

September 2023

Providing better support for children with autism and developmental delay

Dialogue Paper



**Actuaries
Institute.**

About the authors



Maathu Ranjan

Maathu is a Sir Roland Wilson PhD Scholar at the Australian National University's Crawford School of Public Policy and a Councillor of the Actuaries Institute. She is currently on leave from the Australian Government, where she was most recently a Senior Actuary at the National Disability Insurance Agency, leading the Actuarial Strategic Initiatives team to evaluate key Scheme initiatives and priorities. Her doctoral research investigates the impact of government support schemes on the increasing prevalence of autism.



Dr Anthony Lowe

Anthony is a Non-Executive Director, Chair of Actuaries Institute's Public Policy Council Committee, and the former CEO of an NDIS service provider. He was previously CEO at Prostate Cancer Foundation of Australia, co-lead of the National Health and Medical Research Council Centre of Research Excellence in Prostate Cancer Survivorship, and Adjunct Associate Professor at Griffith University.

About the Actuaries Institute

The Actuaries Institute is the peak professional body for Actuaries in Australia. The Institute provides expert comment on public policy issues where there is uncertainty of future financial outcomes.

Actuaries have a reputation for a high level of technical financial expertise and integrity. They apply their analytical and risk management expertise to allocate resources efficiently, identify and mitigate emerging risks and to help maintain system integrity across multiple segments of the financial and other sectors. This unrivalled expertise enables the profession to comment on a wide range of issues including life, general and health insurance, climate change, superannuation and retirement income policy, enterprise risk management and prudential regulation, the digital economy, finance and investment and wider health issues.

Actuaries use data for good by harnessing the evidence to navigate into the future and make a positive impact. They think deeply about the issues at hand, whether it is advising on commercial strategy, influencing policy, or designing new products. Actuaries are adept at balancing interests of stakeholders, clients and communities. They are called upon to give insight on complex problems, they will look at the full picture. Actuaries analyse the data and model scenarios to form robust and outcome-centred advice.

Our public policy principles can be viewed at: <https://actuaries.asn.au/public-policy-and-media/public-policy-framework/policy-principles>

Acknowledgement of Country

The Actuaries Institute acknowledges the traditional custodians of the lands and waters where we live and work, travel and trade. We pay our respect to the members of those communities, Elders past and present, and recognise and celebrate their continuing custodianship and culture.

About this paper

Dialogue Papers are a series of papers written by actuaries and published by the Actuaries Institute. The papers aim to stimulate discussion on important, emerging issues. Opinions expressed in this publication are the opinions of the paper's authors and do not necessarily represent those of either the Institute of Actuaries of Australia (the 'Institute'), its members, directors, officers, employees, agents, or that of the employers of the authors.

ISBN: 9780645903928

Suggested citation:

Ranjan, M., Lowe, A. (2023). *Providing better support for children with autism and developmental delay*. Actuaries Institute. Sydney

Contents

1	Executive summary	3
2	Introduction	4
3	NDIS – Original vision and reality	5
4	Why are the numbers of NDIS participants with autism growing so fast?	6
5	So how can we change the system?	7
6	Why will this work?	8
	References	9





// If you treat an individual as he is, he will remain how he is. But if you treat him as if he were what he ought to be and could be, he will become what he ought to be and could be. //

Johann Wolfgang von Goethe, 1787

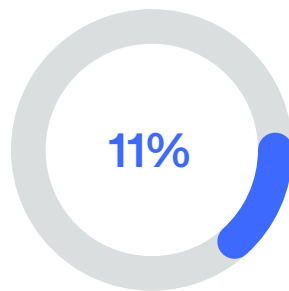
1. Executive summary

- Over the past ten years, the National Disability Insurance Scheme (NDIS) has transformed the lives of hundreds of thousands of Australians living with disability — there is much to be proud of.
- However, the reality of the current Scheme is very different to the original vision. In large part, this is because the Scheme was envisioned and legislated based on the social model of disability but has been implemented using the medical model.
- One of the fastest-growing cohorts of participants is children, particularly children with autism and developmental delay. The system gives families little choice but to seek out formal medical diagnoses, resulting in considerable diagnostic waitlists and the prevention of timely access to early interventions, which evidence shows are most effective.
- We should use this current window of opportunity presented by the Independent Review of the NDIS to implement a social model of disability which would better support children and help make the NDIS financially sustainable by restoring specialist support in everyday settings and ensuring the support it provides is delivered in the most effective way.

