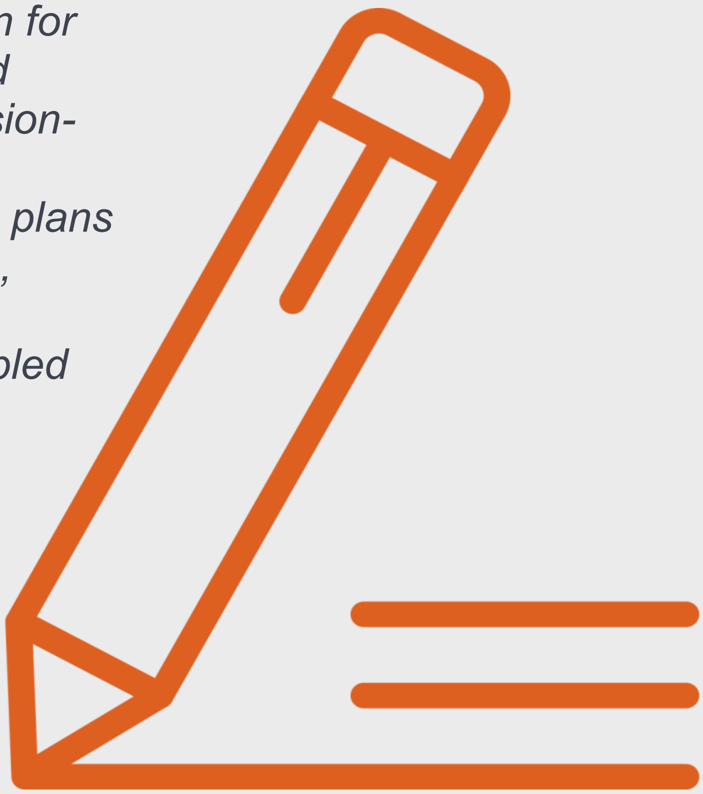
Reimagining the NDIS

by children,
young people
and families

Reimagining a Better NDIS for Children and Young People

"I hope the NDIS Review panel will consider providing more education for all NDIS staff and involve disabled people in this education and decision-making. It will allow for more accessible, fair and suitable NDIS plans which reflect a participant's needs, allowing for more independence, consistency and freedom for disabled people".

(Grace, CYDA Youth Council member, August 2023)



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Children and Young People
with Disability Australia

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A note on terminology:

Terms being used:

Children and young people with disability

The disability community has largely recognised and used inclusive language and terminology for decades. 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. These terms are therefore used interchangeably throughout this submission.

Families and caregivers

CYDA refers to children and young people with disability and their families and caregivers. We use the term ‘families’ as recognition of the different structures and arrangements and ‘caregivers’ to acknowledge not all children live in family environments. For the purposes of this submission, CYDA are detailing the experiences of children and young people with disability who are cared for by their families and caregivers.

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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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.

CYDA welcomes the opportunity to respond to the Independent Review of the NDIS. This submission builds on our previous work /evidence provided about the NDIS which highlights the need for change. Furthermore, it draws on recent data gathered by CYDA from young people and families, specifically pertaining to the NDIS Review, as outlined below.

Note: the NDIS-related data collection for this submission is distinct from CYDA’s work contracted by the NDIS Review Secretariat (Feb-Aug 2023).

Data sources include:

- A survey conducted by CYDA within its community (n = 119), titled 'Your Voice on the NDIS and the Australian Federal Budget,' which gathered responses to the government's announcement of reducing the NDIS growth target to 8% by 2026 (May 2023).
- Online consultation with members of CYDA’s 2022 and 2023 Youth Council (n=8, majority NDIS participants, July 2023)
- Five case studies prepared by young people and families outlining what are the key changes they want to see from the NDIS Review (July 2023)

Data gleaned from past sessions and events run by CYDA, including:

- CYDA’s 2022 survey respondents (n=181) about experiences of early childhood education and care. The majority (97%) responses were from family members or care givers of a child or young person with disability and were published in the ‘Taking the first step in an inclusive life – experiences of Australian early childhood education and care’ report[1]

- Additionally, this submission was shaped by CYDA staff, the majority of whom have personal and/or family experience of disability.

Direct quotes drawn from the data collected are indented from main text, italicised and in inverted commas and anonymised to protect privacy.

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[1] Dickinson, H., Smith, C., Yates, S., Faulkner, A. (2022) Taking the first step in an inclusive life – experiences of Australian early childhood education and care. Report prepared for Children and Young People with Disability Australia (CYDA), Melbourne.https://cyda.org.au/search/details/352/report-taking-the-first-step-in-an-inclusive-life-experiences-of-australian-early-childhood-education-and-care

Summary of recommendations

As a representative organisation for children and young people with disability across Australia, CYDA welcomes the opportunity to make a submission to the Independent Review of the NDIS. Given the compelling evidence highlighting the marginalisation of children and young people with disability, stemming from age-related factors, legal constraints, and limited agency, as underscored by insights from the CYDA community, we urge the NDIS Review panel to adopt the comprehensive set of recommendations detailed in this submission.

Recommendation 1: Guarantee children with disability remain in the scheme until viable and effective early childhood approaches are available for all.

Quality Early Childhood approaches must be at the core of this commitment:

- Build an inclusive, universal, and high-quality early education and care system that specifically caters to children with disability.
- Expand Information, Linkages and Capacity Building (ILC) program funding to include a specific approach to improving mainstream Early Childhood Education and Care (ECEC).
- Foster collaboration and information sharing between the NDIS and the early education and care sector for consistent and clear support in local communities.
- Address child and youth health equity in policy, by applying a social determinants of health approach.

