

# AUTISM QUEENSLAND RESPONSE TO THE NDIS CONSULTATION PAPER: INTERVENTIONS FOR CHILDREN ON THE AUTISM SPECTRUM

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.

Autism Queensland has consulted with parents and carers of children on the autism spectrum, allied health professionals, support providers and community organisations to gather feedback on the NDIS consultation paper. Autism Queensland has provided responses to the consultation questions in the document, along with additional, pertinent information from research, disability sector workforce and families of children on the autism spectrum.

Ahead of responses to consultation questions, and of overriding importance:

Autism Queensland supports the 'Every Australian Counts' *Terms of Engagement for NDIS Minister Reynolds from the disability community*. These Terms of Engagement identify that all proposed changes to NDIS access and planning needs 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.**

## Key limitations of the approach to framing best practice

1. The approach is based on the erroneous premise that functional assessment is a valid tool for identifying level of need/funding. This is widely and strongly opposed, and this current paper should also be put on hold until this is resolved.
2. Participant and provider feedback was not sought through a truly consultative process.
  - Providers and families need meaningful input to the design of intervention supports; not to be asked at the end when the draft Papers have been developed,
  - NDIS have released multiple Consultation Papers with no time for actual consultation.
  - These Papers have been developed exclusively by NDIS staff, reflecting a limited understanding of current approaches to supporting people with disability and a social model of disability.

*"I understand and appreciate you always need to improve and that means change. I just wish more consultation was done with community as it really appears this is a done deal. I feel for so many people ... often we are already at breaking point and need support ... that means listening to the needs of the participants and carers."*

(Parent of a child on the autism spectrum)

3. There is a lack of translation of research into practice into the proposed approach to practice.
  - Information presented as evidence from the Autism CRC report (Whitehouse et al., 2020) is misinterpreted and misrepresented. There is no effort to commence the development of a consensus-based Guideline for early intervention, with comprehensive practice recommendations per the Autism CRC recommendations.

- No family-based supports are included in the proposed approach, despite recommendations by the Independent Advisory Council (IAC) report which the Consultation Paper identifies as a key resource.
  - There is an exclusive focus on medical model terms, such as hours of individual professional input and targeting change to a child's behaviours of concern.
  - There is no emphasis on supports for the family, environmental improvements or reducing barriers to participation.
  - No information is available on how the principles, standards and holistic planning described in the report translate into the model.
  - There is risk of harm for children on the autism spectrum and their families through poor operationalising of research. The Autism CRC report is based on low- moderate quality research, with minimal information provided on adverse effects and no evidence regarding the amount of intervention that may maximise effects on child and family outcomes.
4. There is an overwhelming lack of recognition and understanding of the complexity involved in providing intervention to children on the autism spectrum.

**Autism Queensland does not support the proposed approach to operationalising best practice early intervention funding.**

**Key limitations of the approach to funding best practice**

1. Policy processes for changes to access and planning are currently paused due to the strong feedback from participants and providers on the absence of meaningful and individualised planning. This Paper is based on a similar process of determining funded supports with no knowledge of a participant as a person with self-determination and individual needs.
2. The proposed funding model does not represent a satisfactory understanding of children on the autism spectrum and their families:
  - Representation of children on the autism spectrum is based on features or levels of impairment,
  - Representation of families of children on the autism spectrum is excluded.
3. This consultation paper introduces funding bands with no evidence base for those funding bands.
4. Basing different funding amounts on a child's age is inappropriate:
  - Many children will not be diagnosed until after they start school.
  - Many children, whether or not they have received diagnosis and/or intervention prior to school will experience great difficulties in the school environment and require additional support, not less.
  - Supposed positive impacts of a child reaching school age are not reflected in lived experiences or in the research.
5. We highlight the fact that information about the funding bands is not included in the easy-read version of the Consultation Paper. Parents accessing information about this proposed policy change through this medium will lack critical information that can potentially impact their choice and control.

## RESPONSES TO CONSULTATION QUESTIONS

Autism Queensland is concerned the approach has been designed before appropriate consultation has occurred. There is also insufficient time for actual consultation and the NDIA have not demonstrated meaningful engagement. This feedback on the proposed approach is delivered with an expectation for ongoing collaboration with the NDIA to ensure best possible outcomes for children on the autism spectrum and their families.

Responses to the questions posed in the Paper are presented using the 3-pronged core features of evidence-based practice as described by the Autism CRC in its report that was commissioned by the NDIA and which has been represented as an integral part of the development of this NDIS consultation paper.

This is to highlight that evidence informed practices as defined by the Autism CRC consist of three equally important components:

- Respecting family’s perspectives and experience
- Respecting research findings
- Respecting clinical experience of disability sector workforce



Autism Queensland recognises the Paper as focusing only on the research evidence and not considering two-thirds of the overall picture of evidence-informed practices.

### Section 1: Promoting Best Practices

1. The Autism CRC’s research along with other evidence and research are being used to inform future NDIS operational guidelines, and increased transparency on reasonable and necessary supports. Some of the other considerations include:

- key principles for autism interventions
- standards for the delivery of autism interventions.

Which of these would you use to make decisions about accessing best practice interventions (or services) for children on the Autism Spectrum?

- NDIS website
- NDIS Operational guidelines
- Participant decision making guides (not yet developed)
- My usual NDIS or NDIS partner contact
- Autism organisations or peak bodies
- None of these

2. Where else would you like to be able to find the information you need to make decisions about accessing best practice interventions (or services) for children on the autism spectrum?”

## Respecting family's perspectives and experience

The provided list does not represent choice or access to information for families who are seeking best practice interventions.

- Families have told us they are confused and anxious about information received from the NDIS (see Case Study 1 in Appendix). The reference to 'decision-making guides' that have not yet been developed makes it impossible for participants and their families to understand what these might be, how they might work or comment on whether they are of any use.
- Autism Queensland always directs parents and participants back to the NDIS when the people have anxieties or concerns about any aspect of their NDIS situation. Parents regularly inform us they cannot get in touch with their NDIS contact or to ask for assistance in understanding what the NDIS' response means. Those parents who have a 'usual NDIS partner contact', report they also have difficulty contacting them because the person is not available and does not/is slow to respond to their calls or emails or that contact has changed multiple times. They also report they often receive responses from several different people within the NDIS, most of whom they do not know, adding to the confusion, lack of clarity and inconsistency of information (see Case Study 1 in Appendix).
- Most parents of children with disability do not have the time, energy or emotional resources to be embarking on gaining and maintaining an understanding of ever-evolving operational guidelines. Parents should not be burdened with this expectation. They should have the reassurance that any provider they access is obliged to operate and inform within the parameters of best practice.

