AUSTRALIAN
Advisory
Board on
Autism

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Response to the NDIS Consultation Paper: ‘Interventions for children on the autism spectrum’

The Australian Advisory Board on Autism (AABA) is the peak national umbrella body bringing together the autism peaks of each State and Territory.

Autism comprises more than 35% of NDIS participants. As such NDIS reforms are central to the work of the AABA because they fall disproportionately on the autism community.

The National Disability Insurance Agency (NDIA) is developing:

- an approach to framing best practice early intervention for children on the autism spectrum, and
- a policy position to inform the funding of early intervention for children on the autism spectrum.

While the AABA welcomes the opportunity to provide feedback on the proposed approach it is concerned the approach has already been designed and there is insufficient time or opportunity for meaningful consultation and engagement.

AABA members have consulted widely with parents and carers of children on the autism spectrum, allied health professionals, lead agencies, community organisations and NDIS provider support contacts to gather feedback on the questions posed by this consultation paper.

The AABA supports the ‘Every Australian Counts’ *Terms of Engagement for NDIS Minister Reynolds from the disability community* which identifies that: all proposed changes to NDIS access and planning need to stop; the Government commits to the Terms of Engagement; and an immediate review and strengthening of the governance of the NDIS occurs.

We call on the NDIS to immediately cease the rollout of the policy position and approach for early intervention for children on the autism spectrum pending implementation of best-practice co-design and consultation.

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Following is an outline of our collective concerns regarding the inadequacy of the consultation process, limitations in the policy position and proposed approach, and recommendations for a better approach to best practice in early intervention for children on the autism spectrum.

INADEQUACY OF THE CONSULTATION PROCESS

i) The NDIA have released multiple Consultation Papers over a short period with no time for actual consultation. They have been developed exclusively by NDIA staff and demonstrate limited understanding of current attitudes towards supporting people with disability and the social model of disability.

ii) The release of multiple consultation papers over a short period of time significantly impacts AABA organisations - all of whom have core workloads that focus specifically on supporting people on the autism spectrum and their families. The unfunded weight of responding to the stream of NDIA consultations is challenging and unreasonable.

iii) There is no information available as to where the current consultation paper fits with broader reforms across the NDIS, including policies around plan flexibility, independent assessments and supporting young children and their families early, to reach their potential.

iv) People on the spectrum, their families and providers must be able to provide meaningful input to the design of intervention supports, not after the draft Papers have been developed.

v) 'Information sessions' offered by NDIS staff for families, participants and providers consist of the presenter reading key points in the papers and being unable to answer questions from attendees about how aspects will be implemented, the rationale behind them, or engage in any meaningful discussion on concerns raised by attendees.

vi) The easy-read version of the current consultation paper provides limited information and fails to provide details of the proposed funding framework. This oversight potentially prevents the inclusion of many in the consultation process.

LIMITATIONS OF THE POLICY POSITION AND PROPOSED APPROACH

The Paper both misrepresents and lacks representation of children and families

i) The model seems to indicate a diagnosis of Autism Spectrum Disorder (ASD) is required to trigger the proposed funding model; this is not appropriate as many children will not have a diagnosis.

ii) The complexity of needs for individuals on the autism spectrum and their families is not reflected. Co-occurring conditions and behaviours of concern are prevalent in this population, and families may have additional demands that impact capacity to support their child on the spectrum (e.g., rural locations, low socioeconomic, Culturally and Linguistically Diverse and Indigenous backgrounds and the support needs of other children, other family members on the spectrum, elderly or unwell family members).

iii) Australian Bureau of Statistics data (2017) indicates that two of three people on the spectrum have profound or severe disability.

iv) A diagnosis of ASD represents pervasive impacts across domains of development. There is no consideration the identified 'areas of need' have substantial impact across a child's and family's functioning, across environments and across the life span. To reduce this experience to an 'area of need' in a table is inappropriate.

There is no representation of holistic planning that allows for the provision of capacity building supports through family-centred practice

i) The principles and case studies included suggest that interventions delivered by mainstream services providers will form a substantial component of the child's early interventions supports. A key case study suggests that six hours per week of intervention will be provided by early educators - a large proportion of the required intervention to support a recently diagnosed 3-year-old child on the autism spectrum.

ii) Evidence suggests early childhood programs and schools are struggling to successfully include students on the spectrum (Autism Queensland, 2017). Many families change early childhood programs and schools frequently in search of a program or school that can meet their child's needs, while other families elect not to send their child to an early childhood education service, or to home school.

iii) Substantial input is required to provide education for these mainstream service providers about autism and how to best support inclusion and participation. No information is provided in the consultation paper or any other forum as to how this issue will be addressed.

iv) There is no recognition that such divisive responsibilities make it likely children and families will fall between the gaps.

v) There is no acknowledgement that it is exhausting, distressing, overwhelming and incredibly unsupportive for families to navigate systems that present barriers directly related to their child's disability, and the family's functioning.

vi) There is no reference to family-centred practice. There is no reference to how parents' perspectives will be gathered and included in the holistic plan, including parents who have multiple children with and without disability, other family responsibilities and/or barriers to employment.

