

Supporting young children and their families early, to reach their full potential

Submission to the National Disability Insurance Agency



About the Australian Autism Alliance

The Australian Autism Alliance (the Alliance) is a coalition of 12 autism organisations around Australia that represent autistic people, their parents and carers, service providers and researchers who aim to realise the potential of autistic Australians. Our substantial national footprint:

- Reaches over 170,000 people through our communication channels
- Employs over 3,000 staff
- Employs, or provide pathways to employment, for over 350 autistic adults
- Contributes to the Australian economy by generating and delivering an estimated \$200m of supports and services
- Builds capacity of the broader community through training and advisory services for over 60,000 people per year
- Covers nearly all of Australia
- Has significant national and international linkages for advocacy, research and service delivery
- Provides direct support to over 30,000 autistic people across the lifespan from early childhood to adulthood
- Operates 230 service outlets across Australia.

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. There is a high rate of mental ill-health among the autistic population.

Autism and the NDIS

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.

For further information

The Alliance stands ready to assist the National Disability Insurance Agency (NDIA) to continually improve the NDIS for autistic participants. Alliance Co-Chairs Paul Micallef and Fiona Sharkie can be contacted at chair@australianautismalliance.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

The Early Childhood Approach ought to enable autism diagnosis

1. Require Early Childhood Partners to screen for signs of autism in children, and where appropriate, connect and support families through the diagnostic process.

Overreliance on functional assessments is dangerous

2. De-couple assessment results from determination of plan budgets, which should instead be driven by goals, aspirations and support needs.
3. Make use of contemporary functional assessments obtained externally (provided they comply with the National Guideline) rather than requiring families to go through a repeat process with the Early Childhood Partner.
4. Upskill the ECP workforce to ensure those conducting functional assessments meet the skills and experience requirements set out in the National Guidelines for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia.
5. Provide a complaints and review process that enables scrutiny of assessments, including an avenue to the Administrative Appeals Tribunal.

Short Term Early Intervention does not replace the need for comprehensive autism-informed support

6. Ensure Short Term Early Intervention access is strictly limited to children who do not meet the section 25 entry thresholds for the Scheme. STEI must not be used in favour of individualised supports for autistic children.

Children with developmental delay are at risk of falling through the cracks

7. Amend section 9 of the NDIS Act (2013) and update the Early Childhood Operational Guidelines to reflect a broader definition of developmental delay by inserting '*social and interpersonal relationships*' as an area of major life activity.
8. Ensure children who have entered the Scheme via Section 25 are not inadvertently exited when they turn seven, after which they exceed the age cap applied to developmental delay.

Deferring section 24 entry to the scheme is unreasonable for some

9. Retain the capacity to provide access to the NDIS through section 24 for autistic children with high or complex needs who meet the existing legal thresholds, circumventing the duplicative process outlined in the proposed Early Childhood Approach.

The Early Childhood Approach needs to be deeply connected to mainstream participation

10. Recognise and reward Early Childhood Partners for making lasting connections into mainstream and community supports for children in the Early Childhood Approach.

We need to move away from the all or nothing approach to the NDIS

11. Reframe goal achievement as a trigger for raising expectations about what a child can achieve rather than as a trigger for Scheme exit.

12. Introduce a “plan for all” so that all children in the Early Childhood Approach have a plan focussed on their goals and aspirations, and connections with mainstream services and community supports. This would enable support to be dialled up or down as life circumstances and support needs change.

Early Childhood Partners must be equipped to deliver on their enhanced role

13. Develop a distinct Early Childhood Workforce Plan to train, recruit, retain and develop early childhood workers. Target diverse communities that reflect the demographics and circumstances of families in the Scheme.
14. Explore opportunities to pair metropolitan and remote Early Childhood Partners to build capacity and capabilities.
15. Build and maintain the autism proficiency of planners and delegates working in the Early Childhood Approach. This should be embedded in the contractual requirements of Early Childhood Partners and measured through regular surveys of participants and stakeholders.

Safeguards are needed for guidance on ‘best practice’

16. Strengthen the proposed Operational Guidelines on Best Practice by:
 - Appointing an independent autism research organisation as the custodian of best practice evidence for autism.
 - Engaging autistic people and the broader autism community in their development and updates.
 - Emphasising the importance of parental input when determining reasonable and necessary supports.
17. Ensure determinations about reasonable and necessary supports for autism early interventions are reviewable decisions.

