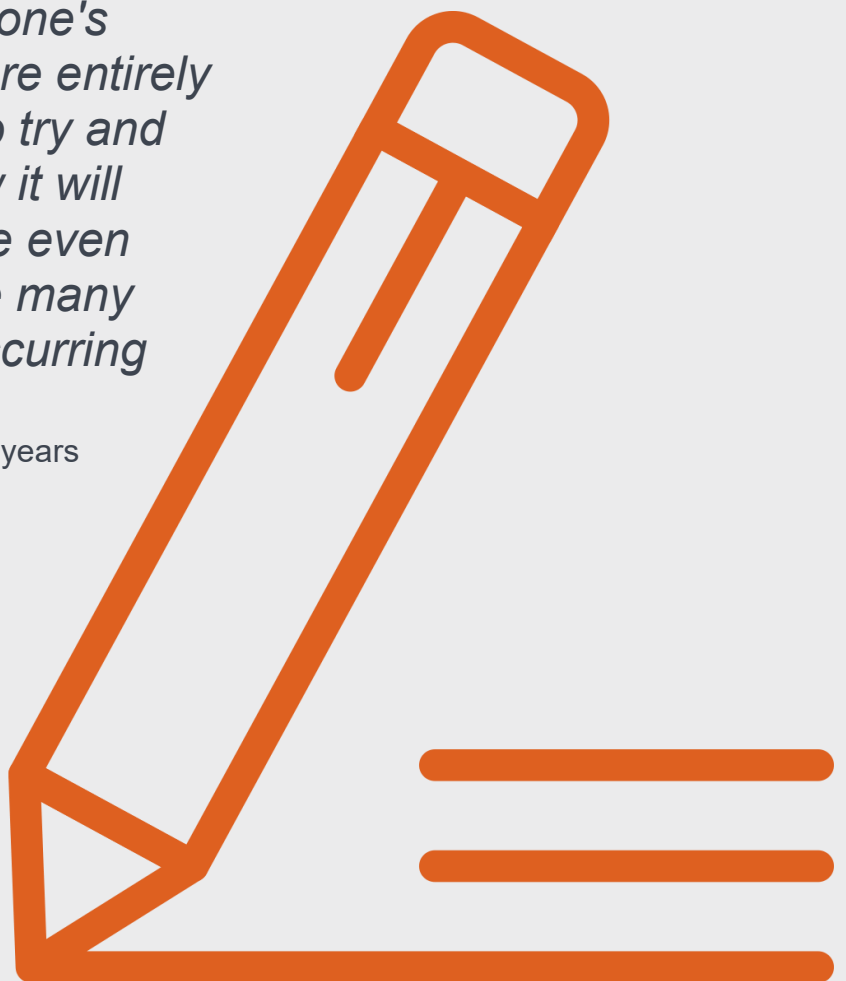


**CYDA's response to the National
Disability Insurance Scheme
Amendment (Getting the NDIS Back on
Track No. 1) Bill 2024
*Consultation on draft lists of NDIS
Supports.***

"NDIS supports should not be defined by a list - everyone's disabilities and needs are entirely unique, it is madness to try and force a list. We all know it will make all participants life even harder and there will be many more funding battles occurring for basic rights".

Young person with disability, 16-25 years

August 2024



Children and Young People
with Disability Australia



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A note on terminology:

Term being used. E.g. Children and young people with disability

The disability community has largely recognised and used inclusive language and terminology for decades. Children and Young People with Disability Australia (CYDA) uses person-first language, e.g., person with disability. However, CYDA recognises many people with disability choose to use identity-first language, e.g., disabled person.

Acknowledgements:

Children and Young People with Disability Australia would like to acknowledge the traditional custodians of the lands on which this report has been written, reviewed and produced, whose cultures and customs have nurtured and continue to nurture this land since the Dreamtime. We pay our respects to their Elders past, present and future. This is, was, and always will be Aboriginal land.



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Recommendations

As the representative organisation for children and young people with disability across Australia, CYDA welcomes the opportunity to make a submission to the consultation on the draft lists of NDIS supports. Children and young people under 25 make up a significant, 60% of all NDIS participants, forming the majority of those supported by the Scheme¹. Yet they continue to face significant marginalisation due to age-related factors, legal constraints and limited agency. Insights from the CYDA community highlight the urgency for the provision of quality NDIS supports that are specifically aligned to their needs. We strongly urge the Government to reconsider their fixed approach to listed supports and instead adopt the seven recommendations outlined in this submission.

Recommendation 1: Extend the time for consultation on the draft list of supports to allow meaningful engagement with children and young people with disability and their families

After intensive lobbying by Disability Representative Organisations' (DROs), CYDA acknowledges the government's one week extension of the consultation period to 25th August. However, this is not sufficient. The consultation on the draft list of supports requires the expertise of people with disability, including children and young people at the forefront and centre of their development and implementation to allow time to:

- fully examine the extent of both benefits and risks of the Draft Supports Lists
- seek greater clarity about the government's communication and consultation process as well as the rules themselves and the context of the proposed changes.

Recommendation 2: Adopt a principles-based approach, as detailed in the DRO joint submission

The proposed lists will have a negative impact on people with disability. Such a specific and non-flexible approach will lead decisions to be based on rigid lists rather than individual needs. CYDA, together with other DROs, strongly recommend a principle-based approach which will allow children and young people with disability and their families to continue using innovative and cost-effective solutions to live their lives within their communities. Below we outline four key principles we believe must be included for NDIS supports:

1. Reasonable and necessary
2. Be related to a person's disability

¹ [NDIS Quarterly 2023-24 Q4 Supplement Report Table E.24 Participant profile per quarter by age group – National](#)

3. Take into account what is provided by other government supports
4. Represent value for money

Recommendation 3: Provide clarity and assurances on exceptions and reviewable decisions:

- Policies and processes relating to exemptions/exceptions and reviewable decisions must be developed in consultation with people with disability and made available in accessible formats. Ensuring people with disability can contest decisions will be crucial if the lists are implemented.

Recommendation 4: Ableism and paternalism: To prevent harm, CYDA recommends a thorough process that centres on the lived experiences of people with disability when determining what are beneficial and effective supports.

- Allowing adults and bureaucrats from government departments to decide what supports are effective and beneficial for children and young people with disability is concerningly paternalistic and not in keeping with the broader objective of capacity building and choice and control.

Recommendation 5: Provide an appropriate timeline for the delivery of co-designed final rules for NDIS Supports, for example, a minimum of six months from the passing of the legislation.

- We are concerned that these NDIS Supports lists will be in place for an extended period of time, despite being not fit for purpose.

Recommendation 6: Implement a rolling review process for the NDIS transitional supports list to ensure it remains responsive to emerging needs and innovations.

- Establishing a rolling review process will allow for the timely inclusion of new supports into the 'in' list, reflecting the evolving nature of required supports, such as advancements in technology including; smart homes, virtual reality and assistive communication apps.
- Ensure that support requests are considered with an open and flexible approach, avoiding automatic rejection simply because they are not currently listed. This will better accommodate the diverse and changing needs of NDIS participants.

Recommendation 7: Government to carefully review and consider the voices of the lived experience responses from CYDA's research conducted during August 2024 specifically around the issue of NDIS supports, as detailed in:

- Summary Report survey of young people, parents and caregivers, children and young people with disability (See Appendix)
- Table of responses from survey participant and consultation with staff who have lived experience of disability and NDIS participation (See Tables 1 and 2)



Introduction

Children and Young People with Disability Australia (CYDA) is the national representative organisation for children and young people with disability aged 0 to 25 years. CYDA has an extensive national membership of more than 5,000 young people with disability, families and caregivers of children with disability, and advocacy and community organisations.

Our vision is that children and young people with disability are valued and living empowered lives with equality of opportunity; and our purpose is to ensure governments, communities, and families, are empowering children and young people with disability to fully exercise their rights and aspirations. We do this by:

- Driving inclusion
- Creating equitable life pathways and opportunities
- Leading change in community attitudes and aspirations
- Supporting young people to take control
- Calling out discrimination, abuse, and neglect.

The number of children joining the NDIS underscores the critical need for the Scheme to prioritise quality supports for younger participants. In the 2023–24 financial year, 69% of the 63,654 new participants were children under 15 years². It is therefore essential that the NDIS strengthens its focus on delivering tailored, high-quality supports to ensure these young participants receive the best possible start in life. Children and young people have the right to say what they think should happen when adults are making decisions that involve them and to have their point of view considered. Giving them meaningful and timely opportunity to have their say about issues that concern them including the proposed NDIS amendment Bill and related rules and transitional instruments, is therefore vital.

We are concerned about the proposed NDIS support lists as they will cause harm to children and young people with disability. They have already created confusion and distress, as outlined in the responses to our community survey summary and staff consultations regarding the proposed lists (see section: Detailed feedback on the proposed lists in Tables 1 and 2)

In our recommendations, CYDA endorses the views of the DRO sector as outlined in the letter and DRO joint submission to The Hon Bill Shorten, dated 19th August, 2024. We detail how a principles-based approach is more effective and consistent with the objectives of the Scheme. If the government ignores the call from the DRO sector for a

² [ndis.gov.au/quarterly-report-2023-24-Q4](https://www.ndis.gov.au/quarterly-report-2023-24-q4)

new approach, we also outline in Recommendation 7, what the lists need to include/exclude.

