

May 2021

Autistic children: investment pays

Submission to the NDIA's Consultation Paper:
Interventions for Children on the Autism Spectrum



About Amaze

Amaze is a community organisation established over fifty years ago by autistic people and their families. We work to build community understanding of autism, influence policy change for autistic people and provide independent, credible information and resources to individuals, families, professionals, government and the wider community. We are closely connected with the autistic community through our national help line Autism Connect, our peer support networks and community capacity building initiatives. Amaze is *not a service* provider (for NDIS or otherwise).

Amaze is a partner of the Australian Autism Alliance. Many Alliance partners have contributed valuable submissions to this process.

About autism

Autism Spectrum Disorder (or ASD) is a neurodevelopmental condition. Autism is not a disease. People are born autistic. It is a lifelong condition and there is no cure, but the way it affects people may change over time as a person grows and matures. Every autistic individual is different.

Autism frequently co-occurs with other conditions including other neurodevelopment conditions (e.g. ADHD, Dyslexia) and Intellectual Disability. 50-70% of autistic people also have mental health conditions.

The NDIS and autistic children

31% of NDIS participants have a primary autism diagnosis and an additional 5% of participants have autism as a secondary disability.¹ In the younger age groups 65% of participants aged 7-14 years and 54% of those aged 15-18 years are autistic.

Acknowledgements

Amaze extends its thanks and gratitude to the many autistic people, families/carers and members of the broader autism community who generously gave their time and insights to inform this submission – through both survey responses and in discussions with us.

Quotes and data are taken from direct consultations with over 80 members of our community, a survey which gathered over 620 responses, and targeted consultations with autism researchers, allied health practitioners, clinicians, advocates, Local Area Coordinators and partners in the disability sector.

Direct quotes from members of our community have been included throughout this submission. They are unedited and illustrate the human impact that this proposal will have.

For further information

Amaze stands ready to assist the National Disability Insurance Agency to ensure autistic children are supported fully in their development. Nicole Rees, Executive Manager of Policy & Advocacy (Deputy CEO) can be contacted on Nicole.rees@amaze.org.au to discuss this submission.

¹ NDIA, 2019. *Outcomes for participants with ASD*. Available at: <https://data.ndis.gov.au/reports-and-analyses/outcomes-participants-autism-spectrum-disorder>

Summary of recommendations

Imposing funding caps is fundamentally flawed

1. Abandon the proposal to introduce funding caps that limit autistic children's access to reasonable and necessary supports.
2. Urgently develop multi-lateral protocols addressing the interface between the NDIS and education systems and their supports for students with disability.

The proposed "funding levels" don't work

3. Abandon the proposal to stream autistic children into one of four discrete funding levels.

Co-designed principles on good practice autism supports would be an important step forward

4. Include in future principles on good practice in autism supports:
 - Family centred practice and strengthening family capability.
 - The use of strengths-based approaches.
 - The experience of families and clinicians as a valued part of the evidence base
 - Flexibility to explore innovative approaches within an evidence-informed setting.
 - The importance of timely access to early intervention and autism supports.
5. Develop a national guideline on good practice autism supports for children. This needs to be co-designed with autistic people, their families and carers, experts and clinicians.
6. Publish a complementary resource for parents to help guide their decision making on good - practice autism supports.

Standards for autism interventions require a robust regulatory framework

7. Clearly and publicly identify approaches that are shown to be harmful so that families are well-informed.
8. Ensure determinations about whether supports meet the standards are reviewable decisions.
9. Require all providers of early childhood supports to register with the NDIS Quality and Safeguards Commission.
10. Support smaller organisations and sole providers to achieve registration, subject to meeting quality requirements.
11. Develop a directory of autism support providers that includes their rating against the quality standards. This could be modelled on the National Quality Framework for Early Childhood Education and Care.
12. Ensure conflicts of interest are managed via a proper and appropriate separation between organisations responsible for providing information and advice to participants and those providing funded supports.

Overview

Autistic children comprise the majority of the NDIS's young participants. Securing an NDIS that delivers effective and timely supports for autistic children and their families is a priority for Amaze.

The National Disability Insurance Agency's consultation paper on *Interventions for Children on the Autism Spectrum* (the Paper) outlines fundamental changes – some of which we hold grave concerns about.

Amaze calls on the NDIA to abandon its proposals to impose funding caps on autistic children's plans. We also call for proposals to introduce mandatory functional assessments, and to use these to categorise autistic children into funding levels to be withdrawn.

We do not reach this position lightly, but rather with sincere and well-grounded concerns about the adverse impacts that the proposed changes will likely have on autistic children (now and throughout their lives), their families, the broader Australian community, and the future of the NDIS.

We take this position after comprehensively engaging with our community; seeking the advice of people with lived experience, clinicians, and researchers; and consulting with autism and disability organisations across the nation.