Recommendation 2: Ensure the NDIS is fit-for-purpose for children and young people (9–25-year-olds).

- Tailor NDIS Plans for specific life transitions. For example primary school to secondary school
- Implement an NDIS practice framework (for ages 9-25) with clear accountability and transparency across the state and territory, education, health and child protection systems.
- Provide a specific pathway in the NDIS for youth, by collaborating with Disability Representative Organisations for evidence-based development.

Recommendation 3: Empower the NDIS workforce to support the unique needs of children and young people with disability.

- Employ people with lived experience across the NDIS system, including Local Area Co-ordinators, Support Co-ordinators and NDIS providers – with a minimum Quota for all participant-facing roles.
- Invest in comprehensive training and support for NDIS staff, Local Area Coordinators, Support Coordinators, educators, teachers, and related professionals involved in supporting children and young people with disability at all life stages.

- Create clear pathways for employment across the NDIA for young people with disability.
- Ensure decisions made by the NDIA Executive and Board are informed by the views and experiences of children and young people with disability.
- Return choice and control to participants and their families or caregivers and provide assurance that participants won't be worse off due to price gouging, fraud or profiteering by providers, specialists or areas of the **workforce** outside of participants' control.

Recommendation 4: Implement better data collection across both NDIS and non-NDIS systems.

- Extend the NDIS outcomes framework survey data collection to include NDIS applicants found ineligible, to ensure no-one falls through the cracks.
- Invest in national and regional mechanisms to prioritise and act on the voices of children and young people with disability by collecting evidence directly from families, children and young people with disability.
- Track the pathways and outcomes of children through different systems by ensuring better data linkage and the joining of data sets.

Recommendation 5: Change the perception of children as a cost burden in the NDIS by showcasing the long-term benefits of investing early in childhood support.

- Showcase the long-term benefits of investing in children with disability, timed alongside the release of the NDIS Review report.

Detailed Recommendations

Recommendation 1: Guarantee children with disability remain in the scheme until viable and effective early childhood approaches are available for all.

Quality Early Childhood approaches must be at the core of this commitment:

- Build an inclusive, universal, and high-quality early education and care system that specifically caters to children with disability.
- Expand Information, Linkages and Capacity Building (ILC) program funding to include a specific approach to improving mainstream Early Childhood Education and Care (ECEC).
- Foster collaboration and information sharing between the NDIS and the early education and care sector for consistent and clear support in local communities.
- Address child and youth health equity in policy, by applying a social determinants of health approach.

The NDIS Review Panel's interim report[2], titled 'What we have heard,' highlights the volume of children registered in the scheme, as a notable sustainability challenge. While CYDA acknowledges the feasibility constraints of encompassing all children with disability, including those with autism and global development delay, we urge the NDIS Review panel not to overlook the imperative of preventing any child from falling through the cracks.

Therefore, 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 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. To achieve this CYDA recommends;

- Building an inclusive, universal, and high-quality early education and care system that specifically caters to children with disability.

  CYDA urges the Australian Government to align the policy priorities of the Early Years Strategy closely to the *Early Childhood Targeted Action Plan* as outlined in *Australia's Disability Strategy 2021-2031.* Especially to:
    - Enable early identification of disability or developmental concerns and develop clearer pathways and timely access to appropriate supports.
    - Strengthen the capability and capacity of key services and systems to support parents and caregivers to make informed choices about their child.

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[2] https://www.ndisreview.gov.au/resources/reports/what-we-have-heard-report

- Expanding the Information, Linkages and Capacity Building (ILC) program funding.

  The delivery of Tier 2 supports through Information, Linkages and Capacity Building (ILC) grants has found investment in ILC to be inadequate[3]. For the number of people Tier 2 is intended to support— roughly 4 million— investment in Tier 2 accounts for less than one per cent of overall investment in the NDIS.

  CYDA therefore recommends;

    - Including a specific approach to improving mainstream Early Childhood and Education Care service provision within ILC.
    - Extending the ILC funding model from time-limited to long term to ensure systemic and sustainable change.

- Fostering collaboration and information sharing between the NDIS and early education and care sector for consistent and clear support in local communities by establishing effective channels of communication, regular meetings, joint planning sessions, and shared data to ensure a coordinated approach in supporting children with disability.

- Providing a system that balances both acute care and prevention by addressing the social determinants of health in policy development.

  According to health researchers[4], applying a social determinants of health approach in child health policy is considered best practice. These include key elements of the social determinants of health in childhood—good education in the early years, free of discrimination—as crucial to tackling inequities in Australia.

  CYDA encourages all Australian child health and education policy makers to develop specific policies to address the needs of children by focussing on the social determinants of health. This is also an opportunity for the NDIS to be trail blazers by implementing the right policies at the right time. Getting policy settings right in the early years, means an improved social and economic trajectory and less reliance on health supports later in life.

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[3] D'Rosario, M. (2023), Not a one-stop shop: the NDIS in Australia's social infrastructure, National Disability Services, Per Capita, Australia, 14 November1

[4] Littleton, C., Reader, C. To what extent do Australian child and youth health, and education wellbeing policies, address the social determinants of health and health equity?: a policy analysis study. *BMC Public Health* **22**, 2290 (2022). https://doi.org/10.1186/s12889-022-14784-4

Recommendation 2: Ensure the NDIS is fit-for-purpose for children and young people (aged 9-25):

- Tailor NDIS Plans for specific life transitions. For example primary school to secondary school.
- Implement an NDIS practice framework (for ages 9-25) with clear accountability and transparency across the state and territory, education, health and child protection systems.
- Provide a specific pathway in the NDIS for youth, by collaborating with Disability Representative Organisations for evidence-based development.