*"The planner should plan accordingly with families and prepare families to understand what will happen with their plan and funds."*

(Parent of a 4- year-old child on the autism spectrum)

- Families have told us that their preferred sources of information and assistance are:
  - . GPs
  - . Paediatricians
  - . Their current support providers if they have any
  - . Community health, primary health care providers
  - . Early Days workshops
  - . Raising Children Network
  - . Playgroups
  - . Early Childhood Education and Care contacts
  - . Schools
  - . Other families
  - . Peak bodies for Allied health providers: Speech Pathology Australia, Occupational Therapy Australia, Australian Health Practitioner Regulation Agency
  - . Support groups

**There is a conflict of interest for the NDIA in providing advice or recommendations about best practice or appropriate interventions while also making funding decisions**

- Families express they feel it is inappropriate to have the NDIA providing advice or recommendations about best practice or appropriate interventions while also making decisions about the funded supports in participant plans.

- Feedback received from parents regarding the impact of NDIS processes:
  - . *Fearful of planning process*
  - . *Fearful of review process*
  - . *Unable to access information and have not been able to voice concerns*
  - . *Unable to understand the scheme and have not been able to voice concerns.*

## Respecting research findings

The provided list does not encourage access to evidence-based practice.

- The origin of information about best practice, regardless of who is providing it (NDIS, providers, others), is current research. Details about how any of the NDIS sources of information from Question 1 would be accessed, interpreted and applied is not provided. The website, operational guidelines, participant decision-making guidelines and NDIS partner organisations would need to have appropriately qualified staff constantly reviewing and updating their information in line with evolving research outcomes. Autism organisations do this as a matter of course to ensure that the supports they provide are evidence-informed and best practice.
- NDIA has a significant conflict of interest in being the provider of information about best practice as it is utilising and manipulating such information to support intervention types and quantities that are focused on reducing funding amounts for a child.
- Prior to the implementation of the NDIS, the national Helping Children with Autism (HCWA) initiative, funded through the Department of Social Services (DSS), provided the Autism Advisor Program and the Early Intervention Indigenous Liaison Officer Program. During the early implementation of the NDIS, these existing services were referred to as precursors to NDIS Partners. The reporting and accountability of these two programs required 6-monthly reporting to DSS, including surveys and case studies. Learnings and gains from these programs could be utilised to develop evidence-based and user-friendly resources for parents and carers.
- Lilley, Sedgwick and Pellicano (2019) in *'We Look After Our Own Mob – Aboriginal and Torres Strait Islander Experiences of Autism'* engaged in consultation with families and found that Federal Government supports are important to assist with the high cost of resources, therapies and other services, but felt that government funds, including the NDIS, do not fully meet children's support needs. Clear recommendations were made that would support families to make choices, such as:
  - Production of a targeted "road map" outlining the post-diagnostic support services available to parents and caregivers of Aboriginal and Torres Strait Islander children on the autism spectrum.
  - Development of targeted support for the mental health needs of Aboriginal and Torres Strait Islander children on the autism spectrum.
  - Improved access to and greater availability of respite for parents and carers, regardless of cultural background, socioeconomic status or geographic location
  - Increased assistance to families of Aboriginal and Torres Strait Islander children on the autism spectrum to access the NDIS and plan supports.
- The approaches outlined above would be helpful for all families requiring clear information to make informed decisions.

## Respecting clinical experience of disability sector workforce

Typical settings and professional staff are not represented:

- There is an existing, robust audit process to which registered providers are accountable. This demanding process, which requires best practice from providers, could be utilised as a guide for families to feel confident in the best practice of providers. Families do not need to become experts in best practice and engage in significant study of what this is at any given moment if they have the knowledge that their provider is obliged to comply with this standard.
- Providers' professional registration standards ensure they remain current in the understanding and use of best practice. Their day-to-day involvement in the delivery of services and interactions with children on the autism spectrum and their families constantly adds to their knowledge and aids their ability to explain all aspects to parents and carers.
- The exclusion of clinicians from the list of sources of information (Question 1) is neglectful and detached from actual conversations about best practice that occur across the nation. These conversations are built from existing relationships between clinicians and families and are based on stringent ethical values and principles.
- Families seeking to make decisions about interventions for their child want to know how it will be adapted to meet their children's needs; this is not information that the NDIS can or should provide.
- Broad principles and standards as laid out in the Paper are different from in-depth analysis of best practice in supporting a child on the autism spectrum and their family. Those working in the disability sector are in the best position to have this information and to be able to convey it successfully to the families they are working with.

### KEY ACTIONS

- **Seek consultation and co-design with key sections of the community who can guide relevant pathways.**

3. Holistic planning is a part of the proposed funding framework for early intervention for children on the autism spectrum... How can we help families to find and connect with other supports outside of NDIS?

### Respecting family's perspectives and experience

- Parents' interpretation of this information was to see that more expectation is placed on them to carry out their children's intervention so that the amount of funding for intervention could be reduced.

*"...they're pushing it on us [parents], but they're not asking us our availability to the participant to be able to deliver the intervention that they're pushing on us."*

- Parents were highly disturbed that the model of funding has a marked diminishment of funding once the child is at school. Many parents reported increased challenges when their child moved into the school environment, partially due to the nature of school itself, partially due to the pressures of different life stages and frequently due to the ill-preparedness of schools to accommodate and include their children on the autism spectrum and their disability-related needs.

"I have a son. He's 10 now, but as of when he was nine, he was flirting with suicide and they're talking about reducing the funding with that age. What are they going to do about flexibility where supports are really needed? Is there an allowance in there for flexibility as far as individual needs, or is this just what they're slamming down in front of us and just going "yeah handle it." That's my main concern - is that flexibility - and what it looks like they're doing is just putting down this and going well that's your guide, you have to work within that, regardless, and it's decreasing as they get older which is obviously not going to suit our situation."

"Mainstream school don't have the experience with ASD to provide the level of support that our kids need."

- A genuinely holistic plan for school-aged children has to acknowledge these challenges. Parents also expressed their concern that what was apparently expected of schools was contradictory, depending on which document you read and/or who you spoke to within the NDIS and/or within the Department of Education.

"I've started [looking at] schools for my son...one of the schools...flat out said they wouldn't take my son because he has low muscle tone and can't climb onto the toilet by himself, although he asks to go to the toilet, he's technically not toilet-trained. Then in my NDIS meeting, I got told no, once he's at school, we don't give you any funding for support."

"My youngest has been diagnosed with intellectual disability. Now I have a lovely special ed teacher but her concern is that she can't give him support because he does not meet the criteria of the Department of Education as a high needs because the cut-off is different from what the NDIS cut-off is. He is on the 75<sup>th</sup> percentile so I can get access for NDIS for it but I can't get access for [special] school because their cut-off is below 70."

## Respecting research findings

- Prior to the section entitled 'Holistic Planning' in section 7.4, on page 21, the only other reference to holistic in the Paper is in *Table 1: Core principles that are important to interventions for children on the autism spectrum*, where the first Core principle is listed as '*Holistic assessment*'. The description for this is "*An initial assessment of an individual's strengths, challenges, goals and preferences is critical to developing intervention targets that are meaningful to the child and family*".
- There is no indication of how the information provided from the Autism CRC report was able to be translated into a specific component of the proposed funding framework entitled 'holistic planning'. No research references are provided and our own searches have not come up with anything that appears to be relevant.
- 'Holistic', 'holistic model of disability', 'holistic approaches' and 'holistic learning' are terms that have some research behind them, although not all are in the area of disability. Relevant information in this area also includes references to the Social Model of Disability. NDIS personnel discussing this Consultation Paper with Autism Queensland have also referenced the intent for a move to the Social Model of Disability. The proposed funding framework presented in the Consultation Paper continues to use a medical model approach, (hours of intervention, reduction

of behaviours of concern) creating a disconnect between the use of the term ‘holistic’ and the funding model.