Drawing on the voices and experiences of children and young people, this submission argues that genuine NDIS reform requires the use of an anti-ableist lens alongside genuine co-design approaches to provide inclusive and quality NDIS supports to children and young people with disability.

In the context of our vision and approach, CYDA responds to the discussion paper that outlines the transitional instrument which will include lists about what NDIS funding can and cannot be spent on. CYDA also eagerly awaits opportunities to contribute to evidence-based reform that will deliver meaningful change to the way the NDIS is delivered to people with disability.

This submission draws on and amplifies our previous submission to the [Independent Review of the NDIS](#) which highlights the urgent need for NDIS reform to be co-designed with children and young people with disability and that it is fit for purpose. In support of the Joint submission 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, August 2024, as well as the results of data collection undertaken by CYDA, we present seven recommendations with supporting discussion, as a contribution to this inquiry.

Additionally, this submission is informed by the insights and lived expertise of children, young people and parents and caregivers in our community. Specifically, we use data from:

- CYDA's survey which opened on Thursday 8th August and closed on 14th August 2024 with **212** responses from young people, parents and caregivers. 87% of respondents are NDIS participants. See Tables 1 and 2, Detailed feedback on the proposed lists, and the Appendix for the summary of survey responses Report.
- Short interviews seeking insights from CYDA staff members who have personal and/or family experience of disability and NDIS participation. See Tables 1 and 2, Detailed feedback on the proposed lists
- Data collected in 2023 as part of a series of consultations for the NDIS review panel (used with permission)

Direct quotes drawn from the data collected are indented from main text, italicised and in inverted commas, anonymised (or pseudonyms used) to protect privacy and minimally modified for brevity and/or clarity.

Overview: CYDA community feedback on the proposed lists

Staff consultation findings

Five staff members with both direct lived experience of disability (or family experience of disability) and NDIS participation provided insight and feedback on the Draft Support Lists. Had more time been given by the government for the disability community to provide feedback on the draft lists, CYDA would have had the ability to organise focus groups with our community.

Staff members responded broadly to questions about how the proposed changes would affect them personally, what supports they thought might be impacted, their thoughts about the approach of the draft lists and of the consultation process itself.

All staff expressed a sense of understanding around why the NDIS might have created an explicit list outlining what is and isn't an NDIS support. However, majority felt the approach was contrary to the original intention of the NDIS—to give people with disability choice and control over their lives. One staff member, however, supported this introduction of a list in the hope that it would increase the fairness for accessing appropriate plans. All staff members had experienced gatekeeping from the NDIS, Local Area Coordinators and/or Plan Managers when they attempted to receive the supports they needed, and all were concerned that the draft lists would create additional ambiguity which would lead to more gatekeeping.

All staff members agreed that some of the supports mentioned on the 'not NDIS supports' list should not be there and should instead be considered supports. They also agreed that some of the language and terminology that differentiates disability from the rest of daily life is both ableist and unhelpful in creating an everyday support system. There was agreement that although reforms were being implemented as cost saving, these would instead harm people with disability and potentially not achieve financial sustainability. Rather, they recognise multiple cost saving measures in the management of their own (or family members') plans and these examples are listed in their responses in Tables 1 and 2.

Survey findings

Preliminary analysis of the survey CYDA undertook to gain an understanding of the impacts of the draft lists on children and young people with disability and their family and support systems reveals the following key findings:

- Respondents were cynical about the credibility of the consultation process, with many concluding that the short time frames meant the government did not have a genuine interest in understanding their perspective.

- Respondents lacked clarity about the legislation and the proposed changes and were confused about the rules due to inconsistent and contradictory information.
- Respondents were fearful that they would be unable to obtain appropriate supports if the lists were implemented and they worried about the loss of existing support and the restrictions on their lives.
- Respondents were concerned that the lists would prevent innovation in their approach to finding and maintaining their own supports.
- Respondents wanted assurances about a process for exemptions/exceptions if the lists are implemented.

Detailed feedback on the proposed lists

Table of responses from three sources; 1) community survey, 2) staff consultation and 3) NDIS review panel data

The following tables detail each of the 36 categories from the 'NDIS supports' and 15 categories from the 'not NDIS supports' from the Government's draft lists. Where applicable, CYDA has provided a comment for each support category based on the data from survey and consultation participants, as well as discussion and peer-reviewed data, to support our position on the proposed categories.

As outlined in Recommendation 2 above, CYDA strongly argues for a **principles-based approach** to replace the lists. Detailed feedback on the proposed list in Tables 1 and 2 below, demonstrates several instances of where a principles-based approach would work better for children and young people with disability.

Problematic terminology and confusion: There are several examples in the Draft Supports Lists of terminology leading to ways of thinking that are detrimental to children and young people with disability. The term "Day-to-day living costs", creates an assumption that these 'everyday' items cannot also be used as disability supports. It also draws a false binary between the concept of disability and 'the everyday' as though living with disability is not part of the everyday for many people. CYDA recognises that ableism is perpetuated through these kinds of communication devices which position disability as "other" in our community.

Additionally, the term "carve outs" is confusing, as it is not commonly used and has not been previously employed by the NDIS. CYDA recommends using plain language alternatives to describe these supports, such as 'excluded supports,' 'non-eligible supports,' or 'ineligible items' for NDIS supports, and 'exceptions' for non-NDIS supports

Table 1 Feedback on Supports that are NDIS Supports

Category	Sub-category	Feedback Summary
Accommodation/tenancy		Due to the limited timeline for consultation, we have no specific comment at this time.
Assistance animals		<p>CYDA seeks further clarification about this category. Does this include the initial task training and ongoing training and re-accreditation? <i>“Yes. Assistance animal supports. How am I supposed to maintain my assistance animal’s health as a non-shedding dog if animal grooming fees are in the excluded criteria? He needs to go to the barber once a month in order to remain healthy and do his job in assisting me. Also, not funding funeral costs and other costs of replacing an assistance animal feels cruel and unusual”.</i> Young person with disability, 16-25 years.</p> <p>Do the current NDIS guidelines still stand? https://www.ndis.gov.au/participants/assistive-technology-explained/assistance-animals</p>
Assistance In Coordinating or Managing Life Stages, Transitions and Supports		<p>CYDA welcomes the recognition of the need to support children and young people through life transitions.</p> <p>CYDA recommends a principles-based approach, that considers the support provided by other government systems, such as education, to effectively assist children and young people as they navigate different life stages and encounter new systems, such as transitioning from primary to secondary school. How they experience these transitions—and whether adequate safeguards are in place—can significantly impact the trajectory of their lives and the opportunities available to them.</p>
Assistance to Access and Maintain Employment or higher education		<p>CYDA seeks further clarification about this category: While NDIS funds can be used for "workplace assistance to obtain or retain employment," the draft lists propose that they cannot be used for "work-specific support related to recruitment, work arrangements, or the work environment." Survey participants found this distinction confusing. For example, Alysha, a 20-year-old survey respondent who is Deaf, requires an Auslan interpreter to communicate with colleagues at work. Under the new rules, would she be able to use her NDIS plan to cover</p>

		<p>this cost? Notably, 43.65% of survey respondents were unsure whether work-specific support would be eligible under the proposed rules.</p> <p>A principles-based approach, which is related to a person’s disability would enable flexible approaches to employment support, tailored to the young person’s needs.</p>
Assistance With Daily Life Tasks in a Group or Shared Living Arrangement		<p>CYDA seeks further clarification about this category. Does this include share housing in a private rental or owned home? Additionally, CYDA calls for a co-designed process to support innovative, cost-effective alternatives to group homes. Like other disability representative organisations, CYDA is concerned that this draft list will prevent innovative alternatives to group homes through the use of unpaid housemates, where the participant won’t be allowed to subsidise that person’s rent in return for informal supports</p>
Assistance With Travel/Transport Arrangements		Due to the limited timeline for consultation, we have no specific comment at this time.
Assistive Equipment for Recreation		Due to the limited timeline for consultation, we have no specific comment at this time.
Assistive Products for Household Tasks	Specialist products to enable cooking, cleaning, washing, home maintenance and other tasks.	<p>CYDA seeks further clarification on this category, particularly regarding the definition of the term 'specialist' product. We are concerned that this may contradict the concept of 'everyday items,' potentially restricting access to products that, while considered everyday items, directly assist people with disability-related needs.</p> <p>For example, one CYDA staff member was able to acquire a ‘Nutribullet’ through their NDIS funding to assist with food preparation that would have to otherwise be done by a support worker due to their disability. <i>“That chops veggies for me which means that I can then save money on support workers by spending the initial outlay on a [Nutribullet]”</i>. As the above example illustrates, Children and Young People with disability and their families use variety of innovative ways to stretch their NDIS funds further. Implementing a prescriptive list would restrict this innovation and negatively impact the sustainability of the NDIS. A principles-based approach would empower individuals to innovate and achieve better value for money.</p>
Assistive Products for Personal Care And Safety		Due to the limited timeline for consultation, we have no specific comment at this time.

Specialist
Positive
Behaviour
Support

CYDA seeks further clarification to ensure this Support category encompasses safe, relational approaches to supporting distress and complex behaviours in children and young people with disability.

CYDA is concerned that without significant redesign and oversight, this category will continue to perpetuate the problematic approaches of some practitioners offering supports under this funding category.