As stated in Recommendation 1, prioritising early childhood is vital and a review of the Early Childhood Approach is a welcome measure. Equally essential, however, is addressing the gap in tailored support for those aged 9-25 years. The NDIS in its current form is not fit for purpose to meet the evolving needs of older children and young people, who are required to navigate complex biological, psychological, and social changes during their first 25 years. This occurs as they confront identity and intersectional challenges, including LGBTQIA+ issues intertwined with disability and diagnosis. Along with these individual changes, children and young people also rapidly transition through different life stages and encounter new systems. How they experience these life transitions – and whether there are safeguards in place – then have flow-on impacts on the trajectory of their lives and the opportunities they can access.

While the Early Childhood approach offers a separate service system for participants aged eight years or younger, the NDIS lacks a targeted approach for youth outcomes during this vital developmental period, this is despite 42 per cent of scheme participants being aged between 7 and 24 years[5]. Factoring how important and influential these early years are, services and systems must have the capacity to understand and support the distinct needs of children and young people, as this CYDA survey participant highlights:

> *"[Plan funding] … was fine for 14-16yo but has been rolled over/extended and is not sufficient for 17-18yo. It is terrifying to face the possibility of funding being cut if we go ahead and seek a review to actually meet the needs of the older life stage"*
>
> *(Family Member, May 2023).*

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[5] As at March 2023; NDIA. (2023). *Explore data.* Available at https://data.ndis.gov.au/explore-data

Currently, the NDIS offers the same support system – with the same workforce – to all participants aged nine years and older.

This generic approach is incompatible with neurodevelopmental theory[6] which encompasses the study of how the brain and nervous system develop and change over the course of an individual's life. Middle childhood is a critical period of growth and development. Furthermore, as individuals progress into their teenage years and young adulthood (ages 13 to 25), they experience profound life transitions. These transitions include the development of identity, autonomy, and the establishment of personal values. Neurodevelopmental theory underscores the importance of these transitions in shaping an individual's overall well-being and functioning and NDIS planning should be tailored accordingly.

One way such adjustments can occur is to provide intensive support during pivotal life transitions. For instance, when adolescents come of age at 18 and gain legal adulthood, the NDIS emphasises their autonomy in decision-making and plan management. Yet, this pivotal juncture lacks adequate specialised assistance. By flagging trigger points at such crucial moments, the NDIS can enable support and skill growth. This aid would encompass essential facets like defining objectives, selecting NDIS providers, liaising with the NDIA and medical experts, as well as fostering self-advocacy and informed choices.

Acknowledging the lack of appropriateness of the current NDIS model and its failing to factor in or cater to the distinct needs of children and young people, CYDA urges the Australian Government to develop an NDIS youth-specific practice framework for working with participants aged 9-25 to ensure service improvement and consistency across gender, geography and other intersecting demographics. This framework should be accompanied by workforce training and clear accountabilities to ensure continuity of support across systems such as education, health and child protection. The framework should be informed by evidence-based practice, intersecting with the Australian Government's Youth Strategy and developed with Disability Representative Organisations to ensure its suitability.

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[6] Spear LP. Adolescent neurodevelopment. J Adolesc Health. 2013 Feb;52(2 Suppl 2):S7-13. doi: 10.1016/j.jadohealth.2012.05.006. PMID: 23332574; PMCID: PMC3982854

Recommendation 3: Empower the NDIS workforce to support the unique needs of children and young people with disability.

- Employ people with lived experience across the NDIS system, including Local Area Co-ordinators, Support Co-ordinators and NDIS providers – with a minimum quota for all participant-facing roles.
- Invest in comprehensive training and support for NDIS staff, Local Area Coordinators, Support Coordinators, educators, teachers, and related professionals involved in supporting children and young people with disability at all life stages
- Create clear pathways for employment across the NDIA for young people with disability through the existing work experience and internship programs by linking successful completion of these programs with ongoing employment at the agency.
- Ensure decisions made by the NDIA Executive and Board are informed by the views and experiences of children and young people with disability through:
    - designating NDIA board positions for young people with disability, mentored by more experienced board members; and
    - the establishment of a NDIS Youth Advisory Council to provide advice to the NDIA board. The Youth Advisory Council could also provide its members with governance training and act as a pathway to NDIA board membership.
- Return choice and control to participants and their families or caregivers and provide assurance that participants won't be worse off due to price gouging, fraud or profiteering by providers, specialists or areas of the **workforce** outside of participants' control.

A better-equipped NDIS workforce is key to meeting the unique needs of children and young people with disability. Training and support for staff, along with the inclusion of individuals with lived experience, will enhance the effectiveness and empathy of the NDIS system as one young person describes:

> *"Yes, employ more disabled people. [The NDIS] is a program and it's a system designed for people with disabilities, employ them. I had to explain what braille was in a planning meeting: I shouldn't need to do that." (Young Person, July 2023).*

CYDA finds the NDIA's aspiration to enhance its current workforce representation, where 17% of employees have personal experience with disability, to be commendable[7]. However, we urge for a more robust approach and advocate for the implementation of a mandatory minimum quota for lived experience in all roles across the entire system, including NDIS partners, especially those involving direct interaction with participants. While targets offer inspiration, quotas provide the necessary enforcement to drive genuine change, as argued by this young NDIS participant.