- Information on the depth, complexity and frequency of challenges at school is readily available and needs to be considered within the context of providing genuinely ‘connected and interrelated’ planning for children on the autism spectrum.

### Respecting clinical experience of disability sector workforce

The proposed model is operationalised in approaches and terminology that focus on impairments and a medical model.

- The enactment of what is referenced in the model as ‘holistic planning’ contradicts the Consultation Paper’s own description and detail on what this is: *All early childhood intervention supports must be connected and interrelated to the child’s life and in the context of the families/care giver role.*
- Everything about holistic planning after this sentence in the Paper is about what each sector (but primarily the NDIS) includes and excludes (primarily excludes) as its responsibility. There is:
  - **no** discussion on how connections between service systems and sectors will be created and maintained,
  - **no** information on effective governing of the NDIS, Education, Justice, Health, Mental Health, Early Childhood and other relevant sectors to address how to overcome siloes and ensure that every child and family is appropriately supported,
  - **no** recognition that such divisive responsibilities make it likely that children and families will fall between the gaps,
  - **no** acknowledgement that it is exhausting, distressing, overwhelming and incredibly unsupportive for families to constantly deal with the message of ‘You’ll need to talk to [insert relevant government department] about that, that’s not our responsibility’.
- Holistic planning should mean the child and family move seamlessly between the supports offered by each sector without having to be concerned about whose responsibility it is and how to navigate this.
- As stated in the Consultation Paper’s definition, *“Holistic planning considers the full environment of the child and family which includes all of the supports that are available to the child and family.”* The only ‘consideration’ of the family in the subsequent representation of holistic planning in the Paper is a regular message of ‘it is reasonable to expect families and carers to provide this support’. There is:
  - **no** reference to family-centred practice,
  - **no** recognition of the toll on parents and carers who are constantly being seen as a de facto therapist, teacher and support worker,
  - **no** context that while it may be appropriate to expect such support from a parent in one area, the expectation that this will occur in all other areas of the child’s life (regardless of other children in the family with or without disability, other family responsibilities, parental employment) is unmanageable and distinctly different from the experience of parents of children without disability,
  - **no** mention of how parents’ perspectives will be gathered and included in the holistic plan.
- Autism Queensland spends considerable time supporting the families of children who are, or should be, attending childcare and school. We have in-depth knowledge of the difficulties and gaps that exist in the mainstream Early Childhood and Education systems. We acknowledge the NDIS cannot address all that is lacking within these systems. However, refusing to respect the fact these difficulties and gaps exist and can lead to horrendous outcomes for children is actively unethical, particularly when there is no evidence the NDIS has sought detailed information from practitioners and advocates, nor is it pursuing any proactive strategies – as a fellow government department – to address these issues.

- The apparent lack of communication between NDIS representatives and Department of Education (DoE) personnel is extremely concerning. If nothing else, there should be constant discussion and updating on where the jurisdiction and responsibilities of each ends, with examples and consideration of potential impact for children where these divisions are problematic.

### KEY ACTIONS

- **Focus on working together with established services and prioritising collaboration.**
- **Consider ‘team around the child’ instead of ‘holistic planning’.**

## Section 2: Reasonable and Necessary

4. The consultation paper outlines specific principles that the NDIS considers for young children with autism as early intervention best practice for young children on the autism spectrum... Is there anything you would like to add?
5. The consultation paper outlines specific standards that the NDIS considers for young children with autism considers as early intervention best practice for children on the autism spectrum.... Is there anything you would like to add?
6. “Reasonable and necessary” is a term from our legislation. Appendix one of the consultation paper includes case studies which might be used to explain reasonable and necessary.....
7. Do you have any other feedback about how we explain “reasonable and necessary?”

### Respecting family’s perspectives and experience

The case studies are not helpful and cause more confusion for families.

*“What if they haven’t developed the skills, what flexibility is there?”*

### Respecting research findings

#### **There is no reference to Family-Centred Practice as a guiding principle.**

- The Reimagine Early Childhood National Action Plan to 2030 (ECIA, 2020) presents well-researched information, which includes co-design with families, to cite sound principles of early intervention best practice, including: ‘Supported families lead to healthy communities, which in turn provides a social and economic dividend for the Australian community... enable the building of family capacity and the achievement of the very best outcomes for families and their children’ (p 3).

#### **The principles do not promote early access to specialised intervention as soon as possible to limit the trajectory of disability.**

- The importance of specialised timely early intervention for young children on the autism spectrum is well documented (Clark, Vinen, Barbaro, & Dissanayake, 2018; Dawson et al., 2012; Estes et al., 2015; Green et al., 2017; Hurth, Shaw, Izeman, Whaley, & Rogers, 1999; National Research Council, 2001; Woods & Wetherby, 2003),
- Many studies have also found that children on the autism spectrum who receive intervention prior to the age of 48 months make greater improvements than older children who enter these programs in later years (Harris & Weiss, 1998; Sheinkopf & Siegel, 1998),

- Further research (Clark et al., 2018) also shows that children receiving appropriate early intervention demonstrated better verbal and overall cognition and were more likely to attend mainstream school and required less ongoing support, than children who accessed support later.

**The “indicative levels of funding” approach outlined in the paper does not correspond with best practice principles.**

- Proposed funding for supports according to therapeutic line items, focuses on clinical intervention provided in a setting that does not include naturalistic environments,
- Indicative levels of funding are a direct contradiction to the Autism CRC recommendations.

**There is contradictory information in the paper relating to the amount of recommended intervention and the delivery characteristics of intervention.**

- Neither amounts nor delivery models of intervention should be included in the Paper recommendations. These decisions are for families and clinical teams to decide, based on therapeutic models and functional needs.
- The Autism CRC report did not consider matters of funding and should not be used to assert a levels-based model.

**Respecting clinical experience of disability sector workforce**

**Generalist intervention through Early Childhood Early Intervention (ECEI) partners Short Term Early Intervention (STEI) is not appropriate: early intervention standards outlined must also apply to NDIS and partners as part of an intervention pathway.**

- The Consultation Paper states, “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” (Informing Reasonable and Necessary Supports: Our legislative decision, p. 17)
- Autism Queensland would like to see the research and data to substantiate this statement.
- None of the information about STEI by ECEI Partners gives any indication that the same principles and standards that apply to autism interventions delivered by providers will be used to measure and evaluate the effectiveness of those Partners in their delivery of STEI.
- The specification that this STEI is generally up to 12 months and “If the child develops more severe and persistent functional impacts, they may access another period of short term intervention...” 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.