Recent peer reviewed research has found “evidence that PBS [positive behaviour support] policies have become informal rules for using restrictive practices, not reducing them”.

<https://pubmed.ncbi.nlm.nih.gov/35285307/>

Also, there are many examples, now in the media³, of NDIS registered supports being shown to exacerbate “behaviours of concern”. We believe including more trauma-informed, relational approaches is a critical part of the solution to ending restrictive practices.

“Parents should also be free to choose what they know will assist their learning and it may not be labelled as disability specific. Eg Dr Ross Greene[’s] highly credible approach to behaviour support . . . is advertised primarily to teachers and allied health. I imagine few planners would . . . understand that this is highly relevant and useful. And extremely cost effective.”

Survey respondent, parent/caregiver, young person with disability 16-25 years.

“When we got a line item in [my child’s] plan for ‘improved relationships’ I spent a long time figuring out how to find someone who could work under that code but not use the positive behaviour support approach as a dressed-up version of ABA [applied behaviour analysis]. I’d spend enough time listening to the voices of older autistic children and adults to realise I definitely didn’t want my [child] doing this kind of therapy. And now that I’ve seen the media on [NDIS provider – name withheld] and others, I’m so glad—that could have easily been [my child]. Putting such a heavy focus on changing kid’s behaviour instead of trying to connect with them, will naturally lead to terrifying examples like this”. CYDA staff member.

³ <https://www.abc.net.au/news/2023-09-27/commissioners-response-to-abusive-ndis-therapy/102903870>

	<p>The Disability Royal Commission research report “Restrictive Practices: A Pathway to Elimination” calls for an end to what it calls the 'legally authorised and/or socially and professionally sanctioned violence that targets people with disability' (p.17).</p> <p>A principles-based approach, which is related to a person’s disability would enable safe relational approaches to behavioural support, tailored to the child/young person’s needs</p>
Communication And Information Equipment	Due to the limited timeline for consultation, we have no specific comment at this time.
Community Nursing Care	Due to the limited timeline for consultation, we have no specific comment at this time.
Customised Prosthetics (includes Orthotics)	Due to the limited timeline for consultation, we have no specific comment at this time.
Daily Personal Activities	Due to the limited timeline for consultation, we have no specific comment at this time.
Development Of Daily Care And Life Skills	Due to the limited timeline for consultation, we have no specific comment at this time.
Disability-Related Health Supports	Due to the limited timeline for consultation, we have no specific comment at this time.
Early Intervention Supports For Early Childhood	<p>CYDA welcomes and acknowledges the inclusion of Early Intervention Supports for Early Childhood and urges the NDIA to ensure families are clear about what early intervention supports can be funded to ensure no child is left behind. Prior to enacting any measure to constrain or decrease the number of children within the scheme, it is crucial to first establish accessible and effective early childhood approaches and foundational supports in mainstream settings. An inclusive, universal, and high-quality early education and care system that specifically caters to children with disability must be at the core of this commitment</p>

Exercise Physiology & Personal Well-being Activities		Due to the limited timeline for consultation, we have no specific comment at this time.
Group And Centre Based Activities		Due to the limited timeline for consultation, we have no specific comment at this time.
Hearing Equipment		Due to the limited timeline for consultation, we have no specific comment at this time.
High Intensity Daily Personal Activities		Due to the limited timeline for consultation, we have no specific comment at this time.
Home Modification Design and Construction		Due to the limited timeline for consultation, we have no specific comment at this time.
Household tasks	Meal preparation and delivery.	<p>CYDA seeks further clarification on circumstances where support with meal delivery may be necessary. For example, would a percentage of meal delivery services in order to cover the labour component but not the ingredients be considered an NDIS support in instances where support workers cancel shifts leaving participants unable to prepare their own meals.</p> <p><i>“That’s a cheap alternative if a support worker cancels on you”.</i> CYDA staff member.</p> <p>As recommended by CYDA, a principles-based approach, which focuses on value for money rather than a prescriptive list, would enable creative solutions such as the example above to reduce costs and provide benefit to the NDIS participant</p>
Innovative Community Participation	Activities not included under other community participation registration groups; for mainstream	CYDA seeks further clarification regarding what is ‘innovative’, including a process for including supports that are yet to be considered ‘evidence-based’ or have an emerging evidence base.

	providers who want to enable participants to access mainstream activities.	
Interpreting and Translation	Assistance to a participant to enable independent communication in essential personal, social or community activities where translation is not available from a mainstream service.	<p>CYDA survey and consultation participants raise concerns that the current wording of this support description is unclear and might prevent children and young people with disability getting the supports they need. They suggest the following alternative:</p> <p>Assistance of interpreters or translators to a participant to enable independent communication in personal, social or community activities.</p> <p>Additionally, CYDA supports the continuation of Auslan classes for the families of children and young people who are Deaf or hard of hearing.</p> <p>As per the NDIS’s own guidelines, “Learning Auslan is a long-term commitment for the child and family and fluency is needed for the best outcomes, including social-emotional wellbeing.” https://ourguidelines.ndis.gov.au/understanding-supports/children-who-are-deaf-or-hard-hearing/developing-your-childs-communication-and-language</p>
Management of Funding for Supports		Due to the limited timeline for consultation, we have no specific comment at this time.
Participation in Community, Social and Civic Activities		Due to the limited timeline for consultation, we have no specific comment at this time.
Personal Mobility Equipment		<p>CYDA seeks further clarification about the process for timely application of these supports.</p> <p>CYDA has numerous examples of children and young people waiting unacceptable lengths of time and energy to secure necessary supports. One parent shared the details of her efforts to obtain a wheelchair growth kit for her young child.</p>

“So the physio also had listed in their report that [my child] needs a wheelchair growth. So [they] still use a wheelchair for community access, [they] just [have] a manual wheelchair. Because [they are] growing, and obviously little ones grow quickly, [they] usually need a wheelchair growth done on [the] chair every 12 months, or within the 12-month plan. That was already stated with a - I think there was an amount stated but it wasn't in a specific quote for the wheelchair growth, that was totally missed so we have no capital funding for a wheelchair growth at all.” After it became clear that the LAC has not included the growth kit in the plan, the parent had to use plan funds to get the physiotherapist to re-write a report to justify a wheelchair growth kit for the child despite existing reports outlining the diagnosis of “cerebral palsy, spastic quadriplegia, and an extensive brain injury”. NDIS Review Participant Consultation participant, Parent/caregiver, young person with disability 0-8 years.

One of CYDA's staff members requires a wheelchair in order to access the community, which largely isn't designed to accommodate their cerebral palsy.

They have been an NDIS participant for three years and have spent two years trying to access a wheelchair, which despite being approved by the NDIS, is being slowed down due to bureaucratic processes. The funds for their wheelchair were designated as agency managed so are locked into the NDIS process for obtaining the wheelchair, and despite calling to ask why, the staff member has not received any clarity.

“I'm lucky that I've got a second-hand wheelchair from a friend who just happened to be not using it anymore.” However, this 10-year-old chair requires frequent repairs—with the repair person explaining during a recent break-down, “I'd be careful with it, only use it when you really have to... [When I called NDIA said], ‘I don't know, that's just the way it is in your plan’. And I said ‘well now I can't get my wheelchair because the agency is not paying the wheelchair company’. Whereas if I was self-managed ... I would have my wheelchair by now... It's been approved [by the NDIA] ...and when I called them they are [...saying] ‘we haven't received a quote from the wheelchair company’ and I said ‘yes you have, you received the quote in the initial report that I sent through on [two previous dates]—because initially they said they never received it even through they did. And then I resent the quote... The NDIS is supposed to enable me to get access to the community”.

The staff member has sent the quote from the wheelchair company to the NDIA three times via email and received auto-generated receipts each time. However, every time they call to check progress the person on the main NDIS line simply puts a note on their file and nothing

		further is done. This person is exhausted by this onerous process and cannot understand why it has been so difficult.
Specialist Disability Accommodation (SDA)		Due to the limited timeline for consultation, we have no specific comment at this time.
Specialised Driver Training	Driver training using adapted equipment or vehicle modification.	CYDA seeks further clarification about specialised driver training, when equipment or vehicle modification are NOT required? CYDA would like to see this open to all young people with disability who would benefit from specialised driving lessons to be able to drive successfully and have better access to their communities. The alternative is likely to be an increase in support worker hours required to transport young people with disability to appointments and access their communities. A principles-based approach, which focuses on value for money, tailored to individual need, would resolve this tension.
Specialised Hearing Services		Due to the limited timeline for consultation, we have no specific comment at this time.
Specialised Supported Employment		Due to the limited timeline for consultation, we have no specific comment at this time.
Specialised Support Coordination		Due to the limited timeline for consultation, we have no specific comment at this time.
Therapeutic Supports		CYDA seeks further clarification about the definition of ‘evidence-based’ and the process for determining this. While this line item supports the use of therapists in a person’s daily life, the use of the phrase ‘evidence-based therapy supports’ is vague, as is many of the NDIS references to the term ‘evidence-based’. Although there are no ‘carve outs’ listed under this item, the list of supports that are not NDIS supports includes many services that participants would likely consider therapeutic. For example, yoga therapy and somatic therapy are both potential supports for people with sensory processing and interoception differences and conditions that impact their ability to notice and understand their emotions and bodily signals like pain, hunger, thirst and needing to use the toilet. Using a principles-

based approach, many of the services listed as ‘not supports’ could be considered **reasonable and necessary** for some people with disability.