Our major concerns include:

- The funding levels and caps proposed by the Paper are not based on evidence.
- Many (likely most) autistic children will have their NDIS funding reduced.
- Drastic cuts (by 40%) to NDIS funding supports once autistic children turn seven will be profoundly damaging. The school system does not have the capacity to fill this gap.
- There will be a gendered impact – with autistic girls who are often diagnosed later being heavily affected.
- Use of mandatory functional assessments to group autistic children into funding streams is fundamentally flawed, untested and unproven.
- The personalised approach that the NDIS was intended to deliver will be eroded.
- The development, educational attainment, and broader life outcomes of autistic children will be severely compromised.
- It is unclear how these changes would interact with other massive changes proposed for the NDIS that are the public domain (e.g. ECEI Reset; plan budget flexibility; independent assessments), as well as those that are not.

We urge the NDIA to go back to square one, and genuinely partner with autistic people and the broader autism community to improve the NDIS for autistic children.

Clear principles on good practice autism supports, operationalised via co-developed guidelines would be a welcome advance. A top-down approach to this needs to be avoided. Rather, these need to be developed *with* the autism community to foster shared ownership and underpin effective implementation.

Supply side issues are pressing. A stronger regulatory framework with oversight, accreditation and transparent rating of providers is *desperately needed to raise and assure quality* to ensure scarce public resources are not wasted, and children and families are not harmed. This needs to be done in way that does not exacerbate existing provider shortages. Urgent action is also needed to address existing and emerging conflicts of interest.

Amaze is committed to working with autistic people and their families, the autism community, the NDIA, and the Australian Government to improve the operation of the NDIS.

Analysis of the NDIA's proposals

Imposing funding caps is fundamentally flawed

There is no evidence base for the proposed funding caps

Research into effectiveness of supports for autistic children is an emerging field. Contemporary literature – including the extensive overview of the evidence for early intervention funded by the NDIA and published by the Autism Cooperative Research Centre² – *provides no evidence to justify the low levels of support* associated with some of the proposed funding caps. Nor does it provide guidance or a position on the amount of intervention that is effective. In this context, it is unclear how the proposed funding caps have been devised.

The capped funding across each funding level is likely to be insufficient to meet many children's needs.

- At the lowest end of the scale, an autistic child aged over seven years in “level 1” attracts funding to support just two hours of professional interventions per month. *None* of the interventions assessed in Autism CRC's Report provided results at such low intensity.
- At the highest end of the scale, a pre-school child in “level 4” allocated the *maximum budget* of \$35,000 would be funded, on average, for *just three hours of therapy a week* (highlighted in the submission by the Olga Tennison Autism Research Centre.)³

For many families, this is wholly inadequate and would see reductions to fundamentally important supports at a critical point in their child's development.

The proposal discriminates against autistic children

Autistic children are the only cohort that the NDIA plans to place into rigid funding ‘levels’ with pre-determined funding caps. There is *no explanation of the rationale* for singling out autistic children.

If these caps were proposed for all those accessing the NDIS, it would be less abhorrent.

Getting supports for him when he was ‘just’ a stroke sufferer was so much easier than before he was diagnosed with autism.

Funding caps run counter to the individualised support approach inherent in the NDIS

One of the revolutionary strengths of the NDIS is its provision of ‘reasonable and necessary’ supports based on individual need and circumstance. The proposed introduction of funding caps would effectively erase this.

As the mother to three Level 2 autistic children - each with vastly different needs - this new system appears to erode what the NDIS is about. That being, to consider each participant's individual support needs, and to tailor funding accordingly.

² Whitehouse, A., Varcin, K., Waddington, H., Sulek, R., Bent, C., Ashburner, J., Eapen, V., Goodall, E., Hudry, K., Roberts, J., Silove, N., Trembath, D. Interventions for children on the autism spectrum: A synthesis of research evidence. Autism CRC, Brisbane, 2020

³ Psychologists are paid \$214.41 per hour; billing for travel for up to 30 minutes each way against the same price; with time allocated to administration and submitting their report to the NDIA.

Moving from a personalised to a generic approach heightens the risk that support will be mismatched to actual needs – with long term consequences for children, their families, the NDIS, other service and support systems, and the broader Australian community.

Without significant support, going through life autistic is traumatic and leaves lasting scars that impact functioning for life.

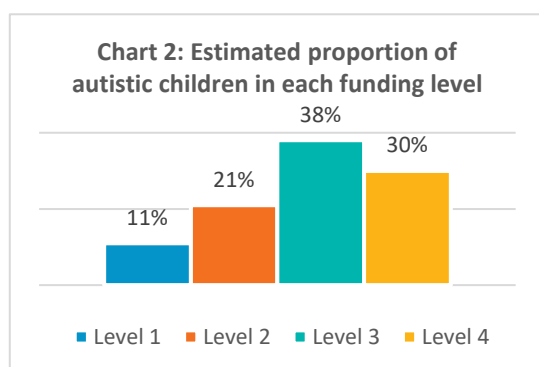
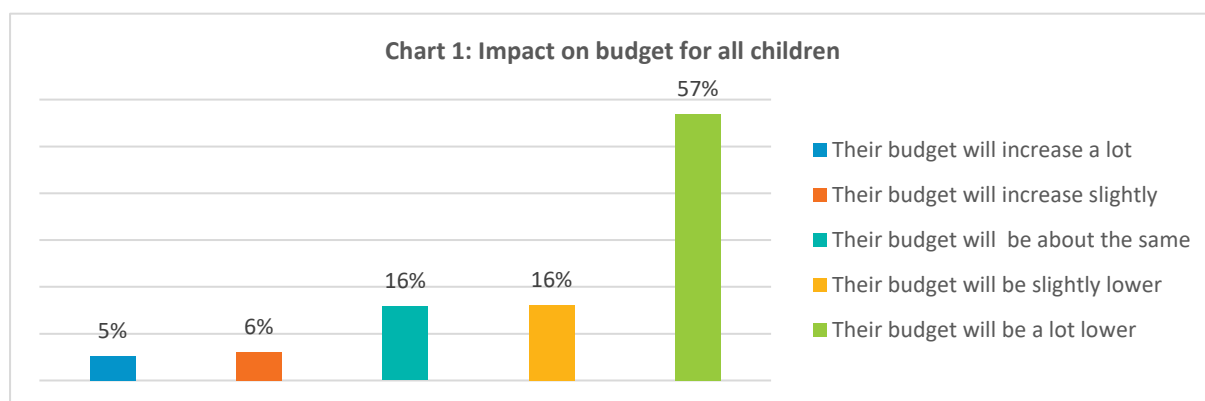
If supports are reduced then potentially ASD children will be ‘in the system’ indefinitely and increase the burden of cost on the country.