> *"Employ more people with disability! It seems silly to me that the NDIA doesn't have a minimum disability employment quota. It makes much more sense to employ people with disability, since we are the ones who know about people with disability best and what our needs are." (Young Person, July 2023).*

We strongly recommend that the NDIS invest in comprehensive training and empowerment programs for its workforce, across the entire NDIS ecosystem for all participant-facing roles. It is imperative that staff understand the critical significance of adeptly addressing the unique requirements of children and young individuals navigating pivotal life transitions. This encompasses a deep grasp of social, biological, and identity-related challenges. By arming the workforce with these insights, this will ensure a more sensitive and effective approach to serving this demographic, ultimately fostering their holistic development and well-being.

> *"I wish someone had recognised my disabilities earlier so I didn't have to grow up without adequate support …I think this could have meant my school teachers being more educated on how Autism and ADHD present in Assigned Female at Birth (AFAB) children, access to counselling that didn't have to involve my parents, early age-appropriate education that LGBTQIA+ people exist". (Young Person, July 2023)*

Evident within Part 2, i) of the NDIS Review's Terms of Reference[8] is the imperative to enhance the handling of breaches and unethical conduct, including the identification of fraudulent activities. Members of the CYDA community, particularly young people, and families, have voiced distressing encounters with exploitative pricing and profiteering. Their struggle to assert grievances underscores a concerning power imbalance within the system. It is not a matter of mere anticipation of complaints, but we argue for a proactive pursuit by the NDIA to actively elicit feedback and concerns. In parallel, service providers must take an affirmative role in not only advocating but also facilitating the process of raising complaints. This approach is fundamental to rectifying injustices, instilling accountability, and fostering a system that genuinely safeguards the rights and dignity of all involved.

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[7] https://www.ndis.gov.au/about-us/publications/annual-report 2021-22

[8] https://www.ndisreview.gov.au/about/terms-of-reference

Recommendation 4: Implement better data collection across both NDIS and non-NDIS systems:

- Extend the NDIS outcomes framework survey data collection to include NDIS applicants found ineligible, to ensure no-one falls through the cracks.
- Invest in national and regional mechanisms to prioritise and act on the voices of children and young people with disability by collecting evidence directly from families, children and young people with disability.
- Track the pathways and outcomes of children through different systems by ensuring better data linkage and the joining of data sets.

Without high-quality data, there are limited opportunities to develop evidence-based approaches to protect children and young people and monitor existing and new interventions.[9] The direct experience of children and young people with disability and the policy experience of CYDA demonstrates that there is a significant need to improve the collection and use of data at a range of levels both within and outside the NDIS. We recommend, therefore, an expansion of the NDIS outcomes framework survey data collection approach to include NDIS applicants found ineligible, to track the outcomes for this cohort and to identify gaps in mainstream systems. Otherwise, they will continue to be marginalised as this parent outlines;

> *“I implore the NDIS panel to consider changes to data collection so that a true picture can be formed of how many people sit in the hell that is the Missing Middle – people let down by NDIS, health systems and the other safety nets designed to protect them. Expanding data collection with a view to assessing the true need of NDIS is not just the ethical thing to do, it is necessary if we are to stop families like mine from falling through the cracks”.*
>
> *(Parent of children with disability – see case study 4, p. 22)*

Additionally, investment is needed in the development and sharing of rigorous research in collaboration with communities, to better understand what works for whom and why in different contexts and settings, especially with Aboriginal and Torres Strait Islander children and families, other Culturally and Linguistically Diverse (CALD)

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[9] Wayland, S & Hindmarsh, G. (2017). Understanding safeguarding practices for children with disability when engaging with organisations. Available at Understanding safeguarding practices for children with disability when engaging with organisations | Child Family Community Australia (aifs.gov.au)

populations and children in Out of Home Care settings (OOHC) and in the youth justice system.

Gaps in evidence and research – Children's voices should be heard

As highlighted in the Australian Institute of Health and Welfare (AIHW)'s report[10] on Australia's children, there are limited instances of gathering children's opinions or experiences as evidence. While national-level monitoring exists, it mainly involves administrative data from service delivery and surveys targeting adults, exclusively. Further, "*there are currently no national indicators to measure how children transition through major development stages, or how children interact with services and move through different systems…[and] … there is limited ability to track children through different data sources to assess their outcomes*". – This is a significant gap.

There is an urgent need to examine how data is used to inform policy and practice in the NDIS, ECEC and education systems. CYDA advocates for the improvement and refinement of data collection from early childhood and school education systems to strengthen the evidence base and improve educational outcomes, as *"…society cannot be equitable unless all children are included, and children with disabilities cannot be included unless sound data collection and analysis render them visible."*[11]

Track the pathways of children through different systems by linking data sets

We recommend the establishment of systematic data collection through interlinking various data sources. We strongly urge the NDIS to endorse the AIHW Children's Report[12], recommendation of integrating data from multiple sources to improve understanding of:

- How children transition between key developmental stages and their outcomes at different stages of their life
- The pathways children take through different services and the points where intervention would be most effective
- The relationships between risk factors, protective factors and outcomes, which interventions are most likely to provide positive outcomes, and which indicators can be used as predictive tools for monitoring
- How children's wellbeing or service use differs among different population and geographic groups, where data on a specific population group may only be available in one data set.

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[10] Australian Institute of Health and Welfare, Australia's children, web report, last updated 25 February 2022. https://www.aihw.gov.au/reports/children-youth/australias-children/contents/data-gaps

[11] United Nations Children's Fund 2013, *State of the World's Children 2013: Children with Disabilities,* United Nations, New York, p. 63.