Vehicle
Modifications

Due to the limited timeline for consultation, we have no specific comment at this time.

Vision
Equipment

Due to the limited timeline for consultation, we have no specific comment at this time.

Table 2 Feedback on Supports that are NOT NDIS Supports

Category	Sub-category	Feedback Summary
Day-to-day living costs	Accommodation and housing related: Rent and rental bonds	CYDA argues that in some circumstances by taking a principles-based approach, rent and bond may be appropriately subsidised by NDIS. For many young people, public housing or supported housing is not available and their only option is the private rental market. One staff member explained to us how their child had transitioned out of the family home and into a private rental, and because of their need for 24-hour one-on-one support worker, an additional bedroom was required. This made the rent and upfront bond more costly.
	Accommodation and housing related: Standard home security	CYDA seeks further clarification regarding the definition of ‘standard’ in the case of home security “[My young person] will open the front door in the middle of the night and wander off... [they] turn the gas on... and there’s also alarms in the bathroom because [they] turn on taps and leave them running and have flooded the floor”. CYDA staff member.
	Accommodation and housing related: General furniture removal	CYDA argues that in some circumstances by taking a principles-based approach, furniture removal and home repairs may be appropriately subsidised by NDIS. “Repairs to rental property following behaviours- this could put us at risk of homelessness- which NDIS will also say is not their responsibility!” Survey respondent, parent/caregiver, child with disability 9-15 years.
	General home repairs, renovations and maintenance	“My child’s disability related behaviour means I have many items which get broken, some big and some small. For the bigger things, I can’t transport them to the tip so I end up having to live with them until the next council hard rubbish collection. I’m aware this would not be the case in most other households”. CYDA staff member.
	Water, gas, electricity	CYDA survey/consultation participants emphasise the need to specify that water, gas, and electricity should be included under the ‘carve out’ clause: “Additional living costs incurred by a participant solely and directly as a result of their disability support needs.” Participants believe this is essential in cases where a person’s disability necessitates above-average use of these utilities and state or territory subsidies aren’t available. Examples include running breathing ventilation machines overnight, using additional cooling or heating for temperature regulation, or

	charging mobility devices. A principles-based approach that considers the availability of other government supports, such as state or territory subsidies, would help address potential service gaps.
Electricity generators	CYDA survey/consultation participants emphasised that this item should be included where people with disability rely on life supporting devices and mobility devices that enable independence. They can and should not be without access to these items if the power goes out.
Standard household items (dishwasher, fridge, washing machine, nonmodified kitchen utensils and crockery, fire alarms, floor rugs, beanbags, lounges, standard mattresses, and bedding), replacement of appliances, including hot water services, solar panels, etc.	<p>CYDA seeks further clarification of the phrase ‘standard’ and ‘everyday items’ as these may prevent children and young people with disability getting the support they need. We also recommend not excluding any particular items based on the categorisation of ‘Day-to-day’ and rather co-design a principles based approach and exemption/exception process which would identify items as disability related supports would result in value for money. For example; <i>Air-conditioning</i> might be required for someone whose disability means they have difficulty regulating their body temperature. In standard rental accommodation, air-conditioning is not a requirement and heating is only required to be included in the main living area. This might not be sufficient for a person with disability</p> <p><i>“Without an air-conditioner I need a lot more support work because I become a lot more dysfunctional, because I don’t regulate my own temperature... I know the spit-system costs a bit but over time the support worker is going to cost a lot more”.</i> They added, <i>“The consequence of this is that there is a lot more admin around doing these basic things as well, like you actually have to put all that effort into getting a support worker”.</i> CYDA staff member.</p> <p><i>Dishwashers</i> can enable people with mobility impairments to be independent in doing kitchen tasks and some people with disability require specific cooking appliance to be able to be independent with cooking.</p> <p><i>“I’m lucky enough to have a dishwasher, if I didn’t, if I had to wash my own dishes I would give up something else in order to do that. Like, the energy that goes towards washing the dishes... I wouldn’t be able to spend that energy at work... Or I would have to employ a support worker several hours every week to do my dishes... So there’s an economic benefit to that initial outlay of a dishwasher in certain circumstances”.</i> CYDA staff member.</p> <p><i>Stove tops.</i> The same staff member cannot use their gas stove for cooking due to the fine motor skills needed to light it and adjust the flame. An electric stove would mean they can do the majority</p>

of their meal preparation themselves rather than getting a support worker to come most days to operate the stove. *“I would be making a one-off spend on, for example an electric stove, rather than a support worker every week for the rest of my life to use a stove that I can’t use”.*

Microwaves. A CYDA staff member pointed out that having a microwave meant that a support worker could pre-prepare food ahead of time to be heated up when required. They said, *“A microwave costs \$50 but if you’re on the DSP [disability support pension] and you’re struggling to pay rent and eat, you’re not going to spend \$50 on a microwave, you’re going to spend it on food”.*

Survey participants also indicated that Bean bags can be a sensory need and additional floor rugs can create non-slip surfaces to ensure safety of a person with disability.

Lifestyle:
Standard toy

CYDA seeks further clarification about the definition of ‘standard toy’ to ensure children and young people can access the items they need. One staff member described purchasing a nursery white noise machine to help with sensory regulation in their older child. *“Does the same thing for babies as it does for [young adult], so technically it’s not a disability related, [they] need it because of [their] disability, but technically it’s not a disability item”.* CYDA staff member.

Lifestyle: Sex
work, sex toys

CYDA recommends including sex and sexuality related services for NDIS participants. We consider this a human rights issue and argue that excluding sex and sexuality related services from NDIS supports could be considered both negligent and ableist. Many young people with disability require direct support in understanding and participating in safe, consensual relationships and to deny this is to suggest that people with disability are missing this aspect of their humanity. *“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.”* Statement: Ten Organisations Call for People with Disability’s Access to NDIS Funded Sexuality Services to be Protected. For a more fulsome discussion, refer to the complete statement. <https://cyda.org.au/ten-organisations-call-for-people-with-disabilitys-access-to-ndis-funded-sexuality-services-to-be-protected/>

A Lancet article from 2021 argues that the concept of “sexual wellbeing” is a public health matter ([https://www.thelancet.com/pdfs/journals/lanpub/PIIS2468-2667\(21\)00099-2.pdf](https://www.thelancet.com/pdfs/journals/lanpub/PIIS2468-2667(21)00099-2.pdf)) . “Our

conceptualisation of sexual wellbeing relates to sexual health and pleasure (a primary motivation for sex), and to social, cultural, and political frameworks of sexual justice. By identifying trauma-informed sex positivity as a central guiding public health value, we anchor our approach to sexual wellbeing with a corresponding recognition of the notable significance of both sexuality and sexual trauma in our lives.” The authors argue that sexual wellbeing is a marker of health equity and a population indicator of wellbeing.

The Australian Government’s own statement about sexual health (<https://www.health.gov.au/topics/sexual-health/about>) says, Sexual health includes:

- respect for the right to healthy relationships, equality and safety
- safety to express individual sexuality, sexual orientation and gender identity
- freedom from coercion, discrimination, violence and stigma

“Able-bodied, non-disabled people are allowed to have sexual experiences, either by themselves or with a partner... who is the government to deny people that right on the basis of their disability”. CYDA staff member.

“You’ve got to think about it more as a mobility aid in this sense, rather than just sex toys... “Some people need physical help and you can’t ask a support worker to do that, that’s highly inappropriate, so you need a sex worker”. CYDA staff member.

“[My young person has] never had sex education. I pushed for this at school all the time, and kept saying they didn’t have the skills. The paediatrician has even suggested we give [them] a vibrator and put [them] in a room and teach [them] ‘that’s private’, but of course school and everyone was really uptight about that. I would love to get some support from someone who was really equipped in this area. It’s about educating [my young person], it’s about giving [them] autonomy and sexual agency, which everyone is entitled to, but it’s also protection from abuse as well. Given [my young person has] already shown some degree of sexual autonomy and sexual desire and desire for pleasure, we also need to ensure [they] can engage in this in ways that are safe and I don’t have the skills for this, I need guidance”. CYDA staff member.

Lifestyle:
Surrogacy,
Menstrual
products, IVF

CYDA recommends that these items (Surrogacy, Menstrual Products, IVF) should not be grouped together or classified as 'lifestyle' items. Although this may be unintentional, categorising them together suggests gender discrimination.

CYDA survey/consultation participants called for menstrual products to be included as an NDIS support for young people with disability.

People with disability have the right to dignity with regards to managing menstruation independently and according to their own preferences. Young people with disability should have access to a range of information and products to assist them in managing their menstrual cycle.

For example, TINA <https://www.tinahealthcare.com/>

And here is the story behind TINA – <https://www.ameridisability.com/feminine-hygiene-just-got-easier-for-people-with-disabilities/>

CYDA supports the position that some menstrual products should be covered by NDIS. For instance, where a person's choice is to use tampons, but their disability means they don't have the physical capacity to use them, they should have access to applicator tampons or other insertion devices as required.