vii) Families have limited access to the practice guidelines and research evidence as the NDIA-commissioned Autism CRC report 'Interventions for children on the autism spectrum: A synthesis of research evidence,' published in 2020 (Whitehouse et al., 2020) includes highly technical language and complex statistics.

viii) Supports outlined in this proposed funding framework do not allow for holistic planning as they exclude specialist supports provided in typical settings such as early education, community, home, or school (requiring providers to travel to and from settings). It also excludes specialist supports directed towards parent/carer involvement and capacity building, particularly for those families with complex support requirements.

ix) There is no attempt to move away from a medical model approach.

x) Families are not supported to access a range of relevant professionals, including educators, allied health assistants, music therapists and support workers. The model exacerbates the existing allied health workforce shortage.

xi) There is poor operationalising of key messages into indicative levels of funding that offer categorised funding options for children who are diverse and require individualised supports.

xii) There is a disconnect between the use of the term 'holistic', whether related to planning, assessment, or anything else within the Paper and the funding model.

xiii) Children on the autism spectrum need a supportive structured environment as their first transition from home. If this cannot be provided in a mainstream setting, specialist services provide a safe learning environment for the child to learn skills in preparation for transition to their local school or early childhood education program. The proposed model does not consider this option.

The Consultation Paper assumes an independent assessment process

i) This consultation paper is based on the erroneous premise that a functional assessment is a valid tool for identifying levels of need/funding. Proposed changes to policy processes for independent assessments for all NDIS participants are currently paused due to strong feedback from participants and providers.

ii) The inappropriate nature of an independent assessment process has already been addressed in previous consultations. All concerns expressed in response to the NDIA's Consultation Paper on Independent Assessments apply to this proposed model.

The research cited as a reference point has been misrepresented

i) Key recommendations from the Autism CRC report have been ignored. Of central importance is the need to include three core elements of evidence-based practice to guide decision making: research evidence, individual preference, and clinical experience.

ii) The Autism CRC report calls for the development of a consensus-based guideline for early intervention, with comprehensive practice recommendations. This has not been factored into the consultation paper.

iii) Reference to the Autism CRC report as the only informing source to best practice guidelines substantially limits growth and future research, as well as families' choice and control - it fails to recognise the importance of emerging practices that are evidence-informed.

iv) As acknowledged in the Autism CRC report (Page 99), a limitation is the focus on intervention categories and practices, and not techniques. For this reason, the review does not include some widely used intervention techniques that have been deemed as evidence-based in previous reviews.

v) Reviews of interventions were excluded because they did not include one clinical trial and/or controlled clinical trial. This meant that reviews of interventions based solely on Single Case Experimental Designs were not included. Yet, interventions such as visual schedules and work systems have been supported in other evidence-based reviews which include the evidence supported by Single Case Experimental Designs.

vi) The Autism CRC report and the paper fail to adequately examine intervention intensity. 'Early Intervention for Children with Autism Spectrum Disorders: Guidelines for Good Practice' (Prior & Roberts, 2012) is a standout paper on best practice guidelines and remains current and useful in its ability to inform policy and practice. Of note, this paper discussed amount of intensity for best practice intervention.

Proposed 'levels of funding' is a fundamentally flawed approach

i) Indicative levels of funding are a direct contradiction to the Autism CRC recommendations. Their report did not consider matters of funding and should not be used to assert a levels-based funding model.

ii) The Autism CRC report found there was inconclusive evidence to determine whether the amount of intervention influenced the effectiveness of the intervention. However, this finding did not provide clear evidence on the minimum or maximum amount of intervention to achieve effectiveness, nor the ideal frequency or duration of the intervention program. This finding does not provide a rationale for the proposed funding levels, nor a rationale for reduced funding which may effectively be the outcome for many children with high support needs if these funding levels are implemented.

iii) Many parents whose children are currently receiving early intervention services report they will be unable to continue to access supports their child/ren and family require under the proposed changes. Families are distressed about the proposed reduction in supports that have previously been deemed reasonable and necessary.

iv) There is no transparency as to how budgets would be calculated. For example, how is a dollar value assigned for the functional impact of reduced mobility, compared with impaired communication?

v) Indicative levels lack the flexibility to cater for the high level of complexity of individual needs for children on the spectrum and their families.

vi) Multidisciplinary therapy, which the NDIA acknowledges to be of the highest benefit to children on the autism spectrum, would not be possible for many children with such low levels of funding.

vii) Based on the provided funding levels, providers will have reduced capacity to offer beneficial models of practice. This will compromise future research and ongoing improvement of services.

viii) Funding bands reinforce the sensation of the NDIA's distrust of early childhood intervention specialists who work to develop informed knowledge of the child's level of need.

ix) Implementation strategies are recommended for providers which are contrary to agreed best practice of individualisation of services for children and families i.e., one childcare visit per term, a mix of weekly or fortnightly therapy sessions.

x) There are concerns about the qualification of the NDIS personnel who will interpret the level of a child's function that will determine the level of their funding.