Quality of providers is critical

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

Providing supports in rural and remote Australia needs innovative responses

20. Trial innovative funding models that facilitate service delivery into remote and regional communities.

Value and build on peer support networks

21. Leverage and strengthen capacity in existing peer networks and informal support structures, rather than duplicating work currently undertaken by local organisations.

Overview

The Alliance welcomes the opportunity to provide a submission to the National Disability Insurance Agency's (NDIA) consultation on its proposed changes to the Early Childhood Approach and acknowledges the background work that has been undertaken to date.

The scope of reforms proposed for the Early Childhood Approach are substantial. We are mindful that details of significant parts of this proposal – including what constitutes reasonable and necessary supports for autistic children, the interpretation of developmental delay, and the design and role of functional assessments for young children – are yet to be released. The Alliance will be better placed to engage with our community and provide a considered and comprehensive response once all aspects of the reforms are revealed.

Based on the information released to date, the Alliance believes there are some positive proposals, some concerning proposals, and some that could have unintended consequences.

There are some positive reform directions:

Upskilling of the Early Childhood delegate and planner workforce is a must, and we call for a focus on building autism proficiency as part of this. The Alliance welcomes the provision of evidence-informed advice about support options; and enhanced provider quality safeguards.

Some proposals are concerning:

Introduction of functional assessments, and the disproportionate role it appears they will play in determining access and plan budgets, risks a raft of negative consequences.

Ambitions to increase the proportion of children exiting the NDIS need to be tempered with the reality that autism is a lifelong condition. The functional capacity and support needs of an autistic person will vary through major life course transitions which tend to be periods requiring elevated support for autistic people. We need to move away from the current all or nothing approach to NDIS assistance. Options to stay connected to the Scheme, and to dial support up and down as and when needed, ought to be explored.

The NDIA's language of being "exited to the mainstream" situates the Scheme as being something separate or other, whereas the Scheme needs to be intrinsically connected to mainstream life. Strengthening interfaces between the NDIS and mainstream and community services for people with disability, whether they receive an individual funding package or not, is fundamental.

Other proposals could be positive, but may have unintended consequences:

We support extending the Early Childhood Approach to age nine, however point to the need to reconcile this with current developmental delay provisions, which cease when a child turns seven. It is critical that children with developmental delay do not lose access to the Scheme simply because they age out of the developmental delay caps.

Strengthening the Short Term Early Intervention (STEI) offering and making it available to more children is a positive, so long as it does not serve to delay autistic children being granted access to the Scheme. Life outcomes for autistic children will be improved by receiving an adequate individual funding package to purchase autism specific supports at the earliest opportunity.

Deferring entry via section 24 until age eight for autistic children with severe and complex disability could create unnecessary administrative hoops for families to jump through, delaying access to long-

term focused supports and forcing them to undergo repeated and unnecessary assessments and access processes.

In summary, we believe a reformed Early Childhood Approach ought to:

- Provide children and their families with immediate access to supports
- Help detect the signs of autism in children and assist families to access diagnosis
- Enable autistic children to have smooth and rapid entry into the Scheme
- Connect families with effective autism supports, informed by the emerging evidence base
- Increase and support participation of autistic children and their families in mainstream life – including early education and school
- Enable families to progressively lift their goals and aspirations for their autistic child.

Feedback on the Proposed Reforms

Autism diagnosis needs to be enabled via the Early Childhood Approach

While the proposed entry pathway into the Early Childhood Approach is not based on a disability diagnosis, the Alliance submits that an autism diagnosis remains a key factor in determining the level, intensity and goals of specific early interventions for autistic children.

Early autism diagnoses enable children to access capacity building supports at a life stage where meaningful improvements to their functional capacity can be achieved. Research undertaken by the Olga Tennison Autism Research Centre (OTARC) has found that Australian children who are diagnosed with autism before the age of two are three times less likely to receive a secondary diagnosis of intellectual disability and 1.3 times more likely to be in a mainstream school than autistic children who are diagnosed between the ages of three and five. OTARC also found that an early autism diagnosis reduces ongoing support needed at school age by 30%.²

Early Childhood Partners (ECP) are uniquely placed to screen for and detect signs of autism in the children they work with whether at initial intake; in subsequent meetings; and when performing assessments or delivering supports. Where such warning signs are present, ECPs should have an explicit role in connecting and supporting families with the diagnosis process.