"Very concerned too about the menstrual products, as one of my two disabled children wears these daily and they're very expensive. They can't use pads or tampons. So I'm concerned about the government ruling out certain supports because they're considered 'normal expenses'. But our need for them isn't normal - it's not a choice. It's disability related and it means the difference between accessing the community, school etc. Without these supports, my kids couldn't go to their mainstream schools or their capacity building appointments". Survey respondent, Parent or caregiver, child with disability 9-15 years.

"I can't physically use [most traditional products] because of fine motor skills so I prefer period underwear... I should be able to have the dignity to be able to use the products that are right for me, that I can use independently". CYDA staff member.

CYDA shares the concerns raised in Women With Disabilities Australia's (WWDA) August 2024 survey regarding the removal of access to menstrual products and the potential consequences if people lack access to safe, adaptive options. WWDA reported that some survey participants expressed serious concerns about losing independence if these products were unavailable, as they would require regular assistance with changing them. There is also a concern that this could lead

to an increase in practices like forced menstrual suppression to 'manage' menstruation. We know that many people with disabilities are not provided with the necessary support and education to manage menstruation, and in some cases, particularly in segregated settings, menstrual suppression is imposed without their free and informed consent.

Lifestyle: Trampolines Lifestyle: General play equipment	<p>CYDA survey/consultation participants called for the inclusion of trampolines and general play equipment for children and young people with disability where a principles-based approach is applied, to determine the functional benefit of the item.</p> <p><i>“Prior to getting our jungle gym for climbing, swinging and hanging, my child climbed on the roof of our house and bungalow multiple times per week and broke three window blinds and two cupboard doors in our home from hanging off them. I’d already purchased a trampoline from my own funds but clearly this didn’t meet the particular sensory need that drove him to climb and hang. Before getting the jungle gym, I needed to be in arms-reach of him every second of the day to try and prevent breakages and injury. Now I can look out my kitchen window and see him swinging upside down off his monkey bars and rocking in a swinging tent—he’s only climbed on the roof once in 18 months since we got it. This equipment was out of my reach financially and without it my child’s safety would have been at risk and my mental health would have been compromised by the constant vigilance that was required”.</i> CYDA staff member.</p> <p>CYDA survey/consultation participants would like a clear definition of “play equipment’ where it is specialist sensory equipment to ensure children and young people can access the support they need.</p>
Lifestyle: Membership of a recreational club	<p>CYDA supports a principles-based approach to determine where membership of recreational clubs should be permitted. For example, where people require frequent access to heated pools as part of their therapy.</p>
Travel related	<p>CYDA support a principles-based approach, which focuses on value for money to determine whether travel-related supports could be included, particularly as it relates to short-term accommodation or where support is required while travel occurs (eg for work or family reasons).</p>

For instance, some travel is related to instances such as attending funerals and other travel might be legitimately cost effective and meeting participant goals despite being 'overseas' or 'cruises' which are on the 'not an NDIS support' list.

"Yes they stupidly don't fund overseas holidays (I crunched the numbers and in many cases you can do a week for those of us who can travel on our own to Asia or whatever) for not much more than what the NDIS and the DES companies charge for weekend camps." Survey respondent, Young person with disability

"Removing holiday accommodation costs that cater for people with disabilities including specialised toilets and bathrooms with hoists, ramp access, air conditioning for those with thermoregulator conditions is unfair and once again targets the vulnerable "tourist/holiday maker" in Australia. What about Western Australia? Long distances no matter where you want to travel. Who ever put some of this together needs to sit in a wheelchair with blurred glasses, and noise cancelling earphones and see what the costs are and how limited specialised accommodation is and how expensive travel costs are. The person should also be on a disability pension for 3 months before travelling and save the travel costs from the pension". Survey respondent, Parent/caregiver, young person with disability 16-25 years.

"We can't attend [an interstate funeral] without support. Whether that is about [the young person] staying home and being supported or whether [they] need to come with us and we access support while we're away". CYDA staff member.

CYDA survey/consultation participants would like a principles-based approach applied to Smart Watches, particularly where they are used for bio-feedback tracking, alerting in emergencies and for executive function assistance.

Clothing related: Smart watches

Several people in our community told us they use smart watches as bio-feedback devices for managing disability related conditions, to assist with executive function impairments and to alert emergency contacts about falls.

"Smart watch (for medication reminders and vibration to tell me I've left my phone behind)". Survey respondent, NDIS participant over 25.

	<p><i>“In NDIS terms [not using a smart watch to maintain a low heartrate] it means your functionality decreases for a period of time and you need a lot more support work... “if you don’t invest in the everyday item you end up needing to invest a lot more in support workers as the work around”.</i> CYDA staff member.</p>
Hair and beauty	<p>In line with a principles-based approach, CYDA survey/consultation participants would like to see some hair and beauty supports funded in circumstances where young people with disability require assistance to wash their own hair. The following quote illustrates how a flexible application of supports, illustrates value for money.</p> <p><i>“In some instances, it would be safer and more cost effective for these supports to be delivered in a salon environment by professionals rather than by a support worker. This is especially the case for hair washing in dysfunctionally [sic] designed bathrooms . . .utilizing an apprentice hairdresser for less than 1/4 of the cost”.</i> Survey respondent, Parent/caregiver, child with disability under 9 years.</p>
Carve outs	<p>CYDA survey/consultation participants would like a principles-based approach applied to gym entry, to take into account where a person is using the facility to receive disability supports.</p> <p><i>“Because the waitlists for places with internal hydro pools at a clinic are ridiculous, I’ve been going to public hydro pools with my physio... With the NDIS as it is now, I can claim the physio time and appointment and the entrance to the hydro pool—because again, I wouldn’t need that if I wasn’t disabled.”</i> CYDA staff member.</p>
Not value for money/not effective or beneficial	<p>CYDA seeks further clarification on the criteria the NDIS uses to determine what qualifies as "effective and beneficial" in terms of disability supports. How does the NDIS plan to incorporate emerging studies and evidence-based, peer-reviewed research in these areas? Additionally, how will the NDIS consider the effectiveness of certain supports based on lived experiences?</p> <p><i>“One of the things on the to be " banned " list is Gaming therapy. I have tried looking up what " Gaming Therapy" is and get very broad responses. My son currently attends Virtual reality physiotherapy - a mix of VR and non VR physio/EP/rehab/training run by physios and EPs. They use VR in the context of very skilled physio /EP/rehab to make it much more interesting. My son is Autistic and we haven't had much luck engaging him in EP/physio/gym work before. Having it wrapped with VR has made all the difference. I am worried with " gaming therapy ' on the banned list and no clear definition of this that an over officious NDIS delegate may decide this therapy is "banned". loosing [sic] it would cause loss of physical and mental health and social connection as it</i></p>

is one of few activities with which he will engage.” Survey respondent, Parent or caregiver, young person with disability 16-25 years.

“Our OT is also trained in Somatic therapy and honestly, it’s the somatic component of her practice that has most helped my child to understand and act on basic body signals like hunger and needing to go to the toilet. I’m disappointed the NDIS isn’t acknowledging the evidence around somatic approaches for people who struggle with interoception.” CYDA staff member.

Article evaluating trial of interoception education for South Australian school student:
https://www.griffith.edu.au/_data/assets/pdf_file/0023/1182353/Publication-Thriving-at-School-how-interoception-is-helping-children-and-young-people-engage-in-learning-everyday.pdf

**Mainstream
– Health**

Sleep
consultant
services

CYDA survey/consultation participants would like a principles-based approach applied to sleep consultation services to incorporate instances where a child or young person’s disability is impacting their sleep.

In recognition that many sleep conditions and disorders are related to people’s disability, numerous existing support providers are NDIS registered. Survey participants have raised concerns that children and young people with disability-related sleep conditions will not get the support they require.

“We have had some on and off support with a sleep consultant....[They are] never going to be a good sleeper, that’s just who [they are], and that can be common with autism. But it’s about making sure that it’s not impacting [their] overall health too much. I mean it’s going to impact [their] health a little, but it’s important to manage this closely”. CYDA staff member.

Carve outs

CYDA seeks further clarification on the process of approval for carve out supports.

Although CYDA welcomes the ‘carve outs’ in this category, we have concerns about how this is implemented.

One of our staff members outlined their need for podiatry as an outcome of the way they walk. *“Who decides that? How will that be standardised? If someone looks at me a goes, ‘that’s not related to [their] cerebral palsy’ then I just can’t do it and that’s not fair because it is related to my disability”.* CYDA staff member.

**Mainstream
– Mental
Health**

Psycho-social
supports

CYDA seeks further clarification on the definition of “ongoing psycho-social” supports.

According to staff and survey responses, there is particular concern in the community about the potential loss of psychological supports, whether it be through a blanket rule or misinterpretation of how this support relates to the child or young person’s disability.