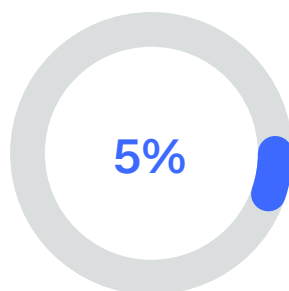
2. Introduction

One of the fastest-growing cohorts in the National Disability Insurance Scheme ("NDIS"/"the Scheme") is children. 11% of 5 to 7 year-old boys and 5% of 5 to 7 year-old girls are NDIS participants. There are now over 313,000 participants under the age of 18, accounting for more than half the Scheme population and a fifth of Scheme costs. 75% of these children have a primary disability of autism or developmental delay. Many participants with developmental delay will go on to receive a diagnosis of autism. With growing recognition of neurodiversity and rising rates of autism diagnoses globally, under the current NDIS model, slowing the growth of this segment of participants seems unlikely.

In this paper, we argue that community-based programs – rather than the individual supports provided by the NDIS – would be better placed to support children with autism and developmental delay, would be better aligned to the original NDIS design, and would be more cost-effective.



of 5 to 7 year-old boys are NDIS participants



of 5 to 7 year-old girls are NDIS participants





IN JUNE 2023, THE
SCHEME HAD
610,502
PARTICIPANTS AND IS
PROJECTED TO RISE TO
1,017,522
BY 2032

3. NDIS – Original vision and reality

Over the past ten years, the NDIS has transformed the lives of hundreds of thousands of Australians living with a disability. There is much to be proud of: the NDIS is a world leader, underpinned by the UN Convention on the Rights of Persons with Disabilities. However, the evolution of the disability services landscape has led Professor Bruce Bonyhady AM, one of the architects of the NDIS, to comment that the Scheme is now “the exact opposite” (Chrysanthos, 2023, June 30) of its original design and intention – one of the main reasons behind the NDIS review, which will report in October 2023.

The Scheme was originally intended to be strength-based, founded on the principles of insurance and early intervention. Australians faced with hardship relating to significant disability would be covered, and early investments in their capability could reduce their trajectory of future need.

It was envisaged that the Scheme, once it was fully rolled out, would support the approximately 475,000 Australians with disability who have the highest support needs and that community-based disability services – including education, health and vocational training – would support the remaining 3.8 million Australians with disability (Productivity Commission, 2017). The reality of the Scheme, as it stands, is very different.

- In June 2023, the Scheme had 610,502 participants and is projected to rise to 1,017,522 by 2032 (Johnson & Gifford, 2022).
- The expected future costs of the Scheme significantly exceed those in the original projections, which were undertaken for the Productivity Commission in 2011 (Productivity Commission, 2011) and updated in 2017 (Productivity Commission, 2017). Total Scheme expenditure was \$34.7 billion (1.5% of gross domestic product (GDP)) in 2022-23. The latest Annual Financial Sustainability Report projects that expenditure will rise to \$89.4 billion (2.6% of GDP) in 2031-32 (Johnson & Gifford, 2022).
- Community disability programs, particularly those funded by State and Territory governments, have typically ceased to exist, potentially driving people with lower support needs to apply for participation in the NDIS when they might otherwise have accessed other programs.

Unlike the State and Territory disability programs that preceded it, the NDIS is a demand-driven scheme with no cap on funding. The NDIS can only be economically viable if it functions as an insurance scheme. If the threshold for access to the Scheme becomes too broad and people receive a lifetime of benefits without a view to improving outcomes, it is no longer an insurance scheme – it is an uncapped social welfare program facing the prospect of unsustainable growth.

4. Why are the numbers of NDIS participants with autism growing so fast?

The number of NDIS participants living with autism has increased markedly, and this cohort now represents almost one-third of new entrants. Jim Mullan, Chief Executive of peak autism body Amaze, has said that the rates of autism suggested by the NDIS statistics were “greater than a scale we would normally expect to see. The increase we’ve seen in [autism] in the NDIS, particularly children, is not explained by what we understand as traditional or conventional autism rates in the population. It could be suggested there is some kind of roting of the system around autism [diagnosis]” (Chrysanthos, 2023, May 19). Whilst research points to a broadening of diagnostic criteria and increasing professional and public awareness of autism and neurodiversity, it is unclear how much of the increase in autism prevalence can be attributed to these factors over the behavioural response to incentives provided by NDIS eligibility processes.

The NDIS Act defines the eligibility criteria for the Scheme and legislates reasonable and necessary supports, including early intervention supports, to all eligible participants (National Disability Insurance Scheme Act 2013, Section 3(1)(d)). Despite being legislated using a social model of disability, the NDIS operates using the medical model of disability¹. In the case of autism, the legislated eligibility criterion of “permanent and significant functional impairment” has been operationalised as needing a diagnosis of Autism Spectrum Disorder Level 2 or higher (American Psychiatric Association, 2022). This is a system that gives families little choice but to seek out formal diagnoses, resulting in considerable diagnostic waitlists and the prevention of timely access to early interventions. Research shows that these early interventions diminish in effectiveness as a child ages (Trembath et al., 2022; Early Childhood Intervention Australia, 2016).