**KEY ACTIONS**

- **Consider lived-experience of families – refer to Appendix 1: Case Studies.**
- **Engage in co-design for developing policy changes.**
- **Individual planning and funding are essential.**

8. Below is an example of a table we might use to explain Indicative level of funded support for children on the autism spectrum under 7. Does this table clearly explain the indicative levels of funded supports?

**Respecting family’s perspectives and experience**

Families are experiencing distress both mentally and financially.

*"Looking at the table and the funding, families are going to be under more financial pressure to be able to access therapy."*

*"It (reduced levels of funding) is determinantal to the parents and the child. They should give sufficient funding .... and let the current enrolment continue for at least a couple of months so parents can plan support for the child, so they are not left without support."*

*"From the day we received (our child's) diagnosis to now, there have been many many hurdles. We have had a lot of doors shut for us and have tried to stay positive and have been trying our best to get... the support he needs...an unpleasant experience and ... (I) do not look forward to confrontations"*

- Mothers of children on the autism spectrum have been found to have lower levels of psychological well-being than parents of children with Down Syndrome and Fragile X Syndrome (Abbeduto et al. 2004). These high levels of parental stress have been found to be associated with the behaviours of concern of children on the spectrum (Osborne, McHugh, Saunders, & Reed, 2008) and the severity of the child's autism symptoms (Duarte, Bordin, Yazigi, & Mooney, 2005).
- Additionally, some cohorts may also face unique challenges in supporting their child on the spectrum (e.g., families living in rural locations, and those from low socio-economic, CaLD, or Indigenous backgrounds).

*"I just think this is all so generalized, for a disorder that is supposed to be so individualized, it just doesn't make sense."*

*"I think every child is different and you can't go by a table".*

*"Every child should be assessed on their individual need.... each child is different".*

- In terms of whether the information presented in the tables was clear, many parents expressed confusion when examining these:

*"What is my child is between 2 or 3 areas at the same time? Are they going to add up the funding? I mean if she qualifies for more than one area?"*

*"They haven't shed any light on what core funding would look like."*

*"Is there any correlation of funding levels to the ASD 1-3 DSM levels given from a diagnosis?"*

*"I have a question regarding what constitutes an area of need. How specific is this?"*

*"Would be good to have high, medium and low defined as it means different things to different people."*

- No information about the indicative levels of funding is provided in the easy-read version of the Consultation Paper which makes Question 8 discriminatory.

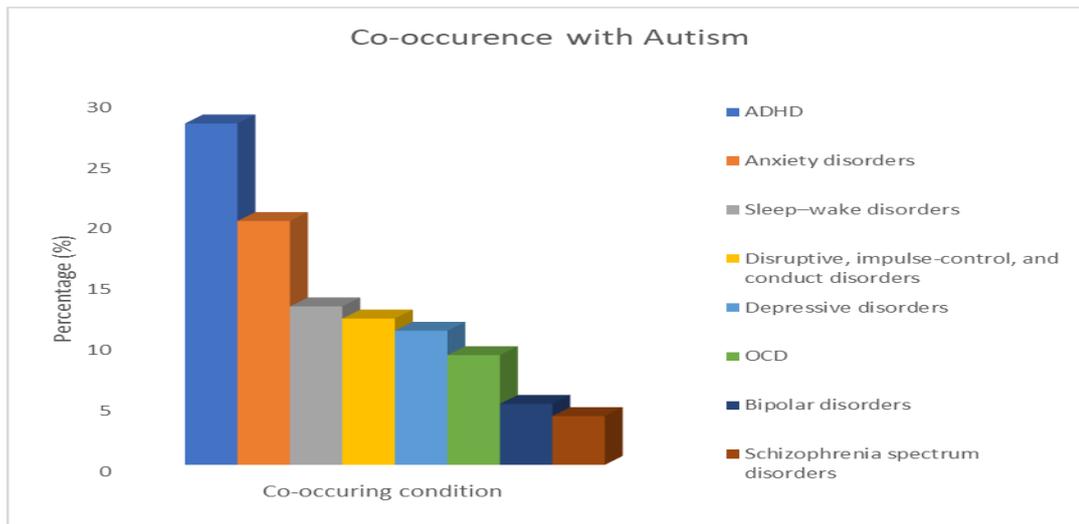
## Respecting research findings

### **Indicative levels of funded support are not appropriate.**

- While the indicative levels of funded supports are explained, any form of rationale to underpin these funding levels in Table 2 (page 27) and Table 3 (page 29) is not provided.
- The Autism CRC report found that 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 required to achieve effectiveness, nor the ideal frequency or duration of the intervention program. Consequently, this finding did 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.
- The Autism CRC report provided information on the intervention types that are most likely to be effective. For example, Table 6 on page 73 of the Autism CRC report shows that studies (mostly of moderate quality) on *Early Intensive Behavioural Interventions* (EIBI) demonstrated effectiveness in improving the social-communication skills, expressive and receptive language skills, cognitive skills, motor skills, adaptive behaviours skills, school/learning readiness and academics skills of children on the autism spectrum. Thus, EIBI was found to be one of the most promising of the reviewed interventions. However, these conclusions were based on a review of studies (Peters-Scheffer, Didden, Korzilius, & Sturmey, 2011; Reichow, Hume, Barton, & Boyd, 2018) that involved implementation of this intervention at intensities ranging from 12.5 hours to 40 hours per week for periods ranging from 3 months to 3 years (see pages 486-487 of the report). This type of intervention would not be available at the proposed funding levels.

### **The complexity of needs for children on the autism spectrum is not considered, including many with co-occurring conditions requiring supports.**

- The descriptions of children in these tables do not reflect **the complexity nor the intensity of needs of the young children on the spectrum** typically seen by service providers. This complexity relates to factors including, but not limited to, co-occurring conditions and behaviours of concern, which are highly prevalent in this population, in addition to the many and varied demands on families that can impact their capacity to support their child on the spectrum (e.g., rural locations, low socioeconomic, CaLD and Indigenous backgrounds and the support needs of other children, other family members on the spectrum, elderly or unwell family members).
- Australian Bureau of Statistics (ABS) data (2017) indicates that two out of three people on the spectrum have profound or severe disability.
- Lai et al (2019) reported that co-occurring mental health conditions are more prevalent in the autism population than in the general population.



- Norrelgen et al (2015) found the proportion of children on the autism spectrum diagnosed at an early age who had not developed phrase speech during the preschool years was about 25%.
- Soke et al (2018) found that over 95% of young children (aged 4- 8 years) had at least one co-occurring medical and/or behavioural condition.