		<p><i>“[Losing] psychology - this would be catastrophic for my children and myself as one of our main supports that we use to navigate life with our disabilities. I actually don’t know how we would survive without it”.</i> Survey respondent, Parent or caregiver, child with disability under 9 years and a child 9 to 15 years.</p> <p><i>“If that was removed because it was argued that it’s a health thing, even though it’s actually my disability, then that is really dangerous”.</i> CYDA staff member.</p>
Mainstream – Child Protection and Family Support	Marriage and relationship counselling	<p>CYDA seeks further clarification regarding who the marriage counselling would be for, is it intended for a participant or parent/caregiver?</p>
	Parenting programs specific to a disability need (could be considered under capacity building supports).	<p>CYDA seeks further clarification on the definition of the ‘carve out’, to ensure families can receive the parenting services and supports they need.</p> <p><i>“Parenting courses have helped me the most out of all supports with my children. To cut this out will significantly disadvantage us particularly when my children refuse/ are unable to participate in traditional therapies”.</i> Survey respondent, Parent/caregiver, child with disability under 9 years.</p> <p><i>“I scoured the internet for books, podcasts, articles and parent programs to help me meet my child’s needs, but it was always as though they weren’t addressing my family situation and all their techniques only made things worse. This was so isolating. I finally found a parent coach who had experience with children who have disability related, high distress behaviours. It was the first time I felt like someone truly understood my situation and I was able to do a 10-week program that created important shifts in my family. I feel so grateful that I was able to claim that through my child’s NDIS package and know that it was a genuine and important support to my child, who at that time was rejecting direct work with therapists.”</i> CYDA staff member.</p>
	Family therapy	<p>CYDA survey/consultation participants would like a principles-based approach applied, to family therapy arguing that this type of support is required to build and maintain capacity in the participant’s support systems—which also commonly act as ‘informal supports’ in NDIS plans.</p>

“[My older child] absolutely loves [their sibling]...but [they are] still really unsure and you can see [them] flinch sometimes in response to particular sounds and movements. I see this as the unaddressed trauma... If [their sibling] squeals [they] just jump, [they are] just so on edge and anxious... I do worry about when I go and we’ve had conversations about the ongoing support [their sibling] will need and it needs to come from a family member. Family therapy would be so beneficial, to restore these family relationships so and replace some of the need to pay others to do certain tasks. So in many ways it would actually take pressure off the system”. CYDA staff member.

“My younger child has had so many difficult experiences that would not have occurred if [they] had a typically developing sibling. Given that [they] will likely be considered and informal support by the NDIS into the future, why can’t I access the psychological and skills-based support [they] need”. CYDA staff member.

Out of school
hours care
Vacation care,
excluding
respite
Babysitting or
nannying
services, au
pairs

CYDA survey/consultation participants ask that core supports be provided transparently based on functional capacity, not the age of the child. Respondents seek an end to harmful gatekeeping practices using the term ‘parental responsibility’ which fail to acknowledge the caring component of many parent/caregivers roles. They are concerned that the families of children with disability are not being provided with adequate support in their homes and that respite opportunities are not defined in the draft lists.

The term ‘parental responsibility’ is only referred to in the Act as a legal definition to identify who has authority to act and make decisions on behalf of a child. At no point in the Act or any of the guideline documents does the NDIA specify the types or levels of care parents and carers are responsible for providing to their children and young people with disability. However, previous and current data reveal many planners and LACs are using the term ‘parental responsibility’ to prevent parents and carers accessing support worker hours. This kind of gatekeeping places families and individuals at high risk of harm.

“So because [my child] had significant complex needs and [they were] PEG fed, I had been told and was trying to advocate for [us] to get some support work hours through [their] NDIS plan because I felt that [they] could not attend mainstream day-care or kindergarten due to [their] high needs. And I think I asked two or three times with the early childhood coordinator and they denied it every time. So it wasn’t until the very – I think in the end I said, ‘Just try’, and we actually got it because she put it in and I was like, ‘Yeah, see?’ But it was like a gatekeeper, they were very

closed so they were very much like, 'No, [the child's] under seven, it's all parent responsibility.' And I was like, 'Well, which parent needs to do all this stuff 24 hours a day and then – ?' I don't know any parent that does that. So there was a lot of gatekeeping, I felt, for support work around early childhood intervention with NDIS." Previous consultation participant, Parent, child with disability 0-8 years.

"The gap in understanding between "parental responsibility" and the realities of day to day care of children with cognitive disabilities creates many issues for many families". Survey respondent, Parent/caregiver child with disability under 9 years.

"There's parenting, but then there's the need for "carers role" on top of normal parenting when the child is special needs." Survey respondent, Parent/caregiver, child with disability 9-15 years.

"Core support workers for before and after school care as my child cannot attend [out of hours school care] anymore or any other before and after school care facilities. Needs a support worker to help as I work". Survey respondent, Parent/caregiver, child with disability 9-15 year.

"Families are being told that only mainstream services are available for school holidays and before and after school care options cannot be accessed instead only mainstream services or alternatively this is now considered parental responsibility." Survey respondent, Professional.

"I'm not eligible for travel or anything like that because it falls under parental responsibility and I've never had this responsibility with any of my other kids where I've had to go to appointments three times a week an hour away". NDIS Panel Review consultation participant, Parent, child with disability 0-8 years.

"When my child was under 7, no matter how significant and complex his support needs were, LACs just kept telling me, 'we can't ask for that in the plan because it's parental responsibility'. I ended up completely burned out and broken from these care requirements that they were defining as a normal part of parenting". CYDA staff member.

Mainstream
– Early

CYDA seeks further clarification about foundational supports and how they will interface with mainstream early childhood development services.

Childhood Development		<p>Additionally, CYDA recommends this support remains in place until viable and effective early childhood approaches, such as quality foundational supports, are established and available for all children.</p>
Mainstream – School Education	School refusal programs	<p>CYDA survey participants seek a principles-based approach to include a school refusal program for students with disability, to address current jurisdictional gaps.</p> <p>The CYDA community highlights that school refusal is often linked to a young person’s disability, arguing that support to help them return to school should be funded by the NDIS as part of enabling community access. Currently, no other government department provides specific support in this area.</p> <p><i>“How short sighted can you get? When [my child] suffered severe trauma at school and was unable to attend for almost a year until we found [them] an alternative, we relied on more NDIS supports because he was at home more and we had to try and address the underlying cause of him not going. It seems to me an NDIS funded program for kids with disability could circumvent this and get them back to school more quickly. Otherwise, parents are flailing around trying to keep their lives together, remain in paid employment and figure out what supports to use to get their kids back to school. Not the smartest approach”. CYDA staff member.</i></p>
Mainstream – Higher Education and Vocational Education and Training		<p>Due to the limited timeline for consultation, we have no specific comment at this time.</p>
Mainstream – Employment	Work specific aids	<p>CYDA survey/consultation participants would like to access NDIS funds to support them to engage in innovative work solutions, where Job Access is not available.</p> <p>Participants should be able to claim aids that assist with them to build a home-based business, including micro-enterprises, where their disability may limit their employment.</p> <p>NDIS supports should enable a participant to engage in economic activity in a way that suits their access needs and their interests. It should acknowledge that working for an employer (who can access Job Access), is not the only way an individual may engage in work.</p>

	<p><i>“Losing supports for being driven to work and having a support worker accompany me to interstate work events is a huge fear, as it may lead to me losing my job or at least miss out on job opportunities”</i>. Survey respondent, Young person with disability, 16-25 years.</p> <p><i>“Our research indicates that employment supports are very confusing for young people and their families. The definition of supported employment needs to be very clear and funding available for eligible young people from 15 years of age.”</i> Survey respondent, professional (Researcher).</p> <p><i>“[My young person] needs tools in the workplace for communication, tools in the workplace to be given some options for the future...maybe [they] want to do something different in [the workplace]... so it’s having someone who’s got those skills to support that development and growth in [their] workplace”</i>. CYDA staff member.</p>
<p>Mainstream – Housing and Community Infrastructure</p> <p>“routine tenancy support” “Rental payments” “Mobile homes, caravans, campervans, tents”</p>	<p>CYDA survey participants advocate for a principles-based approach to include tenancy supports for young people, ensuring access for those who need them due to their disability.</p> <p>Respondents expressed a desire for NDIA to include or subsidise options such as mobile homes, caravans, campervans, tents, and rent for additional spaces needed due to disability-related needs. CYDA recognises that some people with multiple chemical sensitivities may need to stay in a tent to avoid harmful environments. If they are expected to cover these costs through their disability support pension and cannot do so, they lack a safe place to live.</p> <p>CYDA survey participants also seek clarification about whether home modifications are included. For instance, if a gas stove is unsafe or inaccessible, an electric stove could be installed. Offering home modifications could make financial sense by reducing the need for ongoing support worker assistance.</p>
<p>Mainstream – Transport</p>	<p>CYDA seeks further clarification on this category. We are concerned that children and young people will become more isolated without funding for transport costs, especially those who live in rural, regional and remote areas.</p> <p><i>“From my understanding [my young person] is potentially going to lose transport costs but this isn’t clear... and this would mean [my child] is a lot more isolated, [they are] not going to get out in the community ... [they] already live in a regional town so access to transport is important”</i>. CYDA staff member.</p>

Mainstream – Justice	CYDA survey participants advocate for a principles-based approach, in situations where the justice system fails to meet the access needs of people with disability or when their interaction with the justice system is related to their disability. People with disability (particularly young people) are overrepresented in the justice system ⁴ and, therefore, need access to justice supports. In previous consultations, CYDA has heard of troubling cases where young people with cerebral palsy were accused of being drunk and disorderly by police due to the way they walked. Justice supports are essential in combating such discriminatory charges.
Mainstream – Aged Care	Due to the limited timeline for consultation, we have no specific comment at this time.
Unlawful goods and services	Due to the limited timeline for consultation, we have no specific comment at this time.
Income replacement	Due to the limited timeline for consultation, we have no specific comment at this time.

