and policy relevant to NDIS reform. And, or at the very least, undertake further consultation on the draft lists that is accessible and ensures all people with disability can help shape this significant area of NDIS reform.

1. Review and strengthen section 10 of the NDIS Amendment Bill to include principles for NDIS Supports and/or parameters for NDIS Supports rules.

We have numerous concerns about the proposed legislative approach to defining NDIS Supports under section 10 of the NDIS Amendment Bill. The Bill currently requires that the Minister declare (in NDIS rules) which supports are NDIS supports, with few parameters or principles around the types of supports that may be declared. It then states that the Minister 'may' also declare supports that are not NDIS supports but provides little parameters or principles around this decision or the types of supports that may be excluded.

We are concerned that this legislative framework will lead to decision making that lacks flexibility and the individualised approach required for meeting the diverse and complex support needs of NDIS participants. We are also concerned that the legislative framework, driving a list of supports that are NDIS Supports and a list that are not NDIS Supports, risks a gap in the middle or the failure to include certain supports in either list, with no guidance around how those missing supports should be considered on the request of participants (or processes for then including them on the lists where appropriate).

For example, the types of sensory tools that may be funded as NDIS Supports remain unclear as these are not adequately captured in either of the draft lists. In particular, while some specialized sensory equipment may be funded under Assistive Technology, the scope of this equipment is not clear. Furthermore, all mainstream equipment appears to be excluded. Does this include products such as noise cancelling headphones which can be essential to community participation for some Autistic participants and have been funded to date? The lack of clarity regarding sensory tools is particularly concerning given they have long been a grey area, with significant confusion and fear across the community regarding the types of tools that may be funded, and inconsistent advice from planners and LACs. Binary and prescriptive NDIS Support lists should not be permitted to create further uncertainty for participants, or contribute to the fear that claimed items will have to be repaid or that self-management rights will be taken away.

We recommend that urgent action be taken to review the proposed legislative framework and amend section 10 to take a principals-based approach to determining NDIS Supports. These principles should include that NDIS supports are reasonable and necessary, related to a person's disability, cost-effective, individualised and whole of person focused, and lived experience and evidence informed. They should also accord with the Convention on the Rights of People with Disability, do no harm, promote inclusion, take into account other funding systems and responsibilities for funding, and have clear processes in place for seeking exemptions and reviews of decisions to exclude supports from a participant's NDIS Supports.

If the current framework is to remain, whereby the Minister is granted powers to make rules/lists under section 10 of the Bill, this section must be amended to identify clear parameters for NDIS Supports rules/lists and associated decision making. These should mirror the type of principles identified above. It is well recognized that best practice requires clear legislative parameters and oversight of subordinate legislation or rules to ensure they serve their intended purpose without compromising the objectives of the Act or other legal or ethical boundaries. Parameters are also vital to ensuring accountability, clarity and transparency by making clear to all stakeholders the types of rules that can be created and holding Ministers responsible for how they exercise their powers.

Recommendation.

- Urgent action to amend Section 10 of the Act to incorporate guiding principles and/or parameters for Rules regarding NDIS Supports.

2. Reshape the draft lists to balance clarity with a flexible, individualized, whole of person and cost-effective approach.

While we do not support the legislative approach proposed, the following advice and recommendations apply if NDIS Supports lists are to be utilised going forward.

We understand the draft lists subject to this consultation are only intended to apply during the transition phase, however in this time they will significantly impact the lives of participants and it is unclear how long they will remain effective. These lists are also likely set a precedent and influence the content and approach to designing and implementing lists going forward.

In this transition period, the lists should not leave participants worse off than they are under the current approach. Effectively shifting aspects of the Applied Principles and Tables of Support (APTOS) from policy into rules, the need for these lists to reflect the objectives of the Act and the extensive findings of the Federal Court and Administrative Review Tribunal regarding the scope of NDIS Supports, cannot be lost. Most importantly, the lists must meet the needs of participants to access funding for costs related to their disability (that are not covered by other funding systems) and meet their individual goals.

In Appendix 1 to this submission, we provide line by line comments against your draft lists to identify aspects of the lists that require reconsideration, clarity or improved flexibility. Among other matters, these comments relate to the need for:

(a) Flexibility

The lists currently lack the workable flexibilities or carve outs needed to enable individualized and whole of person decision making regarding NDIS Supports for participants. For example, the list of “Supports that are not NDIS Supports” currently states that additional living costs may be funded if incurred by a participant “solely and directly as a result of their disability support needs”. This mirrors the current approach in the NDIS Supports for Participants Rules (s.5.2). However, this high bar has been near impossible for participants to meet as there will inevitably be some other minor considerations in accessing living costs and it is difficult for participants to evidence that their support need is solely and directly as a result of their disability. Participants should be able to access flexible supports that relate to their individualized disability support needs and will not otherwise be met by other governments and/or funding systems.