[12] Australian Institute of Health and Welfare (2022) Children with disability in Australia. Available at: https://www.aihw.gov.au/reports/children-youth/australias-children/contents/data-gaps

Recommendation 5: Change the perception of children as a cost burden in the NDIS by showcasing the long-term benefits of investing early in childhood support

- Showcase the long-term benefits of investing in children with disability, timed alongside the release of the NDIS Review report.

> *“Jean is not a burden as some will have us think. She is not a problem to be fixed. She is resilient, feisty, funny and cheeky. . . . She has a lot to offer her peers, her family and her local community”.*
>
> *(Parent of child with disability – see case study 5, p. 23)*

CYDA has received feedback expressing worry about the widespread belief that children pose a financial burden, and in particular those who are on the NDIS. While we acknowledge the NDIS Review Panel's original intent, the interim report inadvertently reinforced this notion by highlighting the large number of children as a potential threat to the NDIS' sustainability. This messaging, implying that the NDIS is unsustainable and attributing responsibility to people with disability, has had a significant impact, as reflected in the comment from this young person with disability.

> *“Obviously there’s a lot of horrible debate going on about, ‘This NDIS costs too much, disabled people are being a burden.’ I was at the post office the other day and there was this dude on the phone just ranting to his friend about how much it sucks that we spend so much on NDIS, and I’m like, ‘Bro, I’m right behind you, be very careful.’*
>
> *(Young person with disability – July 2023)*

As highlighted in Recommendation 1, while CYDA acknowledges the sustainability challenge of including all children in the scheme, including those with autism and developmental delay, we emphasise that costs are only part of the equation. Long-term benefits and outcomes are equally crucial. We urge the NDIS Review Panel to prominently showcase the advantages of investing in support for children with disability, timed alongside the release of the NDIS Review report.

Benefits of investing in support for children, early—The evidence

Research suggests that for every $1 invested in supporting neurodivergent infants and parents, the NDIS could save at least $3 down the track[13]. Rather than waiting until after an autism diagnosis, very early supports for infants may promote better outcomes while relieving cost pressures and pressure on families.

Early intervention is an effective way to support the development and wellbeing of children with disability, autism or other additional needs including developmental delay. It can help children develop the skills they need to take part in everyday activities. Such an approach will reduce the need for support in programs such as the NDIS as they grow older. [14]

As outlined in the Productivity Commission' NDIS costs report (2017)[15], evidence suggests that providing individualised supports for children with developmental delay can improve outcomes for individuals and reduce costs.

Investing in inclusive education

The NDIS will only be able to achieve its full potential if children and young adults with disability get an education that adequately prepares them for later life.

While the NDIS holds the promise of transforming the lives of individuals with disability and their families, CYDA acknowledges that the scheme alone cannot eliminate all the obstacles they encounter in achieving complete inclusion. To realise its intended impact, the NDIS must also address various other barriers. A prime example is the interface with education, where children and young adults with disability require an inclusive system that adequately readies them for their future. Without an investment in inclusive education that meets diverse learning needs, children won't achieve their utmost potential. Consequently, this situation will not only increase adult support requirements but also curtail their participation in the broader Australian economy.[16]

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[13] https://theconversation.com/what-is-early-intervention-for-infants-with-signs-of-autism-and-how-valuable-could-it-be-205839

[14] https://raisingchildren.net.au/autism/therapies-services/therapies-interventions/early-intervention

[15] https://www.pc.gov.au/inquiries/completed/ndis-costs/report

[16] Disability expectations: Investing in a better life, a stronger Australia

Case studies – young people and families

This section contains five case studies of varying lengths, outlining the real-life experiences of young people with disability and families as they interact with the NDIS. Each case study presents a specific call to action for NDIS improvements, aligning with one of CYDA's five key recommendations outlined in this submission.

Note: The following case studies are presented using the original words of the authors and have only been edited for clarity and brevity. Real names are used, unless otherwise indicated.

Case study 1: Angelique – Aligns with Recommendation 1 (Guarantee children remain in the scheme until viable and effective early childhood approaches are available)**:**

Introduction (*name of the school and an organisation are deidentified for privacy reasons)

My name is Angelique May-Bennett. I have two daughters; my oldest is diagnosed with ASD/ADHD, and my youngest has ADHD. My oldest daughter is an NDIS participant but not my youngest.

Angelique's Story–

We have experienced a profoundly traumatic journey because of an independent school. It turned out to be ruthless and unforgiving, and our family was not protected from the school's archaic methods. We spent an incredible amount of time, resources, and funding to try to fix the school but without legislation that has accountability measures we were insignificant and throw-aways as far as the school was concerned. It was the only independent school in our area and as I'd attended a similar independent school it was something I wanted for my children. We turned to an advocacy service, our local minister, the ombudsman, and eventually another complaints body. All said they could not help because it is an independent school. We should be able to choose what school we want to send our children to. NDIS participants in other independent schools need support and help. The schools have AIS (Australian Independent Schools) to support them but there is no organisation or body to help families.

We ended up spending over half our daughter's NDIS funding that year sending her NDIS experts to the school to help educate them (on the social model (of disability) as they kept blaming our child for the problems in the environment). Our NDIS experts gave an enormous time to the school to try to work out a way forward. The school's methods were wholly based on the medical model, and the practices they suggested, including barring our daughter for 6 months, and asking her to stop wearing an essential oil as they thought it was aggravating her behaviour (?!?). If schools were held accountable, we would have an avenue, like a third-party watchdog, to address the problem, instead of wasting NDIS funding on fixing the school. These are funds that are meant for therapy, not educating schools.