⁴ <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/justice-and-safety>



Case Study

The following case study is a composite based on multiple examples of young people with disability represented by CYDA. It illustrates the need for a principles-based approach to the NDIS supports that are not represented in the lists or on the 'not NDIS supports' lists (such as assistive household products, employment assistance and work arrangements or the working environment)

Ali, a 19-year-old young man, is transitioning from his family home to a share house in a nearby suburb of their city. The dynamic nature of his disability, a type of muscular dystrophy, means that he needs flexibility in his supports. Prior to moving, Ali used support workers for some transport to and from appointments and minimally for assistance with household and personal care tasks, which his family has mostly been doing. Because Ali's goal is to be more independent from his family, he hired a primary support worker to assist with daily living tasks. After only a month, Ali realised that if he could get a few basic kitchen items to help him prepare his meals, he could employ a support worker three times a week instead of every day.

Although he's self-managed, Ali felt nervous about not being reimbursed for the items, so he called his Local Area Coordinator. They said, "the NDIS doesn't usually fund these items" but Ali's tight budget meant he couldn't afford to buy them. Ali asked a group he's part of on social media and they all told him to go back to the LAC and explain that the items were related to his disability. When he called the LAC back, they advised that Ali get a letter from his Occupational Therapist or Physiotherapist to support the purchase. Ali then had to spend \$240 on a letter in order to justify two items that were worth \$320.

The additional cognitive load that came from undertaking this task created extra disability related fatigue, leaving Ali with less time and energy to do the things that are important to him. When Ali began to apply for jobs that allowed him to work from home as part of his goal to gain part-time employment that accommodated his disability, he sought a review of his plan to help with setting up a work station at home. NDIA rejected this request.

Over time, the additional tasks associated with managing his NDIS plan created a pressure that impacted Ali's ability to maintain his independence and meet his goals. After six months of living independently, Ali began to think that he might need to move back home and was feeling like he'd failed at his goal to be independent.



Appendix:

Summary of August 2024 survey responses from Young people, parents and caregivers on the proposed draft lists of NDIS Supports

This submission is informed by the insights and lived expertise of children, young people and parents and caregivers in our community.

On 8 August 2024, CYDA launched a survey to gather feedback from young people with disability, and their families, about proposed changes to the NDIS through the NDIS Amendment Bill.

Over six days, CYDA received 212 responses from young people with disability, parents or caregivers, and professionals from around Australia. This cohort included NDIS participants (87%) and people not currently on the Scheme.

We present the following Summary report of our community survey of children, young people with disability and parents/caregivers which supports our submission.

The Summary can also be found on [our website](#).

Background

The Federal government has suggested changes to the National Disability Insurance Scheme (NDIS) through the NDIS Amendment (Getting the NDIS Back on Track No. 1) Bill. This Bill passed the House of Representatives on 5 June 2024 and which passed the Senate in August 2024. In anticipation, the government released a set of draft lists to define what is and is not an NDIS Support. If the Bill becomes law, the lists will be used by the National Disability Insurance Agency (NDIA) as 'transitional rules' to determine how NDIS plans are used while they make further decisions about what should be considered an NDIS Support. On 4 August 2024, the government launched a public consultation period to gather feedback on the transitional rules. This consultation closes on 25 August 2024.

Introduction

On 8 August 2024, CYDA launched a survey to gather feedback from young people with disability, and their families, about the draft transitional rules. In six days, CYDA received 212 responses from young people with disability, parents or caregivers, and professionals from around Australia. This cohort included NDIS participants (87%) and people not currently on the Scheme.

Survey questions were about how respondents currently use NDIS-funded supports, their thoughts on the proposed new rules, and how they might be impacted by them. It also asked how they would source information to help them understand changes. Respondents were presented with three hypothetical scenarios based on proposed rules around employment, travel-related supports, and parenting programs. They were asked to assess whether the fictional characters in these scenarios could or could not use their NDIS plans to fund various types of supports under the new rules.

Responses to the survey provided key insight into how young people, parents, and caregivers understood and interpreted the rules, and their personal experiences with the NDIS. Questions related to information availability provided useful feedback about where participants and their families source information to inform their decisions.

This survey is part of CYDA's ongoing commitment to understand the experiences of children and young people with disability, and their families and caregivers.

Key issues

1. Young people, parents, and caregivers feel as though they are not being listened to by the government and decision-makers

Respondents strongly recognised that a sense of agency and opportunities to 'have a voice' are safe and effective mechanisms for ensuring services are appropriate for people with disability. Survey responses strongly emphasised that NDIS participants do not feel confident in the government's approach to co-design.

"It's clear the NDIA do not believe in co-design or consulting the disability community in anything." (Young person with disability, aged 16-25yrs)

The Government's approach to this consultation has further eroded the trust children, young people, and their families have in the Scheme, and more broadly in the Government. The short time frames for responses and the complexity of the changes have meant that young people and families feel as though the process is not a genuine one.

"I'm too exhausted from caring, and feeling like the Government, media and community hates us, to go back to list at the moment." (Parent or caregiver of a young person with disability 16-25 years)

2. Young people, parents, and caregivers are concerned about the NDIS Supports lists and their application

Survey responses highlight concerns that creating specific lists of NDIS Supports will remove the flexibility and innovation required to meet individual needs. Up to this point, NDIS participants have been encouraged to be innovative in how they use their funds to ensure the most effective supports can be provided.

"This [definitive lists] limits any innovation in the industry, and the disability community generates innovation." (Parent or caregiver of multiple children under 15 years)

Considering the proposed NDIS Support lists, young people and families are concerned that the lists will result in significant limitations that will result in not being able to get the support required.

"It can't be that black and white. These new rules are entirely ableist. They show no understanding of the differing needs of individuals with disability and fail to provide them with dignity." (Parent or caregiver of a young person with disability aged 16-25 years)

The complexity and individual experiences of disability require a flexible approach. Survey respondents do not believe that a list of supports will enable the individualisation, and therefore useability, of the current system.

"Our disabilities are varied and complex. No simple list will ever meet everyone's genuine need." (Parent or caregiver of a young person aged 16-25 years)

It is noted that 33.8% of survey respondents agreed or strongly agreed that the current NDIS rules are flexible enough to get the supports required. 56.31% stated that it is difficult to know if a support could be considered 'reasonable and necessary' under the current rules.

3. Young people, parents, and caregivers believe there should be exemptions under specific circumstances

Concerns were raised by young people and families that a list would remove the flexibility, and the right to appeal, where a support might be the most cost-effective and suitable option for them. Young people and families noted the importance of ensuring supports enabled disabled persons to have equitable access to life activities.

*"I think exemptions should be available where the request allows a participant to participate in everyday life the same as a non-disabled person."
(Parent or caregiver of a child with disability aged under 9 years)*

Although geographical information about respondents was not collected on this occasion, respondents did acknowledge the difficulties for children and young people in regional and remote communities.

*"There are a bunch of exemptions required for people who live in remote areas so they are able to access supports. It may need innovative thinking to adequately support people in this context."
(Parent or caregiver of a young person 16-25 years)*

4. Young people, parents, and caregivers fear losing essential supports

Survey respondents noted they are concerned supports they currently have will be lost, including essential therapies and services they have been receiving. Therapy can provide skill development and individual capacity building for a child, which in turn will enable them to participate more fully in their community.

*"I'm concerned about the government ruling out certain supports because they're considered 'normal expenses' ... [O]ur need for them isn't normal. It's not a choice. It's disability related and it means the difference between accessing the community, school etc. Without these supports, my kids couldn't go to their mainstream schools or their capacity building appointments."
(Parent or caregiver of a child 9-15 years)*

Young people are concerned that they will lose supports that enable them to participate in education and employment, particularly assistance with travel. They believe that this will disadvantage them in the job market and potentially lead to unemployment or underemployment. CYDA acknowledges the inclusion of assistance with travel/transport arrangements as NDIS Supports, however, the concern remains in the community where implementation may impose limitations.

*"Losing supports for being driven to work and having a support worker accompany me to interstate work events is a huge fear, as it may lead to me losing my job or at least miss out on job opportunities."
(Young person aged 16-25 years)*

5. Young people, parents, and caregivers do not have the information they need to easily interpret and apply the legislation

Survey respondents were asked to provide feedback on their understanding of the current rules for NDIS access and plan utilisation. Only 28% stated that it is easy to understand how they can and cannot use their child's NDIS plan. The current 'reasonable and necessary' criteria are vague and open to inconsistent applications by NDIA delegates. Families feel as though they do not understand how rules are applied because they differ between staff.

*Reasonable and necessary is again interpretation of the NDIS representative of the day, the examples they give are usually simplistic which disability is not, this allows for abuse of the system but also lots of reviews as things that are reasonable for people with complex needs are often not understood by the decision makers.
(Parent or caregiver of a child 9-15 years)*

The rushed consultation and lack of clarity with the NDIS Support lists has also led to confusion among young people and their parents and caregivers. Survey respondents reference the implementation of the PACE system, provider registration, and recommendations from the NDIS Review or Disability Royal Commission, highlighting the complexity of information they are currently trying to understand.