Furthermore, there is a lack of services for families that are not eligible for the NDIS. Once the NDIS rolled out, many existing State and Territory programs for children with disability withdrew their services or transformed into services exclusive to NDIS participants. So, medical professionals are faced with the diagnostic dilemma of providing a Level 2 diagnosis guaranteeing a lifetime package of support in the NDIS (up to tens of thousands of dollars annually, on average) or a Level 1 diagnosis where families face the prospect of self-funding.

Finally, the NDIS pricing structure and system of individualised funding has promoted a medical model of treatment, where individual specialist supports are provided repeatedly outside of mainstream settings. In recent years, demand for specialist preschools has surged (Fitzsimmons, 2022, May 1) and workforce shortages across the allied health and care sector remain a constant challenge (National Disability Insurance Agency, 2023; National Skills Commission, 2022). The program design incentivises providers to ignore outcomes and ensure children remain in the Scheme dependent on therapeutic support rather than building independence and capability, with a view to eventually exit the Scheme where appropriate. This is unsustainable and in complete contrast to the concept of effective early intervention for young children. Research shows effective early intervention for young children is a blend of education, play and specialist support in everyday settings by a team around the child and family (Trembath et al., 2022; Early Childhood Intervention Australia, 2016).



¹ For definitions of the social and medical models of disability, see for example <https://pwd.org.au/resources/models-of-disability/>

5. So how can we change the system?

The NDIS has achieved remarkable outcomes for many individuals and families who are profoundly impacted by disability – individuals and families who are now able to participate in the community, contribute to the economy and access support in a way that was not possible under the previous State and Territory programs. However, children who can benefit from early intervention need a different model of support; one that is embedded in the principles of the social model of disability².

The Scheme has resulted in the diagnosis of individuals with autism in communities where it was previously under-recognised. This includes females, the older population, particularly relatives of those with diagnoses, and communities with culturally and linguistically diverse backgrounds. Growth of the Commonwealth Helping Children with Autism program (Australian National Audit Office, 2016), covering 4,300 children and costing \$16 million in 2009 to 23,000 children and \$79 million in 2014, was a lead indicator of the under-recognition of autism in the community and the demand for supports.

However, individualised funding for a growing population with autism is not only unsustainable, it also does not incentivise best practice in early childhood intervention. A wealth of research shows that quality early childhood intervention is effective when led by parents within school and community settings (Trembath et al., 2022; Early Childhood Intervention Australia, 2016). We can find efficiencies and likely higher quality care and improved outcomes if supports for children with developmental concerns are embedded in mainstream pathways.

The current market model for providers incentivises repeat customers, not the provision of high-quality and outcomes-driven services which lead to Scheme exits where appropriate – this is a conundrum for the entire care market (aged care, disability and injury/rehab). Many schemes have trialled ways to financially motivate providers to focus on individual outcomes, including the recent initiative for blended payments in the NDIS. However, it is difficult to commodify outcomes and may even result in another way for providers to game the system, particularly for children where a range of different interventions in various settings may prove effective.

In summary, we propose three broad changes to the way in which children with autism and developmental delay are supported:

- Remove the need for clinical diagnoses, which are designed to be a means to inform and understand, rather than a measure of function to access supports. Instead, holistic assessments of function by early childhood specialists can identify specific areas and the settings in which children can benefit from early intervention.

This would take away the diagnostic dilemma around levels of function to access supports and enable all children with any developmental concerns to receive timely access to effective early intervention. With a rapidly growing population of children with disability, timely access to early intervention could reduce future trajectories of need, resulting in a more sustainable model.

- Move away from individualised funding and invest in specialised pathways of early intervention support within the education, health and maternal care sectors. Approximately \$5 billion of current NDIS spending for children with autism or developmental delay could be spent in a more sustainable way and in line with the social model of disability. This investment could be used to boost the capabilities of early childhood specialists, upskill professionals in mainstream sectors with specialist disability qualifications, and refocus the system towards building capacity in the community rather than individual provider profit from a model of repeat services.
- Transform the provider market into one that assesses function, measures outcomes and focuses “on what people could do and support them to have good lives, as opposed to focusing on what they can’t do in order to get entry to the scheme and get a package” (Chrysanthos, 2023, June 30). We need a market of quality early childhood specialists who act as the conduit between children and the pathways of support in community settings based on their specific needs. We also need a society that is more aware and actively inclusive of the needs of neurodiverse people, including those with autism.