We acknowledge that the health system (and by extension, the States and Territories) retain the lion's share of responsibility for diagnostic services, however the proposed structure of the Early Childhood Approach offers a rare opportunity to support families to engage with mainstream health supports, while also providing appropriate early intervention and NDIS supports concurrently.

For this opportunity to be realised, it is essential that ECPs and their staff are highly proficient and experienced in understanding how early signs of autism can present, how to identify these symptoms, and how to support families to explore a formal diagnosis.

Recommendation:

- 1. Require Early Childhood Partners to screen for signs of autism in children, and where appropriate, connect and support families through the diagnostic process.**

Overreliance on functional assessments is dangerous

The Alliance holds significant concerns about expanding the role of functional assessments in the Early Childhood Approach. While details of design for the Early Childhood Approach are still unclear, it appears functional assessments will be of huge consequence and form the dominant input into access decisions and plan budgets. This is dangerous and risks undermining the spirit and intent of the NDIS.

Results of the assessments may be unreliable, but have huge consequence

Access to STEI and the Scheme will be contingent on a well-administered functional assessment that

² Clark, M. L., Barbaro, J., & Dissanayake, C. (2017). Continuity and Change in Cognition and Autism Severity from Toddlerhood to School Age. *Journal of Autism and Developmental Disorders*, 47, 328-339. doi: 10.1007/s10803-016-2954-7; Clark, M. L., 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, 92-102. doi: 10.1007/s10803-017-3414-8

accurately reflects the circumstances of the child. While acknowledging that ECPs are well placed to conduct assessments (they have ongoing relationships with the child and their family; and are already undertaking assessments, and are willing to observe children in natural settings), we are concerned that plans to attach such high consequence to these assessment is fraught. A reliable assessment is dependent on:

- A highly skilled assessor, with skills and experience in autism, who can take their time – ideally across multiple sessions - to gain a nuanced and comprehensive understanding of the child.
- A family able to articulate their circumstances with a child who is willing and able to participate.

Without such conditions, assessment results will be unreliable. They will also exacerbate inequities for families with low social capital, low education, distrust of government or low English proficiency.

Functional assessments were never intended to determine funding for disability supports

We understand that the proposed changes will elevate functional assessment results to be the primary determinant of a person's NDIS budget. Using functional assessments in this way is untested, unevaluated and unproven. In our consultations with a range of experts, we have been unable to find an international example where the proposed assessment tools have been used for the purpose of determining a disability support budget.

How the assessment results will be used to arrive at a plan budget has yet to be explained, and key components of the approach, including the algorithms underpinning the Personalised Budget Tool, have not been released.

Consistent advice from expert researchers and clinicians is that the assessment tools have been designed for screening functional capacity and that results cannot be meaningfully converted into a dollar amount that would reliably meet the goals, aspirations and needs of the person assessed.

Families must have scope to challenge assessment results

Assessments will not be reviewable by the Administrative Appeals Tribunal (AAT), effectively ruling out challenges should the process or outcome be unfair or inaccurate. This coupled with the wafer thin grounds proposed for repeating an assessment effectively removes meaningful checks and balances.

Much faith is being asked of families to trust the fairness, accuracy and conduct of assessors, without commensurate grounds for challenging when an independent assessment has been conducted poorly, or its outcome inaccurately assesses a child's functional capacity.

Duplication of assessments is a waste of scarce resources

The National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia (National Guideline) stipulates that as part of the diagnostic process, a child also undergoes a comprehensive functional capacity assessment.

It appears likely that autistic children and their families will be forced to duplicate extensive, contemporary assessments that they would have undergone as part of their diagnosis, using the same tools as those proposed by the NDIA. This represents an unacceptable waste of public resources, and places an avoidable imposition on families.

An NDIS that was interfacing well with the health system would embed the use of functional assessments conducted by external clinicians that accord with the National Guideline in its design.