The survey asked respondents to share who will support them to understand the changes that will impact them. 57% would seek advice from their support coordinator or other NDIS-funded support and only 1 in 6 would receive information from NDIA (including LACs). Almost one third use social media groups as a primary source of information to navigate the Scheme and understand changes.

Honestly, I have no idea [where I will get the information]. I'll seek out knowledge myself from [advocacy organisation] and social groups. (Parent or caregiver of a child with disability 9-15 years)

6. Young people, parents, and caregivers are confused about the transitional rules because they are inconsistent and contradictory

The survey asked respondents to consider three scenarios and to apply the NDIS Support lists to the scenarios. Responses highlighted significant confusion and inconsistency in how the rules could be interpreted.

Scenario 1: Assistance with employment

The proposed rules say NDIS funds can be used for "workplace assistance that enables a participant to successfully obtain and/or retain employment". However the proposed rules also say NDIS funds can't be used for "work-specific support related to recruitment processes, work arrangements, or the working environment".

Alysha is 20 years old. She is Deaf and requires an Auslan interpreter to support her to communicate with colleagues at work. Under the proposed new rules, can Alysha use her NDIS plan to pay for her Auslan interpreter at work?

43.65% of respondents were unsure if this would be considered an NDIS Support under the proposed rules. One third of respondents stated this would not be an NDIS Support. Responses highlight the need for further clarification about the rules, including where carve-outs may apply.

"Frankly, the wording is as clear as mud. I mean, what is 'workplace assistance to obtain and retain employment' vs 'work specific support'. Which is having a support worker do the driving so the participant can do Door Dash for example?" (Parent or caregiver of a young person 16-25 years).

Respondents note that inconsistent application of the rules will likely vary across different individuals. Many are concerned that a lack of clarity about the rules and their intended application will result in people being unable to access supports that are creative or innovative, including those that may be more cost effective or beneficial to the individual.

"Any rule that says "could" will actually mean maybe 1-2 cases across the whole scheme. They NDIA will fall back on how it's unclear "could vs will" and refuse to let you spend funds in this manner." (Young person with disability, aged 16-25 years)

7. Young people, parents, and caregivers are concerned about the impact the NDIS Support lists will have on their lives

Survey respondents noted that the lists would introduce greater restrictions on their choices and the supports they need to live their lives. This was considered a breach of the United

Nations Convention on the Rights of Persons with Disability (UNCRPD) and potentially the Disability Discrimination Act 1992.

"[It] appears to be a human rights violation and against the spirit of what the NDIS was initially set up for. The government should be aware that internationally, countries will be watching how the NDIS is working, and it will set a negative tone for international disability support if this Bill is passed. It's highly concerning and shocking that the youth representatives within the governance systems of the NDIA and NDIS were not consulted in this process." (Young person with disability aged 16-25 years)

Respondents were also concerned that the lists would reduce their options for appeal and, in turn, would increase administrative burden and stress for participants.

Scenario 2: Support with personal tasks while travelling

The proposed rules say that "assistance with and/or supervision of personal tasks of daily life to enable a participant to live as autonomously as possible, in a range of environments, including but not limited to, the participant's own home" are NDIS supports.

The proposed rules also say that "cruises, holiday packages, holiday accommodation, including overseas travel, airfares, passports, visas, meals and activities" are not NDIS supports.

James lives in Brisbane. He is 22 years old and engages support workers to help him with personal tasks like eating and showering. He would like to travel to New Zealand for his grandfather's funeral but will need to have a support worker with him. Under the proposed new rules, what could James use his NDIS plan for?

Respondents had mixed views about which expenses would be considered NDIS Supports in this scenario. 82% of respondents believed James could use his NDIS plan to fund support worker hours during the trip. Support worker expenses were less likely to be considered NDIS Supports with 20% supporting funds for flights and accommodation and 17% for the support worker's meals.

Some respondents felt that the trip would not be considered a "holiday" and therefore should be fully supported, including flights and accommodation and other expenses for a paid support worker.

I read this as James is unable to receive support for the trip, as it is considered travel. So, James effectively can receive support as long as he stays within his own home & doesn't dare wish to live as an independent person, who has the freedom to travel. (Parent or caregiver of child with disability aged 9-15 years)

Respondents reflected on their own experiences, with many sharing that covering costs for a longer period was beyond the scope of their planning budget. This demonstrated a significant discrepancy in planning budgets and the application of existing rules and guidelines within the Scheme.

My 23-year-old daughter doesn't have enough support hours to go anywhere without me. I've never had a break in 23 years. Today I'm in tears, exhausted, and no idea how to give her the life she wants and needs. Worried where she will live when I'm not around to advocate for her and help her. (Parent of a young person with disability aged 16-25 years)

Scenario 3: Parenting programs

The proposed rules say "parenting programs specific to a disability need, could be considered under capacity building (NDIS) supports".

Tammy and Michelle are the parents of two children aged 7 and 12 years, who both have Autism diagnoses and NDIS packages, including capacity building. They have seen a retreat specifically for parents of autistic children, which says it will give parents the opportunity for peer connection and to engage in wellbeing activities. Under the proposed new rules, do you think this parenting retreat could be considered an NDIS support?

There were divided views about whether or not this scenario should be funded by NDIS. 25% of respondents agreed that a parent retreat could be considered an NDIS Support, while 41% disagreed. 21% of survey respondents were unsure how the rule could be applied in this situation.

Young people, parents, and caregivers noted that informal supports were inadequately supported and therefore felt that parent/caregiver support should be included. Many noted that parent education about disability, or a child's developmental pathway, was important, while others focused on parent wellbeing.

Without unpaid Carers our economy would be under far more strain, yet parents are treated like expendable garbage without any needs whatsoever- all while carrying a harder load than these decision makers will ever know!

(Parent or caregiver of multiple children with disability under 25 years)

Some responses reflected general concern about parents receiving accommodation, and 'fun' activities for parents, being included as NDIS Supports previously. Many preferred 'parent programs' to consist of knowledge building that was directly related to their child's disability, which may in turn, include the development of peer networks between parents.

"Long before NDIS when disability supports were good, I did a parenting course for intellectual disability, it greatly improved my capacity as a parent which helped my son's progress. My son has autism too and without me understanding it, I cannot help him. Also, other parents share ideas and help immensely." (Parent or caregiver of young person 16-25 years)

Key considerations

The following are key messages for consideration in the implementation of the NDIS Back on Track Bill, in particular section 10 and the NDIS Supports definitions. These considerations are developed in direct response to the survey responses provided.

Information about changes must be presented in a way that is easy to find, understand, and apply

For young people, families and caregivers to make decisions and manage NDIS plans, it is important that they clearly understand the guideline that inform budgets and spending. The complexities of current reforms have become confusing for participants and their families, therefore leading to misinformation and unnecessary concern.

Information should be considered in three ways:

1. **Information about the NDIS that is used to communicate broadly about the Scheme and its intentions.** This information should be provided in accessible formats, including in plain language and should be easy to find on the NDIS website or elsewhere, including social media.
2. **Information for participants about how to use their plans.** Clear and easy to apply guidelines on plan expenditure is important, so that participants and their families can make informed decisions that are in-line with the intention of the Scheme, while also meeting their disability-related needs.
3. **Information for those who wish to engage in co-design or systemic advocacy.** Currently the information that is currently available from the NDIA does not enable people to engage in co-design in an informed way. Organisations like CYDA, and other DROs, are required to provide a conduit for young people, parents and caregivers, to build their knowledge to enable them to effectively engage in systemic discussions.

The survey highlighted that young people, parents and caregivers, are confused about information that is publicly available, including information published in the media or on social media, and how it relates to their circumstances. NDIA have not been forthcoming with

information, including in relation to this specific consultation, leaving participants to try to make sense of the significance of each aspect of the reforms.

Future communications should be carefully considered to ensure it is clear how each aspect of the reforms may impact on individual lives. Where possible, communications should be directed to participants directly, so they are not reliant on social media or mainstream media for information.

Consultation must be genuine and include time for the community to engage in the content

The short timeframe for consultation on the NDIS Supports was insufficient to meet the communication needs of many young people, parents and caregivers. There was inadequate time to understand the information to an extent that informed feedback could be provided. As noted in the survey responses above, young people, parents and caregivers were confused about the categories, and the role of the lists as a legislative instrument. Information provided to inform the consultation was complicated and not easy to find, with Auslan and Easy Read materials being released well into the consultation period.

Genuine engagement requires knowledge and understanding of the issue, including how new processes will impact the lives of individuals. Combined with improved communications, extended consultation periods are essential to ensure the community feels heard throughout the reform process.

A principled approach in place of stated lists of NDIS Supports to enable ongoing flexibility and individualisation of plans.

The survey highlighted the significant concerns of young people, families and caregivers, who feel they may lose essential supports that are already in place. Some respondents noted that lists should not be included at all and that a principled approach should remain to ensure the highest level of flexibility and innovation.

The disability-related needs of children and young people are changing all the time, as they progress through different life stages, and through technological advancements or further research findings. A principled approach enables careful consideration about the intent of the Scheme, while still enabling flexibility and individualisation of plans to meet the needs of each participant.

Where clear definitions are required, these should be supported by a set of principles to determine their application in specific circumstances.

Conclusion

CYDA acknowledges the experiences of children, young people, and their families and appreciates their time to complete this survey. Their voices and perspectives play a key role, now and always, in designing CYDA's advocacy and informing our messages to government.

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