My son will not be supported to develop the skills he needs to ensure he avoids getting serious mental health issues and to function independently as an adult.

This marks a significant departure from the insurance-based investment model promised by the NDIS.

Many children are likely to have their support reduced with the proposed funding caps

Our survey results indicated that *most autistic children are likely to have their funding levels reduced* compared to what they currently receive – see **Chart 1**.



Families were first asked to estimate which funding level they thought their child would be placed into.⁴ Of the **348 responses**, over two-thirds indicated their child/ren would fit into Level 3 (38%) or Level 4 (30%) – see **Chart 2**.

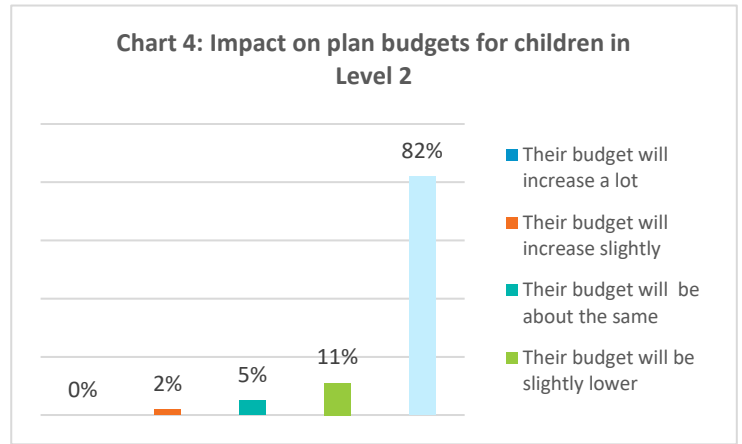
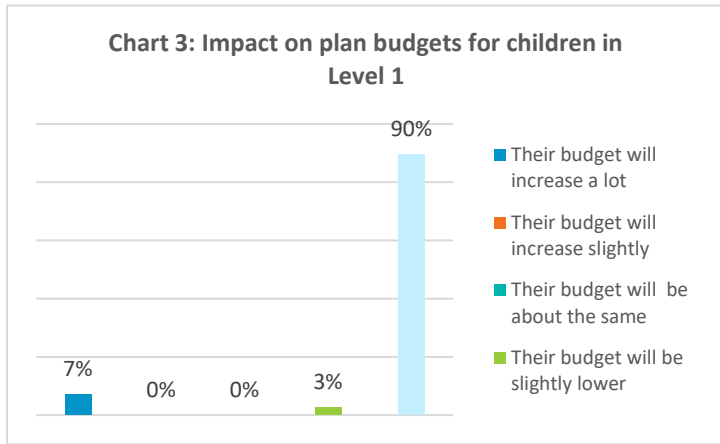
Respondents were then asked to compare their child’s current capacity building budget with the mid-point of the funding band of the level they believed their child would fit into. They were only shown the proposed funding bands once they had estimated which level best described their child/ren.

We used the assumption that what is covered in the capacity building budget would remain consistent with current arrangements. We did not factor in the likelihood that in future, a

⁴ Based on the descriptions of ‘areas of need’ in tables 2 and 3 of the Paper

participant’s core and capacity building budgets may become a single, flexible budget (as signaled in the recent NDIS consultation on Planning policy for personalised budgets and plan flexibility).⁵