Recommendations:

- 2. De-couple assessment results from determination of plan budgets, which should instead be driven by goals, aspirations and support needs.**

3. **Make use of contemporary functional assessments obtained externally (provided they comply with the National Guideline) rather than requiring families to go through a repeat process with the Early Childhood Partner.**
4. **Upskill the ECP workforce to ensure those conducting functional assessments meet the skills and experience requirements set out in the National Guidelines for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia.**
5. **Provide a complaints and review process that enables scrutiny of assessments, including an avenue to the Administrative Appeals Tribunal.**

Short Term Early Intervention does not replace the need for comprehensive autism-informed support

The Alliance supports the proposal to expand and make easier access to STEI for non-participants. However, we caution that STEI is not a replacement for specialised, autism-informed support.

We have heard from some in our community that being involved in STEI has served to postpone their autistic child from accessing the range and intensity of supports that evidence shows makes a significant difference to their trajectory. This is not in anyone's interest – be it the child, their family, the broader community or taxpayers. Providing autistic children with a robust individually funded disability plan at the earliest opportunity will provide the best return on investment for the NDIS in the long run.

It appears that the enhanced STEI offering is only available for children aged up to six years, leaving a questionable support gap for those who do not meet the criteria for Scheme entry through section 25.

A further concern relates to how decisions will be made to stream children into STEI or into the Scheme. It appears that a functional assessment (discussed below) may be pivotal to this. Transparency on the criteria and other guidelines for these decisions is needed.

Recommendations:

6. **Ensure Short Term Early Intervention access is strictly limited to children who do not meet the section 25 entry thresholds for the Scheme. STEI must not be used in favour of individualised supports for autistic children.**

Children with developmental delay are at risk of falling through the cracks

We understand that the NDIA will be publishing a separate policy paper dealing with proposed changes to the developmental delay criteria, on which we expect to provide considered feedback.

At this stage, there are two issues we want to raise.

First, **the definition of developmental delay is too narrow because it omits social and interpersonal skills.** Section 9 of the NDIS Act currently defines developmental delay as:

"developmental delay" means a delay in the development of a child under 6 years of age that:

(a) is attributable to a mental or physical impairment or a combination of mental and physical impairments; and

(b) results in substantial reduction in functional capacity in one or more of the following areas of major life activity:

(i) self-care;

(ii) receptive and expressive language;

(iii) cognitive development;

(iv) motor development; and

(c) results in the need for a combination and sequence of special interdisciplinary or generic care, treatment or other services that are of extended duration and are individually planned and coordinated.

Challenges associated with developing and maintaining social and interpersonal relationships are common among autistic children. We know that there will be a significant proportion of children whose initial diagnosis of developmental delay will subsequently change to an autism diagnosis, once a thorough assessment is completed.

With access to the Scheme being focused on a child's functional capacity, there is a risk that the impairment of children with delay in the domain of social and interpersonal relationships will not be adequately reflected in their assessment results.

To address this risk, the definition of developmental delay needs to be broadened to include social and interpersonal relationships in the list of major life activities. The World Health Organisation's International Classification of Functioning, Disability and Health³ offers a useful foundation from which to base a nuanced definition of social and interpersonal relationships, which would be appropriate to adapt and include in the NDIS Act's definition of developmental delay.

Second, children with developmental delay may be inadvertently tipped out of the Scheme when they turn seven.

The proposed Early Childhood Approach includes a number of inconsistencies where its coverage relates specifically to a child's age, not their functional capacity.

We are concerned that children who have been screened for developmental delay and who exhibit functional capacity challenges that warrant access to either the STEI offering or the NDIS through section 25 will have their access eligibility revoked based on their age.

The development delay criteria applies only to children up to six years and 364 days old. Over half of the new ECEI participants in 2019-20 entered the NDIS with a developmental delay diagnosis, and would face an uncertain future with plans to stretch the Early Childhood Approach to age nine.

We also note that children from vulnerable circumstances with developmental delays often do not have these identified until they start school. They are at risk of being too old to access supports that current cease at age six, leaving them exposed to the risk of long-term deficits that could have been addressed.