### Respecting clinical experience of disability sector workforce

- It is inappropriate and irresponsible to consider that indicative levels of funding are an appropriate way to “operationalise” the finding from the Autism CRC report.
- There are many variables that go into how much support a child/family may need to help them thrive. ‘Functional need’ is one of these variables, but it is only one of many. It is highly likely a child with a high area of need in one ‘area’ only will not thrive unless intensive support is provided. Conversely, it is highly likely a child with ‘three high areas of need’ may require less intensive support.
- Addressing this complexity was the great promise of the NDIS – with ‘reasonable and necessary’ supports provided to a child based on their individual circumstance, and not on how they fit to an arbitrary slicing up of human complexity. The existence of ‘levels’ is a return to an old and discarded model and will simply not facilitate the right level of support to the right child/family based on the right information.

### KEY ACTIONS

- **Include options for intervention that focus on:**
  - **Targeted and specialised early intervention**
  - **Parent capacity building**
  - **Community access**
  - **Responsiveness to individual needs.**

**It is rejected that initial plans will require “extra” supports and then reduce over time - support needs are required across the life span.**

### Respecting family’s perspectives and experience

"I don't think it [support I would like to access] is [represented by the NDIS paper]. Mine [my child] is only very little, but it's starting to look like that. I've only just had his review meeting again, we're talking about things, some of the supports that I would like.... So I want to like to put things in place now, so that when he gets to the teenager years, you've got the tools, and the know-how to do that. But I think the message is, as they get older, they should need less intervention, but they [NDIS] don't understand that as their life changes and the different stages arrive, they might need more support based on, you know, teenage years are quite a big group of years, and you know, you've seen teenage suicide, all that sort of stuff. They don't seem to be putting some emphasis that, especially anxiety, all that sort of stuff. It seems to be we're just going to look at, you know to 12 years, and then that's it. It seems to be they just want to reduce the funding, but don't necessarily look at -well, what is happening in the life cycle or I would say actually at that stage they might need more funding."

"I haven't worked for 2 years due to my child and school avoidance/ running away. We can't access her therapies without NDIS support. It's a spinning cycle."

"My husband and I feel the economic pressure as we don't know what our son's independence will be like in the future so it feels like more pressure on us to set aside a good nest egg for his future (and our other child of course).. But also we want to present and provide the best support for him now. Therapy support helps to spread the load."

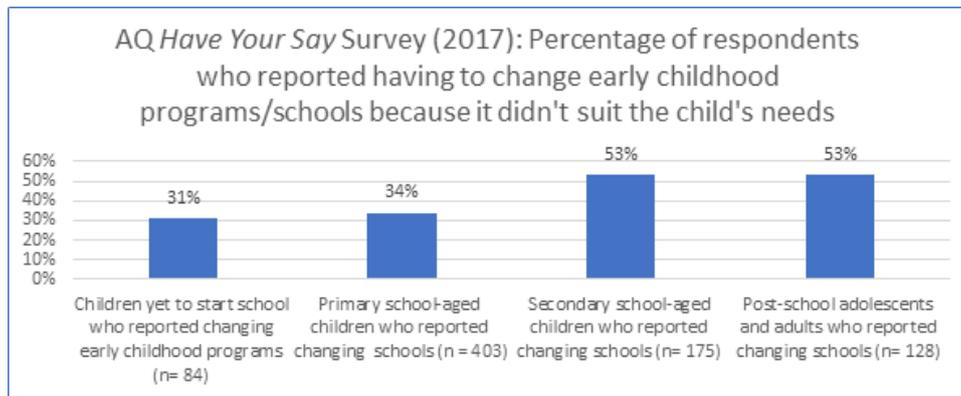
"I'm finding mine (child) needs MORE support the older she gets as life gets more complex."

"I fear (for) when my eldest hits puberty and high school."

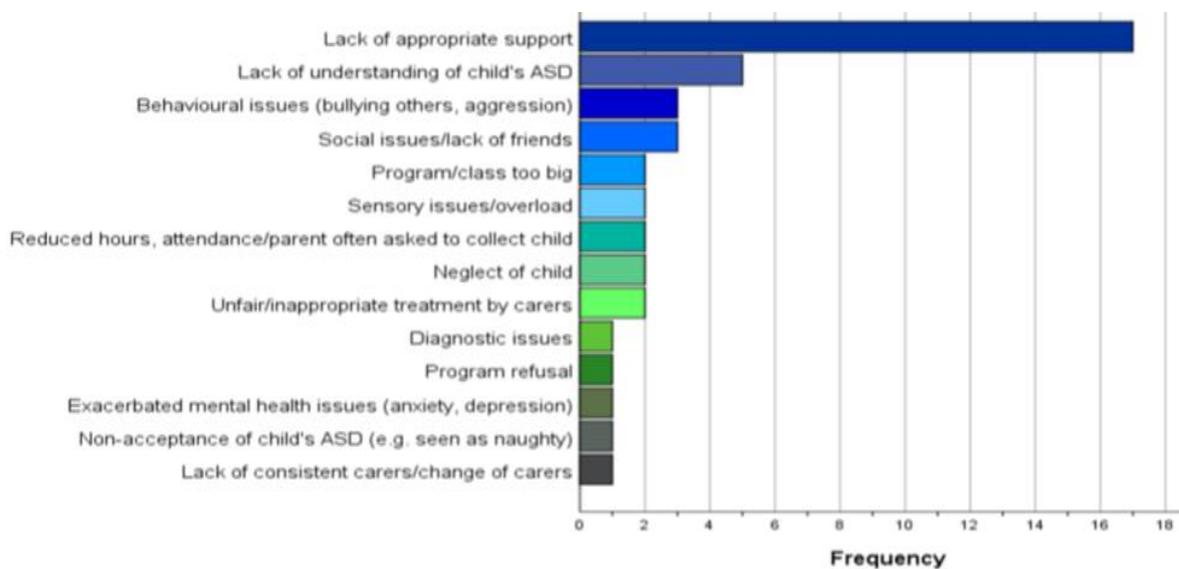
"My son needs more support as his needs change and become more complex due to the gap in his skill set widening as he gets older."

## **Respecting research findings**

Evidence suggests **early childhood programs and schools are currently struggling to successfully include students on the spectrum**. Many families change schools frequently in search of an early childhood program or school that could meet their child's needs, while other families elect to home school. In response to a Queensland-wide survey (Autism Queensland, 2017) 731 parents of children on the spectrum and 59 adults on the spectrum answered this question: **"Has your child/have you ever had to change early education programs/ schools because the early childhood program/school wasn't the right fit for him/her?"** As can be seen in this graph, many parents had changed early childhood programs and schools because they did not suit their child's needs. Furthermore around 30% who had changed schools, had done so more than once, with some changing schools up to 7 times.



