

Young people, parents and caregivers on the proposed draft lists of NDIS Supports

Summary of survey responses collected
August 2024



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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 is expected to pass 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.