Recommendations:

³ *International Classification of Functioning, Disability, and Health. ICF. Geneva, World Health Organization, 2001.*

- 7. Amend section 9 of the NDIS Act (2013) and update the Early Childhood Operational Guidelines to reflect a broader definition of developmental delay by inserting 'social and interpersonal relationships' as an area of major life activity.**
- 8. Ensure children who have entered the Scheme via Section 25 are not inadvertently exited when they turn seven, after which they exceed the age cap applied to developmental delay.**

Deferring section 24 entry to the scheme is unreasonable for some

Proposed reforms will see children under nine almost exclusively entering the scheme through the Early Intervention pathway under section 25 of the NDIA Act. We note that around 65% of autistic children currently enter the Scheme via section 25, and around 35% via section 24.

The NDIA has acknowledged that for children with profound or severely complex disabilities, an 'empathic' option of earlier entry to the scheme via section 24 – the Disability Pathway for those likely to need lifetime support from the NDIS – may be available.

We acknowledge that both sections 24 and 25 give participants access to an individual funding package that can be directed to autism supports. However, we are concerned that families with autistic children with high or complex needs, all of whom clearly meet the threshold of a lifelong disability, will be made to unnecessarily jump through hoops. The resulting stress, the lack of certainty about ongoing support, and need for repeat assessments for scheme entry via different pathways should be avoided.

Recommendations:

- 9. Retain the capacity to provide access to the NDIS through section 24 for autistic children with high or complex needs who meet the existing legal thresholds, circumventing the duplicative process outlined in the proposed Early Childhood Approach.**

The Early Childhood Approach needs to be deeply connected to mainstream participation

The language in the NDIA's consultation papers (e.g. 'exiting to mainstream') speaks volumes about the low ambitions for achieving a Scheme that enables people with disability to be truly and fully integrated in mainstream life. There is so far to go to achieve a seamless articulation between mainstream and community services, and NDIS supports.

The Scheme needs to match the autism community's aspirations for an ordinary life with the opportunity and supports to do so. There are endless examples of people with disability – regardless of whether they are NDIS participants – who find themselves excluded and marginalised from mainstream life.

The Early Childhood Approach reform proposals should place a greater emphasis on achieving a cohesive early childhood approach with NDIS supports working hand in glove with mainstream supports to ensure all children develop to the best of their capacity. Close engagement with mainstream settings – playgroups; early childhood education and care; pre-school; mainstream school; sports and community activities, health and mental health care are key to supporting children with disability, and in many cases will reduce the need for specialised disability supports.

The emphasis must remain on building these connections and move away from the narrative of “exiting children” onto mainstream supports.

While we appreciate that the NDIA and the Australian Government cannot alone deliver on this vision, Early Childhood Partners need to be equipped and have the right incentives to play their part in advancing this including through performance measures in ECP contracts for enduring connections made with mainstream and community services.

Recommendations:

- 10. Recognise and reward Early Childhood Partners for making lasting connections into mainstream and community supports for children in the Early Childhood Approach.**

We need to move away from the all or nothing approach to the NDIS

We agree that it is important to mark and acknowledge when a child and family achieve their goals and outcomes. However, we disagree with the proposition that achievement of goals should be a trigger for transitioning out of the Scheme. Rather, achievement of a participant’s goals should be a trigger to work with families about what new goals might be set. Our view is that both the NDIA and families should enter this process with an optimistic view of the capacity of the child to progressively attain higher goals.

Ambitions to increase the proportion of children exiting the NDIS seem to be blind to the reality that autism is a lifelong condition. The functional capacity and support needs of an autistic person will vary through key transitions and with the changing circumstances of life. We need to move away from the current all or nothing approach to NDIS assistance. Options to stay connected to the scheme, and to dial support up and down as and when needed ought to be explored.

We support the concept (developed by the Brotherhood of St Laurence) of a ‘plan for all’ in the Early Childhood Approach, whether or not the child attracts individual funded supports. It would mean families still articulate goals and aspirations, are assisted to access community, mainstream and informal supports, and have a foot in door for individually funded support should they need them from time to time. This would avoid dropping off the cliff for those who might otherwise be “exited” or “graduated” off the Scheme. Families could of choose to exercise their choice and control to opt out of the Scheme, but should be confident that the safety net remains, should their child need it in the future.