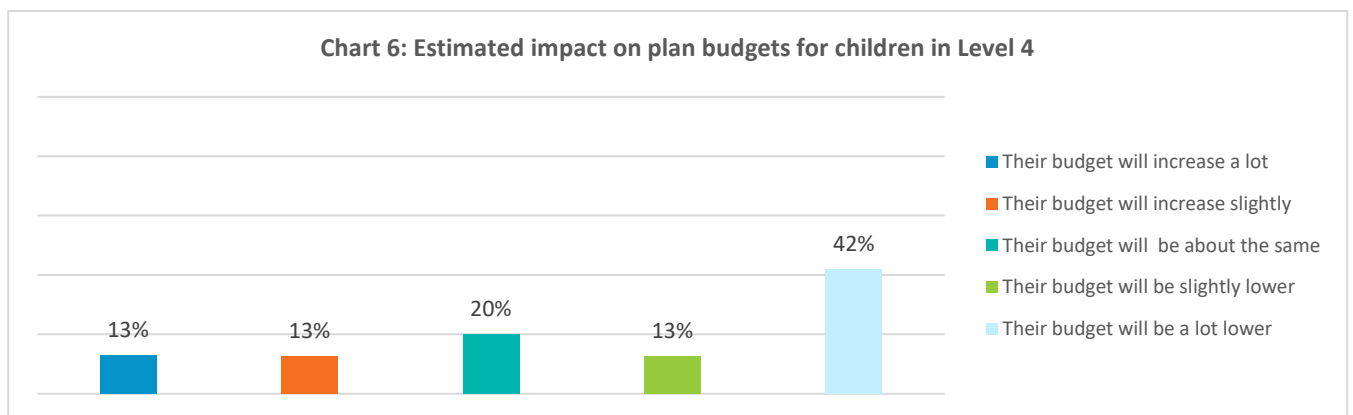
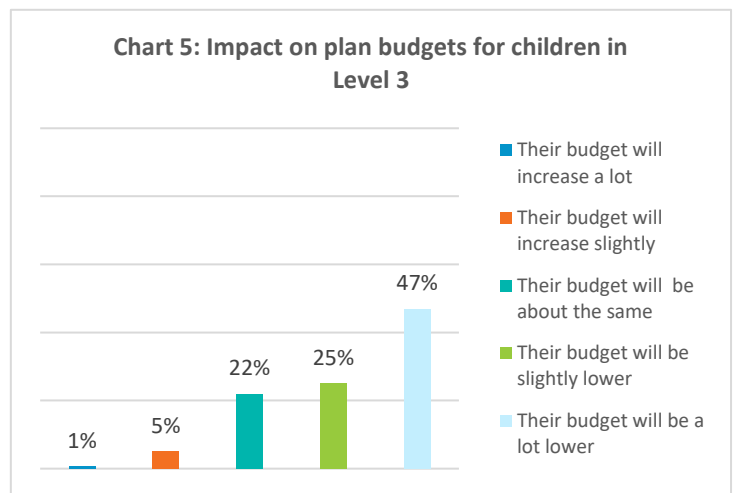
Those identifying as being in Levels 1 (n=38) or 2 (n=72) overwhelmingly reported (90% and 82% respectively) that their child’s capacity building supports would be “a lot lower” under the proposed changes, compared with their currently funding levels – see **Charts 3 and 4**.



Results for respondents identifying that their child would likely be assessed as fitting into Level 3 (n=134) were concerning, but not as extreme – see **Chart 5**.

Almost half (47%) reported their child’s capacity building budget would be ‘a lot lower’; 25% ‘slightly lower’; 22% ‘about the same’ and 6% reported their budget would increase.

Those who identified as level 4 (n=104) reported mixed results, with *over half reporting budgets will be lower* (42% a lot



⁵ Available at: <https://www.ndis.gov.au/community/we-listened/you-said-we-heard-post-consultation-reports/planning-policy-personalised-budgets-and-plan-flexibility>

lower; 13% slightly lower); 20% reporting no change; and 26% predicting a budget increase – see **Chart 6**.

Many respondents shared their concerns about how predicted funding reductions would impact their child/ren and family:

These changes will mean my school aged child would not be able to access his weekly speech and OT. Currently he is functioning, but with a lot of support.

For our family, knowing that the outcome would be restricted funding - when already our funding isn't enough to cover all of the supports our children need - we are devastated.

These changes will absolutely destroy all the progress my child has made. He will regress without the support of his therapies and amazing therapists. He will become aggressive, will self-harm, put other people's safety at risk, he will slowly fade back.

Capped funding = capped potential.

Our life would change dramatically. The support we access assists our child to learn basic life skills, make friends, cope with school and social activities, basically to have a chance of a happy future. Reducing support is frightening and means we're uncertain about how we are going to cope as a family.

These changes will impact every aspect of my children's lives. It takes time and a lot of work to build a therapy team that works and actually starts seeing results and a lot of that is consistency and trust from building a relationship, if the funding is cut and appointments decrease my children will regress.

He would not function without the current level of funding. Our family will suffer as one parent works full time and other parent is on a pension.

It is difficult enough trying to advocate for my children but it has driven me to a state of such poor mental health that I consider suicide on a regular basis.

We are already struggling with plans that do not fund meaningful, useful, individualised supports - we will not cope if it gets worse.

Funding for autistic children could be lower than was provided pre NDIS

Under the Helping Children with Autism (HCWA) Program, alongside state-based contributions, families with autistic children would often receive higher total supports than what has been proposed in the Paper.

In their submission to this consultation, Autism Western Australia estimated that autistic children in WA received a baseline amount of \$22,000 for early intervention supports under the combined HCWA and WA Government schemes – which well exceed many of the funding levels proposed in the Paper.