- Some parents answered an optional open-ended question about their reasons for changing early childhood program, which were coded as follows:



Examples of parents' comments regarding changing early childhood programs:

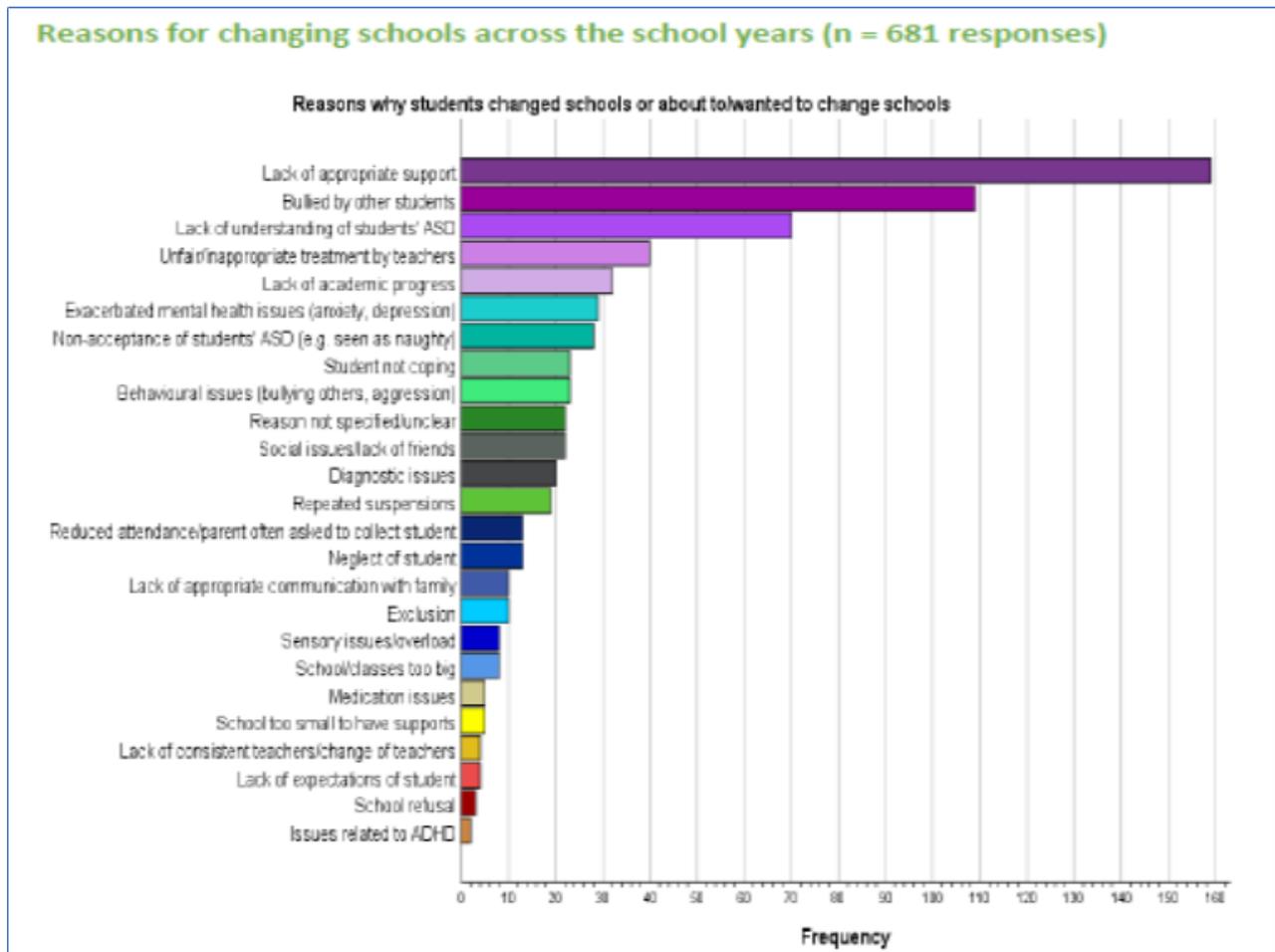
*"[We] Changed childcare centre due to lack of concern for my son's mental wellbeing. My child was being excluded from activities as it is difficult for him to understand or communicate with others. No support offered to him in the centre."*

*"My child's behaviour was too difficult for centre to manage"*

*"early childhood staff did not understand child's needs and don't go through with what they say they will implement."*

- The reasons for changing schools, as indicated by coding parents' responses to open ended questions, are shown in the graph below:

## Reasons for changing schools across the school years (n = 681 responses)

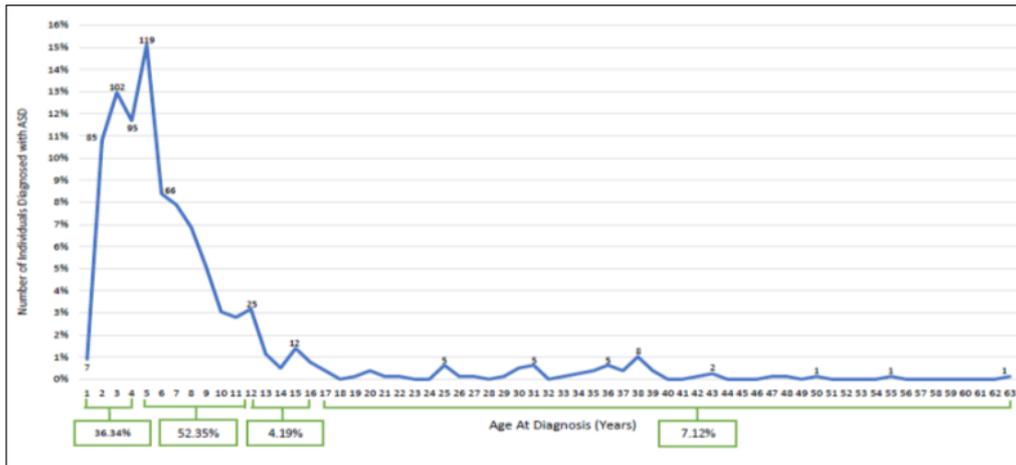


As indicated, schools were not a good fit for many reasons, the most being the lack of appropriate support for students on the spectrum in schools, bullying by other students, and a lack of understanding of the student's autism. This comment from one of the parents typified the experiences of students on the spectrum:

*"We have tried several schools that said they could support my son, but they could do very little for him and he could not continue attending. He could not cope with the social environment of school and was not able to perform his calming rituals and behaviours. We left 4 schools in 3 years, not staying longer than 1 term in each. He was bullied more than enough at each school. The social pressures caused severe depression. Home education worked for a short time, but his symptoms were debilitating, and we had to find a school that could take him on. We moved the family to the city to find a school fit."*

- **With regard to the assumed reduction in the value of plans due to the impact of mainstream services such as schools,** it should not be assumed the support needs of children on the spectrum will decrease when they begin school for the following reasons:
- Autism Spectrum Disorder is by defined by the Diagnostic and Statistical Manual of Mental Disorders. 5th ed. as a **lifelong condition** (American Psychiatric Association. 2013).
- **When children on the spectrum transition into school, they are challenged by increasingly complex social environments, the need for independence academic demands.** For this reason, many children receive their autism spectrum disorder diagnosis when they start school as it becomes more obvious they lack the behavioural flexibility and social communication skills to adapt to this more complex environment.