The draft lists of NDIS Supports also fail to recognise that the goals of participants can vary and be influenced by the complexity of their support needs. While independence may be the leading goal for many participants, some participants may be seeking 24/7 and/or 2:1 supports to achieve the goals of remaining safe at home and in their community. For example, the lists state that day to day living assistance and other capacity building costs can be funded to support participants to “live as autonomously as possible”. Does the scope of “live as autonomously as possible” include supports to achieve goals that relate to being safe, participating in the community, building social skills, exercising self-advocacy and self-determination, and improving quality of life? The Rules should not seek to define a participant’s goals, but rather ensure participants can access the supports required to achieve their own self-determined goals.

Recommendation.

- The lists enable an individualized, whole of person and flexible approach to be taken to the types of supports that may be funded or excluded, including by ensuring participants can access funding for day to day and capacity building costs that relate (instead of “solely and directly relate”) to their disability support needs, and will not otherwise be met by other governments and/or funding systems.
- The lists provide flexibility for participants to access the day to day living assistance, and other capacity building supports they need “to achieve their goals” (replacing “to live as autonomously as possible” throughout the list).

(b) Cost-effectiveness

The draft lists generally declare specialised products and services to be NDIS Supports and exclude mainstream products and services. We are concerned that this shift will increase costs for participants and the NDIS by requiring participants to buy more expensive, specialised products and services where their support needs may have been equally met by safe or low risk mainstream options. We are also concerned that this approach will impact choice and control for participants, who will feel they have to access specialised services over mainstream community options, potentially impacting their community inclusion.

We understand that on Monday, 12 August, the government proposed an amendment to the NDIS Amendment Bill to allow participants to access excluded NDIS Supports if they would replace one or more NDIS funded supports for that participant, at the same or reduced costs of the supports being replaced, with the same or better outcomes. Alone, this measure is inadequate and will place a large burden on participants. It will not be enough for a participant to show that an otherwise excluded support will be cost-effective and meet their support needs, they will also need to show that it replaces other NDIS supports.

A sustainable and cost-effective scheme benefits everyone, including government and people with disability. Flexibility and cost-effectiveness is clearly needed to ensure participants are not required to waste valuable funds on specialised products and services where adequate and more cost-effective mainstream products and services are available.

Recommendation:

- The lists enable participants to purchase cost-effective mainstream products and services, rather than specialised products and services, where they have been deemed safe and equally capable of meeting a participant's support needs.

(c) Understanding and meeting disability related support needs

We are concerned that the inclusion of some of the supports on the list of "Supports that are not NDIS Supports" shows a misunderstanding of how these supports can relate to a participant's disability and require a disability specific approach.

For example, in Appendix 1 we highlight evidence that sleep difficulties are a very common co-occurring condition experienced by Autistic children. They can result in challenges and stress that impact various aspects of a child's life, and the lives of family members. These challenges can clearly relate to a participant's disability and require targeted sleep consultant services (currently excluded in the draft lists) delivered by consultants knowledgeable in the specific sleep support needs of Autistic children. Similarly, eating disorders such as anorexia and Avoidant Restrictive Food Intake Disorder (ARFID) commonly co-occur with autism, often requiring neuro-affirming autism specific supports by skilled practitioners (that can differ significantly to generalised eating disorder treatments). School refusal is also often related to a student's neurodivergence and can require comprehensive disability specific and/or 1:1 approaches (outside of those supported by state governments) to reduce the risk of disengagement, re-engage a student in schooling or support a student unable to return to school.

In Appendix 1 we also highlight the need to provide more clarity regarding the types of disability specific childcare service fees that will be excluded from NDIS Supports, to ensure early intervention groups are not captured, and to ensure students are adequately supported in out of hours care.

Recommendation.

- Address the aspects of the draft lists requiring reconsideration, clarity or improved flexibility identified in Appendix 1 to this submission, including exclusions relating to disability specific childcare services, sleep consultants, eating disorders treatments and school refusal.

(d) Clarity regarding responsibilities and obligations for funding excluded supports.