Children with multiple disabilities could be severely impacted

The Paper makes a single reference to the impact of the funding model on autistic children with multiple disabilities and/or behaviours of concern. Given the high co-occurrence of autism with other conditions and disabilities this a crucial gap. It is unclear if a child with multiple diagnoses will have their capacity building funding capped by virtue of their autism diagnosis.

My son has multiple complex diagnoses, but every time we have a review they try to shove him in the autism box and ignore the rest of his needs. I'm afraid under these changes he's going to get streamed under the autism packages.

All of my children have multiple disabilities and conditions that mean they are highly complex. These include generalised anxiety disorder, auditory neuropathy spectrum disorder, bilateral hearing impairments requiring cochlear implants which due to late diagnosis and implantation has resulted in significant speech and language delays, acquired brain injury, hydrocephalus, dyslexias, and attention disorders etc.

Reducing funding by 40% at age seven will stifle the developmental trajectories of autistic children

The significant funding cuts proposed when an autistic child turns seven are fraught with risk. It may compromise educational attainment, which is already appallingly low for autistic children,⁶ adversely impact wellbeing, and diminish future life chances.

Autistic children with a later diagnosis will miss out on early intervention supports

Our survey found that almost one third (32%) of respondents' children were diagnosed between the ages of six and 12 years. For them, funding will be drastically reduced at a time when they ought to be able to access intensive early intervention (that are age and developmentally appropriate) to help their social, emotional and communication development.

Regardless of the age at which a child is diagnosed as autistic, the supports they receive immediately following the diagnosis are critical for their long-term development.

Both our children were not diagnosed until they were 12 years old, even though we'd sought help for both of them for many years beforehand, both privately and through school. Both children struggled throughout primary school and were offered little to no support.

This will have gender impacts that disproportionately impact girls

Girls are, on average, being diagnosed later than boys. Nearly two-thirds of female respondents to the Study of Australian School Leavers with Autism (65.9%) were diagnosed at age nine or older compared with 37.7% of males.⁷ They would be heavily impacted by the NDIA's proposal which would see their access to supports severely reduced in the critical years immediately following their diagnosis.

We are only now getting a diagnosis as my child is a girl, is gifted with high IQ and above average expressive language- so hasn't been seen as acute or needing

⁶ Approximately one third of autistic students only achieve a year 10 or below, compared to 17% of neurotypical students

⁷ La Trobe University Olga Tennison Autism Research Centre. *Response to the Select Committee on Autism Inquiry into the services, supports and life outcomes for autistic people in Australia*. July 2020. Submission number 55, pg. 8.

helping- I was told by local CAMHS to come back when she becomes suicidal (not if, when).

Developmentally my child will need greater assistance during adolescence, these changes appear to further disadvantage and discriminate against girls on the spectrum who are diagnosed later

Autistic children's needs fluctuate over time and during key transition points

Development, progression and support needs are not linear for autistic children. They ebb and flow with life circumstances and transitions, particularly heading towards puberty and the move to secondary school. Capacity building supports must remain flexible and be able to be adjusted to meet the current goals and needs of each child.

As my child becomes older, it's become more apparent that he has other diagnoses that impact on his functional capacity. When he was first diagnosed with autism at age 5, we didn't realise that he also had significant anxiety, a moderate language delay, ADHD, dysgraphia, dyspraxia, auditory processing disorder, low muscle tone and joint hypermobility. His support needs have in fact grown

Increased capacity may not necessarily translate to lower support needs, as goals and aspirations change.

Our son's needs change across time and plans should be flexible and adaptive to accommodate this.

My daughter, now 10 years old, requires significantly more capacity building supports than she did a few years ago. Helping her with social challenges has become a big focus.

The Paper proposes a significant funding reduction coinciding with the early years of primary school. This seems at odds with the proposal in the Early Childhood Approach consultation paper to extend ECEI (to be renamed the Early Childhood Approach) to children aged up to nine years. We understood that part of the rationale for this change was to better support the transition to primary school. Cutting funding at such a critical point seems inconsistent with this.

Assumptions that children can access capacity building supports through school are unrealistic

Disability supports in school vary widely and wildly across sectors and around the nation. State funding for students with disability and access to school-based support services (e.g. allied health) is highly rationed.

Many autistic participants in the NDIS are not eligible for disability support at school

There is no direct correlation between eligibility for NDIS and school disability support systems.

My 8-year-old attends mainstream, he had a cognitive score of 71 and is not entitled to extra support in school.

I have two sons on the NDIS, neither meet the criteria for support under Victoria's Program for Students with Disabilities

My son gets no funding assistance from the education sector, simply because his IQ is over 70. Without NDIS support he will have nothing to help him achieve what his peers will achieve in life.

My son lost disability support funding moving from grade 6 to year 7, it's so common...

Schools have little or no capacity to provide dedicated support

An all-too-common theme that we hear from both families and educators is that school simply do not have the capacity or capability to support autistic students.

The school system does not have the capacity to provide the supports my children need. I have been told at two different schools that they "do not have the funding" and even if they had more funding, it wouldn't be enough to provide the supports my children need.

He has to keep up in a class of 23 children. His school cannot meet all his extra needs without support of therapy and family.

I am a senior administrator in a Victorian school and manage support for students with disability, and a mum of an autistic child. Our current enrolment figures are 250% above "capacity". Even though we want to, we just cannot offer support autistic children need.