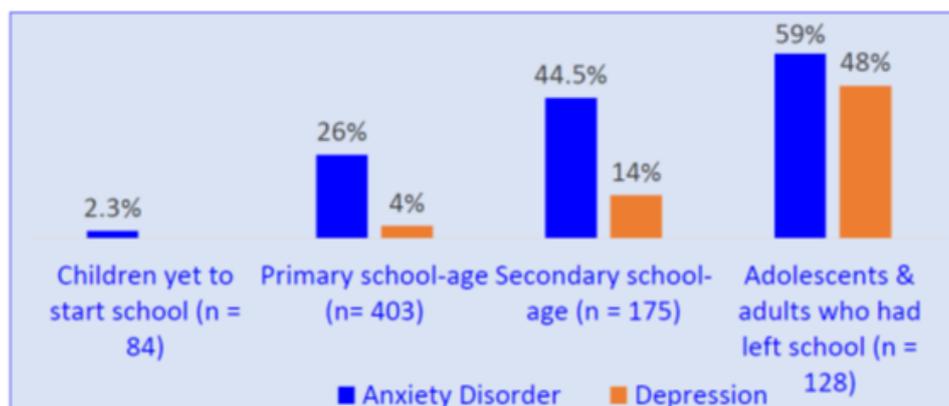
The graph below from Autism Queensland's 2017 *Have Your Say* survey of 790 children and adults on the spectrum, the age of diagnosis peaked at 5 years.



It therefore should not be assumed their support needs will decrease when they reach school.

- ABS (2017) indicates that of the young people (aged 5-2020 years) with autism who were attending school or another educational institution, 83.7% reported experiencing difficulty at their place of learning. Of those experiencing difficulties, the main problems encountered were fitting in socially (63.0%), learning difficulties (60.2%) and communication difficulties (51.1%). While it is the responsibility of schools to support the learning of these children, they often require interventions from other services to further develop their social and communication skills.
- Better management of the mental health of children on the autism spectrum during the school years is especially important to reduce progression into more serious mental health conditions in adulthood. The prevalence of mental health conditions in adults on the spectrum can lead to outcomes which are devastating for the individuals themselves, and expensive for society as a whole. For example, Paquette-Smith, Weiss, and Lunsby (2014) reported a 36% suicide attempt rate in 50 autistic adults, greatly exceeding the 4.6% general population lifetime prevalence rate. Autistic adults have been found to be over 10 times more likely to be admitted to a psychiatric hospital than neurotypical people (Weiss et al., 2018).

The graph below (Autism Queensland, 2017), shows mental health issues of children on the spectrum increase substantially as they grow into adulthood.



While early intervention is crucial for young children on the spectrum, older children and adolescents on the spectrum will continue to need support. This is particularly the case at times of transition into more complex environments.

## Respecting clinical experience of disability sector workforce

- Autism Queensland’s experience reflects the above research. Considerable time is spent supporting families around issues at school – children who are being bullied, children who are refusing to go to school, children who are on ‘managed attendance’ so only allowed to attend for shortened hours (often as minimal as an hour per day), parents who are being called nearly every day to come and collect their child, children being continuously suspended, and children whose behaviour presents challenges to the school that cannot be managed safely.
- These needs cannot be adequately addressed by schools whose primary focus is, understandably, educational outcomes.
- Mainstream services require additional supports to achieve successful supports for children on the autism spectrum. This is due to factors directly related to the impacts of a child’s disability. This can be achieved through appropriate, individualised funding for provision of services.
- Substantial input is required to provide education for these mainstream services providers on autism and ways to include these children. Additionally, substantial input is required on ways to support the needs of individual children on the spectrum from service providers who specialise in autism.

### KEY ACTIONS

- Offer individualised planning and support, based on actual needs of participants.
- Change focus of policy to recognise life-long nature of autism and build in flexibility to increase funding promptly when it can be foreseen this would be of benefit.
- Support providers to support mainstream agencies.

## Section 4: Supporting Parents and Carers to Exercise Choice and Control

11. We want to support children and parents in implementing plans using the Autism CRC research and best practice. In [Section 8.2](#) there is a suggested list of questions for parents and carers. These can be used to understand different interventions and whether and how a provider is applying best practice. ... Are these questions helpful for parents and carers when selecting providers?
12. What other guidance or tools do families need to feel confident to implement plans in line with the Autism CRC research and best practice?

## Choice and control are limited by the NDIS’ misinterpretation of the Autism CRC report

### Respecting family’s perspectives and experience

*“I feel like they want us to think we have control and choice but really they want to control and choose the interventions etc we access.”*

*“I just see so many new ideas and different ways of therapies coming up. And I'm constantly thinking, is this actually going to be covered by our NDIS is funding, how is the NDIS going to be adaptive and quickly be able to move on the*

*best way to support our kids, if the therapies have to have all of this research behind it, I just, I'm more concerned just about people having new fabulous ideas all the time that are working, and how is the NDIA going to move quickly enough to adopt those?"*

*"You can't have choice and control if your budget does not allow for appropriate interventions/ activities."*

## **Respecting research findings**

The Autism CRC report has limitations and subsequent restrictions to application across all early childhood interventions:

- No consideration of interventions that are primarily delivered to support the mental health outcomes of children on the autism spectrum,
- No consideration of interventions that primarily focus on supporting the needs of the family rather than those of the child on the autism spectrum,
- No consideration of interventions primarily designed for use with children with comorbid visual, hearing, or physical disabilities,
- A 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.
- 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.
- 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.

## **Respecting clinical experience of disability sector workforce**

- Supporting parents and carers to exercise choice and control requires their access to relevant information.
- For many years, early intervention service providers have worked collaboratively with parents on strategies they can implement at home, with the aim of generalising newly acquired skills to the home environment. However, an over-reliance on parents to provide the bulk of interventions for their child on the autism spectrum has the potential to increase the stress levels of these families which are already known to be high.
- The case study on pages 43-44, suggests that interventions delivered by parents will form a substantial component of the child's early interventions supports. The example suggests that 14 hours per week of intervention will be provided by parents (2 hours per day). This increased burden will prevent workforce participation and contribute to poverty.
- There is a risk of harm as the model proposed disproportionately disadvantages children whose parents lack the capacity to provide these interventions at home and is therefore fundamentally inequitable.
- A family's capacity to exercise choice and control, and therefore to adequately support their child on the spectrum may be reduced for many reasons (including financial constraints, and the

support needs of other family members such as other children, other family members on the spectrum, elderly or unwell family members).

- There is a distinct lack of choice and control, due to the consultation paper statement that *“Once a plan is finalised and budget allocated, children, families and carers are able to negotiate with their provider on the frequency and pattern of supports within their available funding.”* Access to information about best practice and available interventions is required before funding decisions are made to allow families to exercise choice and control over the supports that they wish to access.
- These questions must also apply not just to the EC Partners providing STEI, but also all NDIS personnel providing advice, information and making planning decisions.

## KEY ACTIONS

- **Utilise early childhood pathways that promote access to unbiased information.**
- **Require all providers of early intervention services to be registered with the NDIS.**
- **Parents require:**
  - **Access to information**
  - **Access to support**
  - **An early intervention pathway that can be easily navigated**
  - **An absence of expectation to interpret research papers.**

## Section 5: Conflicts of interest

13. This question relates to [Section 8.3](#) of this paper: “Addressing conflicts of interest.” How can we support families and carers to feel confident to make decisions about what is in the best interest of the child and family?