If there had been the following, our experience entering the education system would have been very different:

Call to action:

- NDIS participants deserve a third-party, neutral-party, watchdog to be grass-roots, with lived experience otherwise they won't understand the challenges that NDIS participants face in the education system.

- Children with a disability, especially invisible disability, are the most vulnerable population in Australia. Independent schools should not be allowed to discriminate against them.

- ALL NDIS participants should have special protection.

- ALL schools should have MANDATORY inclusion/disability training to protect these vulnerable children. Independent schools should be held accountable– but it should not be up to the families to make them accountable.

- If schools and teachers were all educated adequately, they would not behave in ableist ways and simply ask children to stay home. Any time a child is asked to stay home it should be reportable.

Case study 2: Monica – Aligns with Recommendation 2 (Ensure the NDIS is fit-for-purpose for children and young people (9–25-year-olds)**:**

Introduction

I am a Sydney based disability advocate who showcases and spreads awareness online about Tourettes and neurodivergence. I am passionate about disability advocacy as I see Tourettes as one of the most misunderstood and stigmatised disability and as a person of colour too I see the gaps in representation when it comes to showcasing the experiences of those from ethnic/migrant backgrounds.

I have been an NDIS participant for 5 years.

Monica's story

As a person who lives with Tourettes I have been very lucky to have a mother who was able to provide me access to the NDIS through her in depth understanding and readings. It has helped me access many things that I would not be able to fund today, ranging from therapy, support work, transportation to dance classes.

I have always been a very assertive person and been able to strongly communicate my needs and know what I want however this wasn't always the case, especially when your younger and do not understand the logistics of things. My plan started off with a plan manager who would occasionally see me and afterwards we switched to self managed plan for better ease and flexibility however when I was younger and had a plan manager, I didn't always feel that they fully understood my needs/preferences for things. I recall them booking in a personal trainer for me that I today, would've never booked as I didn't resonate with him. I didn't understand and kept seeing him, thinking I had to stick it out cause this was chosen for me.

It was only that once I got older that I was able to know what types of services and people were best suited to me and my circumstances.

As a person with Tourettes I'd like to say that I am very lucky to be on the NDIS as I know of others who cannot get on the NDIS despite being more then eligible, this also goes for conditions such as M.E/CFS and Ehlers Danos syndrome. I believe the NDIS has a long way to go improvement wise with being empowering and accessible rather than restrictive and providing more barriers to the disabled community.

Call to action:

I call the NDIS to tailor plans to better suit life transitions as when we grow up, preferences and choices can heavily change. I believe this can be done by giving younger children a better voice and autonomy, including them in joint decision making and not just depending on their 'parents' opinions.

Case study 3: Grace– Aligns with Recommendation 3 (Empower the NDIS workforce to support the unique needs of children and young people with disability):

My name is Grace, and I am a 24-year-old disabled young person. I am autistic, chronically ill and have a genetic connective tissue disorder, Ehlers-Danlos syndrome. I also have a certified assistance dog who helps me stay independent and manage my sensory needs. I am an NDIS participant and have been since 2020. I am looking forward to contributing to this NDIS Review, as many things have influenced my experience and the support I have received.

Grace's story.

My journey to getting on the NDIS was long, and there have been many positives since being approved. However, there have also been difficulties during the application process, the planning phase and the ongoing navigation of my NDIS plan.

I applied for NDIS several times for my psychosocial disability whilst getting declined each try. I received my autism diagnosis in 2020 and was finally approved for NDIS. The residential facility I lived in had staff who knew the correct wording for my application, so I could get adequate funding to transition into the community. I am lucky and privileged to have had this formal support to apply and my family's informal support, which not everyone has. I have endless stories from friends who did not receive enough funding for their needs, had awful experiences during the planning process and others whose funding was randomly cut and no support or someone to advocate for them. The outcome you receive within your experience of the NDIS depends entirely on what administration or Local Area Coordinators (LACs) you get looking at your file. This needs to change, and I believe education must be given to NDIS staff to ensure everyone receives fair services and support.

There are practical things that could change to improve the quality of care, supports, accessibility and fairness provided to participants. Firstly, hire more disabled people within the NDIS. We are the people who should be making decisions and guiding conversations around what affects our lives. We have perspectives and skills to bring that should be seen as an asset within the NDIS. It is crucial to hire people who have a first-hand understanding of disability. Ensuring that the LACs assigned to a participant fully understand the conditions they are assessing for access to NDIS or within the planning process is essential. Providing extra training to administration staff and LACs, coupled with opportunities for disabled people to share their knowledge within this training, would be transformative for the NDIS. Disabled young people hold intrinsic worth and deserve to have a role in decision-making for the NDIS.

Call to action: I hope the NDIS Review panel will consider providing more education for all NDIS staff and involving disabled people in this education and decision-making. It will allow for more accessible, fair and suitable NDIS plans which reflect a participant's needs, allowing for more independence, consistency and freedom for disabled people.

Case study 4: Nicki – Aligns with Recommendation 4 (Implement better data collection across both NDIS and non-NDIS systems)**:**

Nicki's story:

My name is Nicki, and I am a proud mum to Emily (16) and Riley (12). Emily, Riley and I all live with disabilities that impact our daily functioning, however we have been unable to secure NDIS funding. The combination of our conditions results in significant impacts to our families functioning, yet our access to interventions remains poor at best.

In my family unit I live every day with Bipolar Disorder and ADHD, Emily lives with Sensory Processing Disorder and ADHD, and Riley lives with Type 1 Diabetes and ADHD. As you can imagine, each condition is disabling, and when combined, our daily lives are complex, chaotic and require significant ongoing treatment at a high private cost. The health system doesn't support us (even with T1 Diabetes, they cover the medical aspects, but not the significant social and emotional burden).