For students with disability, even if we can find a therapist who is willing to visit the school, there is just no space available for them to work.

I completed a Teacher's Aide certificate and from my training experience I can state that there was no capacity building training included for children with ASD.

His (mainstream) school thanked me for moving to a special school because they just didn't have the funding.

This is even the case for those in **specialist school settings**, which are attended by disproportionately high numbers of autistic children.

My 6-year-old son attends an autistic school that does have any therapists on staff. We rely on private speech and OT. If he loses 40% of his funding at 7 years old, it will have a detrimental effect on his development.

Despite the Disability Standards for Education, **autistic students are frequently not supported by effective adjustments and modifications** to support their learning and well-being at school,^{8,9} let alone with additional capacity building supports. A sizeable proportion of Victorian autistic students do not have Individual Learning Plans,¹⁰ suggesting an absence of explicit efforts to meet their individual needs.

⁸ Amaze's Autism Connect service data reveals over 55% of the education related calls are about lack of adjustments and school inclusion barriers. See also Spirakovsky, C., Joseph, S., and Smith, M. *Improving Education Outcomes for Children with Disability in Victoria*. Monash University, 2018.

⁹ Sagers, B et al. 2019. *Promoting a Collective Voice from Parents, Educators and Allied Health Professionals on the Educational Needs of Students on the Autism Spectrum*

¹⁰ Amaze's *Learning in Lockdown* survey (2020) indicated 25-30% of autistic students do not have Individual Learning Plans

Trying to rely on school systems to offer support as our kids get older is a ridiculous notion, when schools are struggling to even teach and regulate typically developing children.

It is hard to secure appointments out of school hours

The Paper explicitly rules out funding capacity building supports delivered outside of school settings, during school hours. This places a significant obstacle between autistic children and access to support. It will act as a de-facto restriction on funding as the challenges faced by parents in accessing allied health supports in the community are compounded by barriers related to therapists visiting schools.

High rates of autistic children are home-schooled

Many parents who engaged with Amaze via our survey and community consultation indicated their children were home-schooled or are disengaged from school. This anecdotal feedback is supported by recent data from the New South Wales Education Standards Authority.¹¹

Home-schooling is on the rise because the schools are failing in the first place.

Many state-based disability support schemes, such as Victoria's Program for Students with Disability, are not available for home-schooled students. For parents who have been forced to engage in home-school after state education systems proved inappropriate for their children, they will effectively be left to manage the funding reduction on their own. The Paper makes no mention of if and how NDIS funding would be adjusted to reflect this.

Work to reform the NDIS/School interface is urgently needed

The interface between the NDIS and the education system continues to cause friction at the systems, local, and individual level, with real life impacts for autistic children.

The NDIA's unilateral proposal to significantly reduce funding at age seven on assumptions about school supports, and to apply strict rules about the settings in which NDIS funding can be used in school settings, is an example of siloed and disjointed operations between two critical service systems.

Proposals that would result in widespread impacts across service systems and jurisdictions must be considered carefully and through agreed intergovernmental channels and processes, not unilaterally.

It is an urgent priority to address this interface, a set of agreed protocols must be developed between the Commonwealth Government, the NDIA and the states and territories.

Recommendations:

- 1. Abandon the proposal to introduce funding caps that limit autistic children's access to reasonable and necessary supports.**
- 2. Urgently develop multi-lateral protocols addressing the interface between the NDIS and education systems and their supports for students with disability.**

¹¹ NSW Education Standards Authority, 2020. *Home Schooling Data reports relating to 2019*. Available at: <https://educationstandards.nsw.edu.au/wps/wcm/connect/426e1f11-5752-4c1c-bdcc-68b880c0e0b3/Home+Schooling+Data+relating+to+2018+for+publication+on+NESA+website.pdf?MOD=AJPERES&CVID=>

The proposed “funding levels” don’t work

The funding levels fail to reflect real life circumstances and need

Clinicians, researchers and families have told us that the proposed matrix for grouping autistic children into one of four “funding levels” fails to reflect real-life circumstances and needs. Many felt the descriptions were not appropriate.

Meltdown, not tantrums. The descriptions in the paper don’t fit autistic kids.

Pacing and rocking – if that’s self-soothing behaviour then why would you try to eradicate it?

Some felt that it was difficult to know which level to place their child into, or that the levels should not be used.

The funding levels just aren’t realistic. Both of my sons will fit neatly into each of the four levels on any one day, based only on their mood or whether they had a good sleep or any of the other big or small things that affect their behaviour!

Not everyone can fit into a neat box and which box they supposedly fit into could change hour to hour and day by day

Placing children into (very subjective) tiers of funding doesn’t appear to take into account individual nuances

I worry that kids on the spectrum are being placed in certain categories according to skills - ALL kids on the spectrum need sufficient support - but also the right kind of support.

Others reflected that the matrix failed to capture their child’s complexity and circumstances.

On this scale, my child would rate as a “level 10”.

Families regularly told us that the language and development of the funding model and its matrix were confusing and hard to understand, particularly the terminology of ‘funding levels’, which was immediately confused with the autism diagnosis levels established in the Diagnostic and Statistical Manual.