### **Conflicts of interest occur in all arenas of public and private life and there are systems in place to manage these.**

There are potential conflicts of interest across the entire arena of children with disability seeking supports. The NDIS consultation paper has exclusively focussed on the conflict of interest that could occur for service providers.

Parents of children with disability seeking to assist their child rely on information and support provided to them by external sources, including medical professionals, the NDIS and other government departments and service providers. All these parties, if they choose to act in an unethical manner, can have conflicts of interest. Any coverage of this issue in any form needs to acknowledge this. It is not acceptable for only service providers to be highlighted in this way.

### **Respecting family’s perspectives and experience**

During Autism Queensland’s consultation with parents in preparation for its submission to the NDIS about Independent Assessments, it was frequently expressed by parents they valued the insight and advice of appropriately trained professionals who had worked with their child and/or had specialist expertise in autism. Parents were not supportive of the idea of starting to work with somebody who did not know their child. Not only did they emphasize their wish to not have to again provide all the background information and explanation regarding their child, they noted they found an ongoing

relationship with people who had in-depth understanding of autism to be extremely helpful and reassuring.

NDIS support to families in this area should reflect that professional staff working as providers have professional standards that include appropriate management of conflicts of interest. The NDIS should pass on the confidence that providers are focused on best outcomes for children and families and let parents know if they have concerns they can communicate these to the provider and to the Commission. Creating further insecurity in parents that the very people they are going to for support are potentially doing them a disservice adds to the stress and confusion the parents are feeling and actively works against a positive therapeutic relationship.

Autism Queensland has had concerns over a number of years about the outcomes for families from culturally and linguistically diverse backgrounds or who are disadvantaged (e.g., impact of parental disability, low literacy levels). Information from those parents after their NDIS plan has been received indicates that no attempt was made by the Partner/Planner to probe the parents' responses or suggest appropriate supports. Typically, those families have less funding in their plans, and it could be seen that the NDIS representatives have a conflict of interest in this situation as accepting the parents' information on face value enables a lower cost plan.

*"How much input from children's therapists (who knows them best) will be used to determine these areas of high/low need for funding? Or will all areas of need be determined from independent assessment which can be problematic depending on skill of assessors and limitations of the assessment process?"*

### **Respecting research findings**

**The NDIS should not have the combined responsibility of determining what supports are in the best interests of a participant along with determining the funding that the participant should receive as these are potentially in conflict.**

There is also no information or data available about NDIS Partners' or NDIA staff members' potential conflict of interest. Investigation into the forces at play outside those of the child's needs and situation when NDIS funding decisions are being made is necessary – e.g., requirement to keep overall plan funding for a particular cohort of participants below certain amounts.

### **Respecting clinical experience of disability sector workforce**

**Being a provider does not mean that a professional is unable to recognise and ameliorate any conflicts of interest.**

Those working in the disability sector are guided by a significant number of standards and policies that must be adhered to or run the risk of being individually or organisationally de-registered and subject to many other consequences.

More relevantly, individuals and organisations working in the sector, especially those who are NDIS-registered, intrinsically value the importance of supporting children and families appropriately. This includes ensuring the needs of the child and family always come first and that families are supported to make the best decisions for themselves.

The sector has a long history of managing conflicts of interest, most recently through the delivery of the Autism Advisor and Better Start programs where organisations took on the role of providing comprehensive and unbiased information about all the services and approaches available. Throughout the 12-years of the Autism Advisor Program, which was overseen by the Department of

Social Services (DSS), no concerns about breaches of conflict of interest were ever raised. The decision by DSS to give the contract for the delivery of this Program to each state and territory's autism organisation was due to the value placed by DSS on ensuring families had access to professionals with a strong knowledge of autism. The complexity of this field meant families needed the certainty of getting accurate and unbiased information from an appropriate source.

Continuous mention of the potential conflict of interest for service providers is not assisting the development of a strong and positive working relationship between the NDIA and providers. The NDIS has articulated concern about service providers' potential conflict of interest since its inception. There does not appear to be any research or data on how many such incidents have been reported and the outcome of investigations of these.

### **KEY ACTIONS**

- **Update references to conflicts of interest to reflect that these occur across the board, not just for service providers.**
- **Provide data on:**
  - **Number of investigations that show providers breaching conflict of interest standards.**
  - **How NDIS manages its own conflict of interest in relation to funding decisions.**
- **Improve NDIS communication with families so that they feel confident, empowered and supported.**

## Appendix 1: Case studies

### *Case study 1 (4-year-old child)*

- ASD level 2
- Indian cultural background
- First language is Hindi
- Child is non-verbal
- Sensory aversions cause him to bite and hit others in all settings – family do not go out due to this.
- Child is not yet toilet-trained
- Delayed fine motor skills
- Relies on prompting around self-care and self-help skills

Significant complexities and problems relating to NDIS funding for specialist early intervention services:

- NDIS plan end date 25/3/21
- Funding in plan ran out end of January 2021
- Family expected funding in new plan to be able to cover gap between January and March
- Multiple and frequent communications from NDIS Partner to family continued to use NDIS jargon and no checking of understanding was carried out
- Family highly confused, in financial distress, also extremely upset that they would have to cease accessing a service that they were finding very helpful for their child
- Family interpreted standard information on page 1 of their plan as stating that the NDIS did not approve of the early intervention provider. The statement in question is:

*All of [child's name]'s requests for support and the information provided to us were considered against the requirements of the NDIS Act and NDIS Rules.*

- Service provider in position of deciphering NDIS messages to family – many hours spent on this
- Family reluctant to make any complaint or express dissatisfaction with NDIS due to fear of recrimination against their child.

### ***Case study 2 (6-year-old child)***

- ASD Level 3
- Speech and language delay with echolalic and learnt scripts as expressive language.
- Phobia of using any toilet other than at home
- Difficulties with communication, emotional regulation, and social skills.
- Extremely limited diet, consisting mostly of bread and crackers with a multivitamin supplement given by his parents. Child does not currently have any protein, dairy, fruits or vegetables in his diet.

Prep State School 2021

NDIS funded specialist early childhood intervention provider delivered support at school Term 1 & Term 2 2021

- Child has achieved goals (able to use toilet at school by Week 8 of term 1).
- Classroom teacher and aide have demonstrated skills gained through delivery of specialist service.
- The Head of Special Education Services has:
  - removed visual supports from the classroom that the child requires.
  - dictated when the service should cease.
  - commented that the specialist provider was only carrying out services to “tick off boxes to get NDIS money”.
  - delayed the commencement of services in Term 2 by requiring an additional internal school approval.
- The school’s stance has caused the family emotional distress.
- The specialist provider has been required to justify this service to the school Head of Special Education Services in depth and at length multiple times.
- No consideration given by school staff to the parent’s choice and desire for these services to take place.

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