These proposed reforms would help address the significant challenges children with disability currently face around embedded discrimination and exclusion, particularly in the education system where a lack of funding and adequate staff with knowledge and training have contributed to poor outcomes (Cassidy, 2023, August 17). A recent national survey by Children and Young People with Disability Australia (CYDA) found that school systems at all levels failed to adequately support students with additional learning needs, calling for the prioritisation of funding and programs for students with disabilities in the 2024 National School Agreement (CYDA 2023).

The reforms need to be implemented as part of an interconnected system of supports that foster inclusivity in society. It would be for National Cabinet to agree how best to implement the reforms. Whilst State and Territory governments are responsible for programs in school, health and community settings, the Commonwealth government is also developing the National Autism and Early Years Strategies.

² For definitions of the social and medical models of disability, see for example <https://pwd.org.au/resources/models-of-disability/>



6. Why will this work?

Under these proposals, more children will access timely supports, current NDIS participants will receive higher quality support embedded in their everyday lives focused on achieving outcomes, and taxpayers will increasingly see value for money through sustainable government spending.

A separate model of support for children with autism and developmental delay creates the opportunity to provide evidence-based and timely early childhood intervention in everyday settings. It could also result in an NDIS for Australians with the highest support needs in line with the original design and initial costings by the Productivity Commission.

A policy window to effect lasting change has been created with the development of a national autism strategy and the NDIS Review. Australia is world leading in disability service delivery – now is the time to make it last.

References

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.) (DSM-5).
- Australian National Audit Office. (2016). *Early intervention services for children with disability*. Retrieved from: <https://www.anao.gov.au/work/performance-audit/early-intervention-services-children-disability>
- Cassidy, C. (2023, August 17). 'A form of discrimination': Australia's school system accused of failing neurodiverse kids. *The Guardian*. Retrieved from: <https://www.theguardian.com/australia-news/2023/aug/17/a-form-of-discrimination-australias-school-system-accused-offailing-neurodiverse-kids.html>
- Children and Young People with Disability Australia. (2023). *Disappointment and discrimination: CYDA's surveys of learning experiences of children and young people with disability in 2022 and 2023*. Retrieved from: <https://www.cyda.org.au/resources/details/402/report-disappointment-and-discrimination-cyda-s-surveys-of-the-learning-experiences-of-children-and-young-people-withdisability-in-2022-and-2023>
- Chrysanthos, N. (2023, May 19). Sharp rise: More than 8 per cent of young school children now on NDIS. *The Sydney Morning Herald*. Retrieved from: <https://www.smh.com.au/politics/federal/sharp-rise-more-than-8-per-cent-of-young-school-children-now-on-ndis-20230519-p5d9rc.html>
- Chrysanthos, N. (2023, June 30). NDIS now 'exact opposite of what was intended', says scheme's godfather. *The Sydney Morning Herald*. Retrieved from: <https://www.smh.com.au/politics/federal/ndis-now-exact-opposite-of-what-was-intended-says-scheme-s-godfather-20230629-p5dkf3.html>
- Early Childhood Intervention Australia. (2016). *The national guidelines for best practice in early childhood intervention* (1st edition).
- Fitzsimmons, C. (2022, May 1). Demand for specialist preschools after surge in autism diagnoses. *The Sydney Morning Herald*. Retrieved from: <https://www.smh.com.au/national/nsw/demand-for-specialist-preschools-after-surge-in-autism-diagnoses-20220426-p5ag7a.html>
- Johnson, S., & Gifford, D. (2022). *National Disability Insurance Scheme: Annual financial sustainability report 2021-22*.
- National Disability Insurance Agency. (2023). *National Disability Insurance Scheme: 2022-23 annual pricing review*.
National Disability Insurance Scheme Act 2013
- National Skills Commission. (2022). *2022 Skills priority list: Key findings report*. Retrieved from: <https://www.nationalskillscommission.gov.au/reports/2022-skills-priority-list-key-findings-report>
- Productivity Commission. (2011). *Disability care and support, report no. 54*. Canberra.
- Productivity Commission. (2017). *National Disability Insurance Scheme (NDIS) costs, study report*. Canberra.
- Trembath, D., Varcin, K., Waddington, H., Sulek, R., Pillar, S., Allen, G., Annear, K., Eapen, V., Feary, J., Goodall, E., Pilbeam, T., Rose, F., Sadka, N., Silove, N., & Whitehouse, A. (2022). *National guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia*. Autism CRC. Brisbane.