There are many variables that influence the supports an autistic child needs

Using the narrow lens of functional capacity, depicted in the matrix of funding levels, is only a partial indicator of the level of support a child will need.

Family networks and informal supports around the child; child and family readiness to receive support; goals and aspirations; and levels of coping and resilience are important variables that the NDIA’s matrix does not factor in. By solely focusing on ‘areas of need’ to the exclusion of other influential variables, the model risks resulting in funding outcomes that are not accurate or appropriate.

The existing ‘reasonable and necessary’ paradigm for determining individual supports is better suited to understanding and responding to the broad complexity and individual circumstances of autistic children.

How can a child be pigeon holed into a group with set funding when every child has different areas of concern and different goals. ASD is a spectrum and affects each person differently.

Using contested mandatory assessment processes to determine funding levels is untested, unproven and high risk

The Paper sits in the context of the highly contested mandatory (independent) assessment rollout, which is currently paused amidst a parliamentary inquiry and concerted and the well-informed opposition of independent experts and the broader community.

Amaze endorses the [submission](#) the Australian Autism Alliance made to the Joint Standing Committee on the National Disability Insurance Scheme's inquiry into independent assessments, which sets out our detailed concerns about how mandatory assessments will operate for autistic people.

Introduction of a time limited, high consequence functional assessment conducted by a clinician with undetermined training and expertise in autism, who is unknown to the family, is likely to result in inaccurate and invalid outcomes.

The use of such assessments to allocate a child to one of four funding levels with direct impact on their funding and access to critical supports is untested, unproven and has a high-risk of stifling an autistic child's developmental trajectory.

Recommendation:

- 3.** Abandon the proposal to stream autistic children into one of four discrete funding levels.

Co-designed principles on good practice autism supports would be an important step forward

Our community want to be empowered with clear information about effective approaches and supports to enable children to realise their potential.

The draft principles put forward in the Paper need to be tested and further developed through deep engagement with autistic people and the broader autism community. Feedback we received in discussions with our community about the principles included:

- There needs to be an overarching principle about using **strengths-based approaches**.
- **Family-centered practice** needs to be elevated into future principles. Strengthening family skills and knowledge about autism and building capabilities to support their child's development has real impact.
- **The experience of families and clinicians** who are observing benefits from approaches that are not yet backed by a high-quality evidence base need to be valued.

This is consistent with the Autism CRC's characterisation of evidence-informed practice as comprising three equally important components: individual preferences (family experience/perspectives); clinical experience; and research evidence. These first two of these are missing from the NDIA's draft principles.

- Provide sufficient flexibility to **enable innovation**, noting that autism practice is rapidly evolving
- The need for autism supports to be delivered in a **timely manner**.

This feedback is aligned with research evidence, which shows that children who receive timely and appropriate early intervention demonstrate better cognition and required less ongoing support.¹²



Principles should be operationalised through a co-developed national guideline

There is a mountain of information about early intervention and autism supports for children that professionals struggle to navigate. Parents and carers face huge challenges in scoping and understanding their support options, and synthesizing information from a variety of sources to determine what is most appropriate for their child.

A practical and accessible guideline on good practice early intervention/autism support is needed. This would transform the disparate elements of the research, principles and standards, into an independent and authoritative resource against which to guide and assess supports.

¹² Clark, M. L. E., Vinen, Z., Barbaro, J., & Dissanayake, C. (2018). School Age Outcomes of Children Diagnosed Early and Later with Autism Spectrum Disorder. *Journal of autism and developmental disorders*, 48(1), 92-102. doi: 10.1007/s10803-017-3279-x

The guideline cannot be developed using a top-down approach. Instead, a collaborative process that brings together autistic people, their families, researchers and clinicians needs to be embarked upon.

Inspiration can be drawn from the process used to develop the *National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders*, which was informed by consultation with the autism community and broader state, territory, and commonwealth stakeholders. The result was a nationally consistent guideline that adds rigor to the provision of autism assessments and diagnoses.

An independent and credible autism research organisation should act as the custodian of what constitutes 'good practice'. This would ensure the guidelines reflect the rapidly emerging evidence base on autism supports while also managing concerns about the potential for a conflict of interest if the Scheme funder is also determining 'best practice.'

This should be complemented by a decision-making guide for parents on autism supports

To complement the guideline, a resource providing clear and accessible information for parents to support and inform their decision-making ought to be published. This should build on the [Raising Children Network's Autism website](#), which is a well-used and trusted information source.

It is essential that the advice and decision making of the NDIA planners and partners be aligned with the evidence-base in both the early intervention guideline and its partner resource for parents.

Recommendations:

4. Include in future principles on good practice in autism supports:

- **Family centred practice and strengthening family capability**
- **The use of strengths-based approaches**
- **The experience of families and clinicians as a valued as part of the evidence base.**
- **Flexibility to explore innovative approaches within an evidence-informed setting.**
- **The importance of timely access to early intervention and autism supports.**

5. Develop a national guideline on good practice autism supports for children. This needs to be co-designed with autistic people, their families and carers, experts and clinicians.