It has been difficult for us and our community to provide feedback on the draft lists in the absence of clearer guidance regarding whether other funding systems or participants are/will be responsible for meeting the costs of excluded supports. For example, the NDIS Supports lists fails to identify any tertiary education supports that would be funded by the NDIS, only providing an extensive list of excluded supports. Considerable essential employment supports are also excluded. It is difficult to comment on the appropriateness of these exclusions without greater clarity regarding mutual understandings of funding obligations between universities, governments and other stakeholders, particularly given we have heard from many community members who have been unable to access some of the excluded supports, including from their tertiary education provider or employer.

Further and significant clarification will also be required on the introduction of Foundational Supports to ensure a clear understanding of which supports (in the next iteration of the NDIS Supports lists, if proceeding) fall within the realm of Foundational Supports, which supports are to be funded by other governments and/or funding systems, and which supports will fall to the individual. A failure to ensure mutual understandings will inevitably lead to harmful gaps in support and again make it difficult for the community to comment on the appropriateness of draft NDIS support lists going forward.

Accordingly, as an addendum to the draft lists, we would recommend that a table be provided identifying who (another funding system, employers, participants etc.) is responsible for supports that are not NDIS Supports. Where it is identified that participants are responsible for costs, the table should identify why (i.e. not lived experience or evidence informed, risk/safety concerns, family responsibility, age etc.). This approach would provide clarity regarding funding obligations for governments and the community and promote transparency and accountability. It would also support participants to challenge exclusions on the lists or seek review of decisions to deny them requested supports.

Recommendations.

- As an addendum to the draft lists, provide a table identifying who (another funding system, employers, participants etc.) is responsible for supports that are not NDIS supports.

3. Co-design, or at the very least further community engagement should be prioritized.

The short timeframes and inaccessibility of this consultation have significantly compromised the opportunity for these important reforms to be informed by people with disability, their families and carers, and the disability sector. On Friday, 9 August we [wrote to Minister Shorten and DSS](#) to raise our concerns about the short timeframe (Sunday 4 August to Sunday 18 August) and the consultation's inaccessibility for many people with disability. It is unacceptable that the draft NDIS Support lists were only made available in Easy English via the consultation website on Tuesday 13 August – 5 days before the consultation was initially scheduled to close.

While we were pleased the consultation was extended by another week, to close Sunday 25 August, this time period still remains too short for meaningful consultation on reforms with this level impact for our community. A further three weeks should be provided, consistent with best practice outlined in the Office of Impact Analysis' 'Best Practice consultation' guide for policymakers'. Within this time, the Easy Read, Auslan, and multiple language translation versions of the Discussion Paper and draft lists should be widely promoted.

It also remains unacceptable that the only way of engaging in this consultation remains in writing. An accessible process, capable of reaching people with a diversity of lived experience should include multiple options for participation, such as via focus groups, interviews, webinars and targeted approaches to engage hard to reach and vulnerable cohorts. As discussed above, to help inform feedback clarification is also required regarding funding responsibilities and obligations for supports that are not NDIS supports.

Even meaningful consultation is grossly inadequate for reforms of this nature. As outlined in our [submission to the NDIS Amendment Bill consultation](#), the design and implementation of reforms that will significantly and directly impact the lives of NDIS participants should be undertaken in co-design with them, as well as their families/carers and sector organisations. Urgent steps should be taken to table a comprehensive co-design framework with the NDIS Amendment Bill. Consistent with best practice, the Co-design Framework should be developed with a diversity of stakeholders, promote mutual understanding and ensure the co-design process is accessible, respectful, equitable, accountable and transparent.

Recommendations.

- Table a Co-design Framework with the NDIS Amendment Bill to apply to the design and implementation of all law and policy relevant to NDIS reform.

And/or

- At the very least, supported by further clarification regarding funding roles and responsibilities, undertake further consultation on the draft lists to ensure people with disability are able to help shape this significant area of NDIS reform. Further consultation should include more time to respond to the consultation survey, wide promotion of the Easy Read, Auslan, and language translation versions of the Discussion Paper and draft lists, and multiple options for engaging (such as focus groups, interviews, webinars, and targeted approaches to engage hard to reach and vulnerable groups).

Please contact me by email at david.tonge@amaze.org.au or by phone on [03 9657 1600](tel:0396571600) if we can assist by providing further information or answering any questions you may have.

Yours sincerely,



David Tonge
Acting Chief Executive Officer