Recommendations:

- 11. Reframe goal achievement as a trigger for raising expectations about what a child can achieve rather than as a trigger for Scheme exit.**
- 12. Introduce a “plan for all” so that all children in the Early Childhood Approach have a plan focussed on their goals and aspirations, and connections with mainstream services and community supports. This would enable support to be dialled up or down as life circumstances and support needs change.**

Early Childhood Partners must be equipped to deliver on their enhanced role

The role of Early Childhood Partners is proposed to expand considerably. Key functions will include:

- Providing initial supports to children and families
- Conducting functional assessments
- Delivering Short Term Early Intervention supports for ‘non-participants’
- Supporting the access process to the Scheme
- Advising families about local providers who represent best-practice and supports that are evidence-informed
- Supporting the creation of individual plans and assisting families to implement their children’s plans
- Building connections with mainstream and community supports
- Building disability inclusion in their regions.

There are many benefits in devolving such responsibilities to community organisations with local expertise and connections. However, they need to be equipped to deliver.

The Alliance has concerns about the current readiness of the early childhood workforce to successfully deliver on the vision of their expanded role. A consistent concern among our partners and community is the high turnover of ECP staff and the lack of depth in the workforce, captured in the following quote:

My main concern and disappointment is with the constant shuffling of staff, which disrupts the continuity of care/information dissemination and relationships. As an autistic person myself, I find dealing with new people, with bureaucracy/paperwork/form filling/questions (feel like interrogations) draining and difficult and it takes me a long time to build up trust in that relationship. We have been with the NDIS 4 years and have had three people in that planning role so far. Next year we will also get someone new as our son will have aged out of the ECEI pathway. I am dreading it. It is exhausting to have to go through his history all over again.” (Respondent, Australian Autism Alliance Autism Community Survey 2020)

We support the creation of a distinct early childhood planner and delegate workforce. But ensuring such a workforce is available at scale, and is not dependent on luring workers from the disability or adjacent sectors cannot happen overnight. The NDIA’s *NDIS National Workforce Plan* needs to include a specific strategy for training, recruitment, retention and development of an early childhood workforce. There is significant opportunity to recruit a diverse workforce that reflects the demographics and circumstances of families in the Early Childhood Approach, including staff with lived or family experience of autism.

The very high representation of autistic children in the Early Childhood Approach necessarily demands a workforce that is proficient and experienced in supporting autistic children and their families. Building and maintaining autism proficiency ought to be considered a permanent and ongoing professional development commitment, with staff remaining informed of changing evidence and best-practice, both generally and in local contexts. This could form part of the contractual conditions of ECPs, with performance monitored through regular participant and stakeholder surveys.

The absence of Early Childhood Partners in some remote areas entrenches disadvantage and requires urgent attention. Opportunities for collaboration between metropolitan and remote ECP should be explored, including avenues for virtual assistance and support.

Recommendations:

- 13. Develop a distinct Early Childhood Workforce Plan to train, recruit, retain and progress early childhood workers. Target diverse communities that reflect the demographics and circumstances of families in the Scheme.**
- 14. Explore opportunities to pair metropolitan and remote Early Childhood Partners to build capacity and capabilities.**
- 15. Build and maintain the autism proficiency of planners and delegates working in the Early Childhood Approach. This should be embedded in the contractual requirements of Early Childhood Partners and measured through regular surveys of participants and stakeholders**

Safeguards are needed for guidance on ‘best practice’

Building the capacity of families to understand what constitutes ‘best 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 support the development of a clear decision-making framework to guide how best practice is determined, subject to the following caveats:

- First, families’ needs and understanding of their child’s needs must be heard and accorded sufficient weight.
- Second, when developing new Early Childhood-specific Operational Guidelines, the NDIA seeks detailed input from the autism community.
- Third, an independent and credible autism research organisation acts as the custodian of what constitutes ‘best practice evidence’ for autism interventions. 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 evidence.’

The Autism CRC’s review of autism early interventions⁴ offers the foundations from which to base a robust national early intervention guideline, which would need to be buttressed by clinical wisdom the lived experience of autistic people and their families’.

We note the likely role of ECPs in guiding decision making on what constitutes a reasonable and necessary support for autistic participants. While our specific feedback on this recommendation will be reserved for the related consultation, we want to emphasise that empowering ECPs to rule on the complex and sometimes contested evidence base on early interventions for autism is fraught with risk. It is essential that parents and service providers have scope to question the rationale of decisions made by ECPs in this regard, and to ensure ECPs can explain and justify their decision making in a transparent and public manner.