6. Publish a complementary resource for parents to help guide their decision making on good - practice autism supports

Standards for autism supports need an effective regulatory framework

Tackling supply side issues are an important part of the equation to improving the effectiveness and efficiency of the NDIS. Too little attention is being paid to the gains that would flow from improved market stewardship, regulation and oversight.

Clear information on unsafe practice is needed

‘Choice and control’ must be balanced against the need to protect autistic people and their families from providers offering unsafe or disproven interventions.

The Paper refers to several interventions as examples of harmful or unsafe practices. These need to be clearly identified and published by the NDIA, rather than being left for parents to determine

Recommendation:

- 7. Clearly and publicly identify approaches that are shown to be harmful so that families are well-informed.**

The views and preferences of families need to be valued

Different children will respond in varying ways to autism supports, making it difficult to determine fairly and accurately what is going to be effective for each child.

During consultation with our community, many parents identified potential challenges with applying the standards as proposed:

- The proposed standard “*that the intervention provide significant and long-lasting benefits*” raised concerns about the subjective interpretation of what constitutes “significant” and “long-lasting”. For families, the understanding of significant and long-lasting may differ from that of the NDIA or a planner.
- The draft standards related to “*value for money*” likewise raised concerns, with families reporting that sometimes itg takes a long time for their child to show positive impacts from therapies.

Some kids take longer to achieve skills than others.

My child has been in therapy for five years and is only just starting to make progress. The high turn over of therapists hasn't helped. He doesn't connect straight away. He requires a lot of rapport building.

Value for money? I can't control how much the therapists charge!

When applying the standards, it is important that some flexibility is retained to ensure supports that “work” for one child remain a viable option. In practice, this means ensuring a balanced, two-way dialogue is entered into with parents when there is a dispute about whether an intervention meets the standards. We emphasise the importance of listening to and respecting the advice of parents with regards to the efficacy of specific interventions.

We note the likely role of Early Childhood Partners (ECP) in guiding decision making on what constitutes reasonable and necessary support for autistic participants. It is essential that parents have scope to review decisions made by in this regard, and to ensure Partners/Planners can explain and justify their decision making in a transparent and public manner.

Recommendation:

- 8. Ensure determinations about whether supports meet the standards are reviewable decisions.**

Providers of autism supports should be registered

The Australian Autism Alliance made clear recommendations in favour of registering all NDIS service providers in its submission to the consultation on the Early Childhood Pathway, which we endorse.

We are not in favour of industry-led accreditation systems given some of the problematic practices and conduct. Instead, we urge bringing all funded providers under robust regulatory oversight.

This would need to go hand in hand with a scheme to support smaller organisations and sole providers to achieve registration (subject to meeting quality requirements) to ensure that good providers are not lost to the NDIA.

Will waitlists get longer if providers need to adhere to guidelines?

We are mindful that many self- and plan-managed participants enjoy the freedom of choosing a provider that they feel best meets their needs, regardless of their registration status. However, the priority must be on providing families with assurance that their local NDIS providers are robust, evidence-informed and have a high-quality offering.

Recommendations:

- 9. Require all providers of early childhood supports to register with the NDIS Quality and Safeguards Commission.**
- 10. Support smaller organisations and sole providers to achieve registration, subject to meeting quality requirements.**

A directory of autism support providers, rated against the standards/guideline is needed

Regulating service providers to ensure their offerings are high quality and safe must be a priority for the NDIA.

Currently, parents need to sift through hundreds of pages of information about registered NDIS providers to locate local options, including those that offer autism supports. This is time consuming, lacks critical information about quality and safety, and is a significant barrier for parents from culturally and linguistically diverse background, autistic parents, people with disability, and others who may experience challenges accessing such a dense resource.

Building the capacity of families to understand what constitutes 'good practice' and which providers are best placed to offer supports that align with their child's needs and the family's values is critical. Access to such independent and valuable advice will be welcomed by many families.

We propose establishment of a public directory of autism support providers that parents to search by location, specialisation, registration status and price. Critically, this directory should also rate providers on their performance against standards/guidelines.

This could be modelled on existing approaches in the early years learning setting. This rates provider performance against the seven quality areas of the National Quality Framework for Early Childhood Education and Care.

Such an approach would complement the proposed autism supports guidelines and parents' decision-making resource.

Conflict of interests must be urgently addressed

Conflict of interest issues must be addressed as a priority. There is a high potential for conflicts of interest when a company involved in the delivery of independent assessments, provision of advice about local support providers, or is involved in the participant planning process also has direct links to subsidiary companies that provide NDIS supports.

While these links may not be apparent to parents engaged in the NDIS market, that they exist undermines community confidence in the NDIS and has the potential to undermine clinical care and decision making for autistic people.

The existing NDIS Quality and Safeguards Commission Code of Conduct for Service Providers¹³ needs to be urgently reviewed and amended to prevent such conflicts from occurring.

Recommendations:

- 11. Develop a directory of autism support providers that includes their rating against the quality standards. This could be modelled on the National Quality Framework for Early Childhood Education and Care.**
- 12. Ensure conflicts of interest are managed via a proper and appropriate separation between organisations responsible for providing information and advice to participants and those providing funded supports.**

¹³Available at: <https://www.ndiscommission.gov.au/providers/ndis-code-conduct>