If we had better data collection across both NDIS and non-NDIS systems, we would truly be able to see the impact on families and individuals like me, who are unable to access the NDIS, and are therefore missing out on valuable intervention and treatment opportunities. My families data is rarely taken into account when NDIS decisions are being made, because we simply can't access it – but that doesn't mean that our need doesn't exist.

The way we currently assess whether NDIS is meeting Australian people's needs is by reviewing the data of Australians currently accessing the NDIS or who have applied. There is a huge group of people in need of funding due to their disability, or a combination of their disabilities, that remain unable to access NDIS funding and therefore have never even applied. These families are desperate for someone to recognise their unmet needs, but how do we do this if we aren't even capturing data from those who are self-funding treatment?

If we threw the net a bit wider, collected data from all people who identify as having a disability requiring funding (despite what the NDIS definitions currently are), and reviewed their outcomes, their ability to access support, and the inevitable economic and social burdens, it would show that there is a '**missing middle**' - Australians living with disability who are unable to access NDIS and public health services, and therefore are unable to thrive and live their best lives. How can we say that NDIS is meeting our needs, without the data from those desperate, yet unable to access it?.

Call to action: I implore the NDIS panel to consider changes to data collection so that a true picture can be formed of how many people sit in the hell that is the Missing Middle – people let down by NDIS, health systems and the other safety nets designed to protect them. Expanding data collection with a view to assessing the true need of NDIS is not just the ethical thing to do, it is necessary if we are to stop families like mine from falling through the cracks.

Case study 5: Jean – Aligns with Recommendation 5 (Change the perception of children as a cost burden in the NDIS)

Jean's story: *name changed to protect privacy

We and our two children live a life of privilege. We live in our own home, in a suburb of a large city, close to amenities and family. We have no experience of violence, addiction or significant mental health issues. We speak English as our first language, have professional qualifications in demand and have lived in our local community for 16 years. Both our children attend "fairly" inclusive and welcoming government schools. We both work in supportive workplaces, close to home and have a level of literacy that allows us to navigate the complex systems that surround us.

After a tumultuous first five years of life for our youngest child Jean, we live a delightful and relatively ordinary life of two kids, two parents and two incomes. Both parents will be in their mid to late 50s when the children turn 18. Between now and then, we will navigate high school, first jobs, learners permits and first loves. We will also attempt to secure our family's long-term wellbeing and financial future with work and care responsibilities.

Over the 12 years of her life so far, both her parents have adjusted their work and financial arrangements. Both her parents have made changes to how we imagined our family and our careers. These changes have not been made because of our daughter's disability but because of the systems and the world we navigate to ensure she is loved, learning and living as typical as possible life of an 12-year-old.

Our child is a loved and loving member of our family. She is our second child. She has a rare genetic disability that impacts her physical, social, emotional, communication and cognitive engagement with everyday life. She has for the most part a very ordinary childhood. She goes to the same school as her older brother did. She attends after school hours care two days a week. She pats our dog, fights with her brother over the remote control, and raids the fridge when she's hungry.

When your child goes blue at home, stops breathing at 10 weeks old and you call 000, your husband's job security or arrangements are not top of mind. You question every move and decision you have made for the last 10 weeks and what could have changed this situation. You assume that the medical professionals you did and will now interact with, will provide you with all the information and professional insight you need to be the best possible parent to this tiny girl. You don't realise that ableism will now present itself at almost every interaction you have with medical staff, employers, bureaucrats and bank managers.

Jean is not a burden as some will have us think. She is not a problem to be fixed. She is resilient, feisty, funny and cheeky. She has life long, permanent disabilities that will mean she will need support and adjustments for the rest of her life. She has a lot to offer her peers, her family and her local community.

The overall NDIS plan value has remained at similar levels for the last six years and meets all of the current needs. This level of stability is due to our close management of it and in spite of a fairly horrendous transition process. We have never had the same NDIS person from plan to plan and each review requires telling "her story" over again. The lost work time spent engaging with this system is far above the value of any services or supports received or frankly, needed.

Jean's case study continued

Topic area	My child with disability has experienced the following….	This meant…
NDIS	Straightforward plan: Transition to NDIS at age 7 from previous Disability Services model. Currently on 5th NDIS plan. Arduous regular process: Before school and with over six years of early intervention and medical trauma under her belt, Jean appeared wary of and weary with adults and their expectations of her to repeat the same linear development milestone driven tasks over and over with the same expected outcome. We were also tired of explaining that Jean didn't appear to measure her happiness or quality of life by whether she would respond to her name, eat certain food, or say B for ball. People and professionals who were focused on frameworks and forms missed that B is for bath, formula was her saviour, she knows what her name is, and if you are over the age of 20, you are merely a means to an end and should not assume you are her friend.	Straightforward plan: Our child's NDIS plan is relatively straightforward, and we self-manage. Arduous regular process: The paperwork, the people and the process are all completely different to those completed under Health, Education, Inclusion Support Program, and kindy. For every plan we are required to prove again that our daughter has a permanent, lifelong disability – physical and intellectual. She has a rare genetic syndrome that is not an acquired disability and for which she has experienced over 500 sessions of early intervention either physiotherapy, speech therapy and occupational therapy.
Baby and maternity services - family and caregiver information and supports	Poor education and supports: The paediatrician didn't advise us she likely had a rare genetic syndrome that required early intervention and adjustments to support her development. The possible and eventually diagnosed syndrome was noted on her day 1 medical file, as accessed via FOI. None of the health professionals involved in maternity care supported us to understand what care might be required for our baby.	We as a family were not prepared or informed as to how we could and should prepare ourselves, our finances, our home set up and our mental approach to parenting. When her health declined at 10 weeks old at home, we had no provision for parental or sick leave, work breaks or financial buffer for the care that could have been anticipated and was required for the first few years of life.
Early childhood education and care	Limited access to care: Long day care options that were supportive, safe and suitable were limited.	Lack of access to early education and care with her same age peers and restrictions on work options for one parent, up until kindergarten age
Health	Poor experience with health staff: Experiences of discrimination and ableism have meant lengthy wait times for services	Our child has been unable to have bone density scans since 2017 because the state-based children's hospital medical imaging department is unwilling to make