The assumed decrease of supports as a child ages is misinformed and detrimental

i) It should not be assumed the support needs of children on the spectrum will decrease as they age, or as they begin school. There is compelling evidence of better outcomes when support is increased at all points of transition across the lifespan.

ii) Autism Spectrum Disorder is defined by the Diagnostic and Statistical Manual of Mental Disorders (5th ed.) as a lifelong condition (American Psychiatric Association, 2013).

iii) Unlike many disabilities that are identified at birth, autism is not diagnosed on average until the age of four when the child is likely to be entering mainstream services such as childcare or schooling. Their support needs also extend across the lifespan. Information collected from AABA organisations showed over a third of responding families received a diagnosis for their child when they were aged between six and 12 years.

iv) More supports are often required during the school years when children are challenged by complex social environments, greater demands for independence, academic pressures, and increased stimulatory environments.

v) There is the additional risk of disadvantaging large sections of the population, including females and children from rural and remote areas, Indigenous and Culturally and Linguistically Diverse families who often receive a diagnosis later in life, often not until they have started in a school setting.

Allocation of children to bands of functional impact is fundamentally wrong

i) In line with best practice guidelines, supports need to be individualised to meet the specific needs of children on the autism spectrum and their families.

ii) There are no assessment tools that can be used to allocate children with disability into bands of need.

iii) Identification of a child's support needs across all affected areas of development requires input from a range of professionals. It is against professional standards and unfeasible for a child's support needs to be assessed and allocated by a sole clinician or planner.

The delivery of Short-Term Early Interventions by Early Childhood Partners is questionable

Early identification and intervention for children on the autism spectrum are widely regarded as two of the most important factors for improving long-term outcomes.

i) The AABA rejects that "many children on the autism spectrum will benefit from short-term early intervention that is delivered through our early childhood partners and may never need to become participants of the Scheme" due to lack of evidence.

ii) There is no information available about the quality, efficacy or cost-efficiency of Short-Term Early Intervention (STEI) delivered by NDIS partners.

iii) The specification that this STEI is generally for up to 12 months and, "If the child develops more severe and persistent functional impacts, they may access another period of STEI…", presumably for another 12 months, is deeply concerning. It is unacceptable for a child on the autism spectrum to have delayed access to targeted and specialised early intervention.

iv) There is robust research that supports that targeted, specialist early intervention for children with a diagnosis of autism will minimise the trajectory of the disability (e.g., Clark, Vinen, Barbaro, & Dissanayake, 2018; Dawson et al., 2012; Estes et al., 2015; Green et al., 2017).

v) Children who present to NDIA without having received a diagnosis need to be linked in with a paediatrician and simultaneously receive short-term supports to ensure early access to diagnosis and specialist early intervention. There is no indication this would be undertaken by the Early Childhood Partners as part of STEI.

'Transition out of the Scheme' approach is fundamentally flawed

i) This assumes once outcomes are achieved, the child's environments remain unchanged. It shows no understanding of autism and the significant challenges experienced by children on the spectrum that are exacerbated at as they move through life stages and transition points. Support needs to be ongoing and flexible to meet the needs of the child and family at different points in time.

ii) It assumes schools and community environments have the skills, knowledge and capacity to support children on the autism spectrum independently.

iii) Families have told us repeatedly that support needs are not reducing over time and they are not being listened to at a crucial stage where appropriate supports would make a difference to long term outcomes for young people.

In summary, investment in these proposed changes will not deliver the stated sustained positive outcomes and will place an unacceptable burden on families.

> *"Myself and my husband are getting stressed out in taking care of him. We have to take care of our two daughters as well. Therefore, it is very difficult for us to bear the burden …. and we will be broken both personally and financially".*
>
> *Parent of a 4-year-old on the autism spectrum*

AUSTRALIAN ADVISORY BOARD ON AUTISM RECOMMENDATIONS

1. Immediately cease the rollout of this approach and policy position on intervention for children on the autism spectrum.

2. Engage in co-design with participants, families, carers and the sector for a solution best supported by evidence.

3. Shift autism interventions to allow cultural and practice changes that create inclusive communities for both the child and their families and carers.

4. Provide accessible information to enable choice and control to all families of children on the autism spectrum.

5. Undertake economic modelling to further understand the supports required to reduce the trajectory of disability related to a diagnosis of autism.

6. Outsource a robust and transparent evaluation of the methodology applied to the indicative levels of funding, including the funding amount allocated to these levels.

7. Individualised approaches to planning and funding are essential.

8. NDIS ECEI partners should be required to register as an Early Childhood Practitioner based on evidence of their practice, skills, training and support and supervision structures. This would be in line with the rigorous processes in place for current registered providers to provide evidence of the provision of quality intervention and the NDIS Quality and Safeguards Commission regulations for the registration of PBS Practitioners.

9. A registration requirement for all early intervention providers that offers public protection by ensuring principles and standards commensurate with this scope of practices are met.

10. All processes undertaken by NDIA should be subject to review and appeal.

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