⁴ 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.

Recommendations:

16. Strengthen the proposed Operational Guidelines on Best Practice by:

- **Appointing an independent autism research organisation as the custodian of best practice evidence for autism.**
- **Engaging autistic people and the broader autism community in their development and updates.**
- **Emphasising the importance of parental input when determining reasonable and necessary supports.**

17. Ensure determinations about reasonable and necessary supports for autism early interventions are reviewable decisions.

Quality of providers is critical

The Alliance supports the proposal to enhance provider compliance with the Practice Standards. There is a broad range of support options in the NDIS marketplace and for many families, understanding which of these provides the best value and is evidence-based can be confusing. Accordingly, we support changes that would improve the ability of families to discern between various support offerings and to make informed decisions about the support mix that is appropriate for their child. This includes providing families with confidence that all providers are offering a trustworthy and quality service.

We are cautious about implementing an industry-led 'best practice' accreditation system, noting that while accreditation itself is positive, it should be led by an independent body with regulatory oversight over NDIS providers.

We also note that for many providers, the burden of multiple and overlapping accreditation requirements is significant. When considering adjusting the regulation of the sector, it is important that the NDIA assesses the balance of regulation and ensures that the end state is an approach that is smarter and provides a level playing field, particularly for providers who have made the early commitment to register with the Quality and Safeguards Commission and adhere to the Practice Standards.

We prefer one of the stronger mechanisms proposed, namely making registration with the NDIS Commission compulsory for all providers working with young children. 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.

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:

18. Require all providers of early childhood supports to register with the NDIS Quality and Safeguards Commission.

19. Support smaller organisations and sole providers to achieve registration, subject to meeting quality requirements.

Providing supports in rural and remote Australia needs innovative responses

Providing early intervention supports in rural and remote communities continues to be a considerable challenge. We note that thin markets across Australia prevent many participants and their families from accessing timely local supports, and that in areas of market risk (i.e. not just Modified Monash Model areas 6-7, but including areas 4-5), a scarcity of allied health providers serves to unintentionally constrain access to NDIS supports.

The NDIA's existing approach of limited market intervention has not resolved market risk in many areas. Price incentives for participants in remote and very remote areas, while valued and necessary, have not translated into widespread access improvements. Service providers that the Alliance has consulted report persistent barriers to delivering early intervention supports to families in rural areas, including restrictions to funding for travel and the difficulty of applying a funding model built on the concept of 'billable hours' in remote communities. When combined, we see significant risks to the development opportunities for children. These concerns are affirmed by parents of Scheme participants who report considerable wait times to access allied health supports in their local areas.

We believe the NDIA should consider alternatives to the existing paradigm of individualised funding in areas of identified market risk. While the Alliance does not have a firm preference for how this might be applied, examples include allowing participants and families to coordinate and 'pool' funds and incentivise providers to offer supports in rural and remote areas. Other suggestions include engaging with mainstream providers to consider introducing mixed funding models to address market risk, leveraging existing public and community providers (such as schools, early education providers, public hospitals, multipurpose services and Aboriginal and Torres Strait Islander Community Controlled Health Organisations) and supporting them to offer early intervention supports through a portion of block funding, in partnership with state and territory governments.

Regardless of the mechanism, there is an ethical imperative to explore 'non-traditional' NDIS funding mechanisms to ensure families living outside of metropolitan and regional areas can access timely and appropriate supports.

Recommendation:

20. Trial innovative funding models that facilitate service delivery into remote and regional communities.

Value and build on peer support networks

Peer support networks play a crucial role helping families understand the NDIS and their rights and responsibilities in the context of the Scheme, and importantly, connecting families to others who have experience in raising children with disability. In this context, we believe there is value in ECPs taking a role in connecting families into existing networks.

In this light, we welcome the proposal that ECPs engage in a more active role connecting families and young children to these networks. However, we caution the risk of duplicating existing approaches. We suggest that a short stand-alone consultation piece is warranted, in which existing

peer support networks and groups are identified and the most efficient means of linking families to them is agreed upon, rather than directing ECPs to remake existing networks or duplicate the work of well-established organisations.

Recommendation:

21. Leverage and strengthen capacity in existing peer networks and informal support structures, rather than duplicating work currently undertaken by local organisations.