Topic area	My child with disability has experienced the following….	This meant…
	and barriers to accessing services and supports Public and private health admissions and services: over the last 12 years we have navigated the public and private systems punctuated with a key theme of limited communication between the two systems. Our child has at one time been under the care of the following (not exhaustive list): 1. GP 2. Paediatrician 3. Neurologist 4. Cardiologist 5. Endocrinologist 6. Respiratory and Sleep physician 7. Ear Nose and Throat specialist 8. Gastroenterologist 9. Orthopaedic surgeon 10. Plastic surgeon 11. Dietician 12. Speech therapist 13. Physiotherapist 14. Occupational therapist 15. Paediatric dentist	reasonable adjustments for a patient who uses augmented and assistive communication and has an intellectual disability. There is no one health person who has carriage or knowledge of our child. We as parents are required to hold and communicate the knowledge – medical and otherwise – between professionals and systems. The 15 listed professionals correspond by letter with each other before and after appointments as part of the referral process. This is often the extent of the communication and there is no one case manager – other than her parents.
Education	Siblings expected to be at the same school: We have two children who are three school years apart. Our son had been at school for three full school years before his sister started school, and our daughter Jean* had been front and present at the school that whole time – pickups, drop offs, on my lap at concerts, playing with the other children at the local pool during holidays and birthday parties, noisy like all little sisters at the Christmas assembly, etc. Inclusive education: Jean got to this place, year 5 at her local school, because she turned up on day 1, excited, dressed in the same uniform, with her Dad carrying her bag, her things named, and ready to learn. She was welcomed, her needs were anticipated and planned for, and everyone had high expectations of her – academically and socially.	Considerable time and energy spent on advocating with school and others for all of the components of physical, social and curriculum inclusion: In the year before Jean started school, therapists, doctors and other professionals peppered conversations with questions about school preparation and planning. Those questions appeared to be focused on how Jean would 'cope' and what level of effort the school might go to for her 'benefit'. Fortunately, our conversations with the school team were different. Almost all of the conversations started with the question "Is Jean excited to start school?" Meetings and kindy visits were organised that looked at what Jean was up to, what she enjoyed about kindy, what sorts of adjustments helped her to interact with her kindy classmates and what goals were we working on at home. I asked a cross section

Topic area	My child with disability has experienced the following….	This meant…
		of staff from school, kindy, then Disability Services Team, external therapy, and the Department transition team, to join together for a meeting in a local coffee shop. It was the first time any had experienced this, and it seemed to me to create a sense of excitement and collegiality that they were all to be part of Jean's transition to Prep. These and other subsequent conversations didn't avoid the mundane arrangements that needed to be made and didn't skirt around Jean's disability. Now in grade 5 and an older brother in high school, I would spend at least 3 hours a week advocating for or organising educational adjustments for our child. Based on the lack of connection to the other systems in her life, I don't expect this will ever change. 320 weeks to go.

Jean's case study continued…

How do we feel about the NDIS?

The NDIS makes me and my family feel like they are saying......

- *"Your inclusion is reliant on having someone you don't know in your home, taking you places or helping you with the things you want to do with your friends and/or family."*
- *"You are a participant first, a person second."*
- *"Raising a child is a parent's role but we want a professional's opinion on your child's disability."*
- *"Set goals for your life so we can tell people how well WE are doing."*
- *"We will give you choice and control but only if…"*
- *"We only report by primary diagnosis because the data is for us not you."*
- *"We will set prices and keep a register of providers but you have choice and control."*
- *"We only regulate the registered. You have to let us know if there is a problem."*
- *"Your data is our data until you want to see it and then you need to ask for it with a different form."*

"It's not you. It's me. The NDIS is selfish."

Imagine if…..

Imagine if children and young people were supported in their local communities to enjoy and fully participate in the everyday – embracing new life, starting school, finding a career path, moving out of home….

Imagine if when a baby is born, their family opens a *welcome baby box* that includes a story book about inclusion and diversity, a roadmap to supports in their local community, a message of support… **AND** a pre-populated NDIS access form based on their health record….

Imagine if when a child begins school, day 1 starts with a warm welcome, supports in place, a connection to children they know from local places – pool, park, pre-school, shops etc… **AND** an agreed approach to balancing learning, inclusion and intervention/therapy…

Imagine if all children, with or without disability, were asked what they want to be when they grow up and supported to explore those dreams as they develop and learn… **AND** an NDIA that actively partners with employers to create a diverse and accessible job market that values the skills and contributions of all young people with disability in economic life…

Imagine if when a young person with disability decides they want to leave home they have the same options as their friends… **AND** these options inherently address accessibility and community connection, enabling independent lives with the necessary support in place….

Australian children and young people with disability know the NDIS can do better, can be better. Make this happen for them. Reimagine a better NDIS for all.

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