28 April 2023

Department of Social Services
Australian Government
Canberra ACT 2601

Early Years Strategy - Public Submission

General comments

In developing a Commonwealth Early Years Strategy to create a new, integrated approach to the early years and prioritise the wellbeing, education and development of Australia's children, Autism Queensland (AQ) contribute the following:

- All areas have equal weight in determining positive outcomes for children and families; physical health, emotional and mental health, learning and development, love and nurture, positive sense of identity and culture, opportunities for play, rest and leisure, material basics (water, housing, clothing, and food), strong and supportive families, safety, children's perspectives are sought and respected, participation in social and community activities.
- Families must be central to decision making.
- Much work has already been done to inform a national approach to the early years – a national strategy should build on existing information.
- Workforce must be supported in being able to deliver high quality services, including a focus on qualifications, training, pay and recruitment to build workforce capacity and resilience.
- Disadvantaged and vulnerable children and families must be prioritised.
- Collaboration between service providers at grassroots levels is essential for implementation.

SUNNYBANK HILLS
437 Hellawell Road
Sunnybank Hills QLD 4109
P: 07 3273 0000

BRIGHTON
136 North Road
Brighton QLD 4017
P: 07 3631 6300

GLADSTONE
5/281 J Hickey Avenue
Gladstone QLD 4680
P: 07 4904 9600

ROCKHAMPTON
373 Lakes Creek Road
Koongal QLD 4700
P: 07 4923 4800

MACKAY
10 Macrossan Street
East Mackay QLD 4740
P: 07 4841 8300

CAIRNS
15-17 Marr Street
Edmonton QLD 4869
P: 07 4034 6600

Patron: Her Excellency the Honourable Dr Jeannette Young AC PSM, Governor of Queensland

Autism Queensland ABN 79 253 351 418 autismqld.com.au

QUESTION 1. Do you have any comments on the proposed structure of the Strategy?

AQ observes that the proposed structure of the Early Years Strategy is robust and is modelled from existing structures that allow interrogation of practice and measurement of set outcomes. Reflective learning in early childhood spaces could be captured in a cyclical model that allows for key policy priorities and indicators to be reviewed and improved over time and in response to community feedback.

The longevity and application of the proposed structure could be boosted by:

- Swift progress to reform based on existing outcomes identified by the Australian Research Alliance for Children and Youth's *'Building on the Early Years Summit 2020.'*
- Urgent community consultation on policy priorities and indicators as a priority
- Scheduled community consultation on policy priorities and indicators as a feature.

QUESTION 2. What vision should our nation have for Australia's youngest children?

No child left behind or left out.

No family left behind or left out.

QUESTION 3. What mix of outcomes are the most important to include in the Strategy?

- Inclusion for all:
    - Identification of barriers and enablers to inclusion, with particular attention to specific vulnerable cohorts and intersectionality, such as children with disabilities, carers with disabilities, First Nations peoples, culturally and linguistically diverse families, regional and remote families, socioeconomic disadvantage, families experiencing trauma, neurodiverse perspectives, and combinations thereof
    - Consideration of design of early childhood environments to be modified/ built for inclusion (not just access)
    - Ready access to multimodal information – overcoming multiple communication and information-access barriers.
- Outcome measures to reflect the variable intended outcomes of the identified vulnerable cohorts.
- Improved quality of life for all
- Equality over equity (considering disadvantaged children and families)
- All children's voices are clearly represented and listened to
- All families are valued.

- Safety and wellbeing for all:
  - Refer to the National Principles for Child-Safe Organisations

  https://childsafe.humanrights.gov.au/national-principles/download-national-principles

  1. Child safety and wellbeing is embedded in organisational leadership, governance, and culture.
  2. Children and young people are informed about their rights, participate in decisions affecting them and are taken seriously.
  3. Families and communities are informed and involved in promoting child safety and wellbeing.
  4. Equity is upheld, and diverse needs respected in policy and practice.
  5. People working with children and young people are suitable and supported to reflect child safety and wellbeing values in practice.
  6. Processes to respond to complaints and concerns are child focused.
  7. Staff and volunteers are equipped with the knowledge, skills, and awareness to keep children and young people safe through ongoing education and training.
  8. Physical and online environments promote safety and wellbeing while minimising the opportunity for children and young people to be harmed.
  9. Implementation of the national child safe principles is regularly reviewed and improved.
  10. Policies and procedures document how the organisation is safe for children and young people.

QUESTION 4. What specific areas/policy priorities should be included in the Strategy and why?

- Policies contained in the National Housing and Homelessness Agreement, in addition to the state and territory governments policies, as they relate to improving outcomes for children and families.
- National Mental Health Policy
- The National Plan to End Violence against Women and Children 2022-2032
- Australia’s Anti-Discrimination Law, especially policies relating to disability, race, and sex.
- #All families, children, and communities can access the support they need when they need it.
- #All children have access to early childhood education and care that is free, high quality, accessible and culturally safe.
- #Children, families, and communities are partners in decision making.
- #All the children residing in Australia have the same opportunities regardless of where they are born.

- #Support and promote First Nations self-determination, Closing the Gap for young children and beyond.
- #Australian society values and invests in young children, their families and those that support them.
- #Children's outcomes are measurably improved because of a sustainably funded service system.
- #Families are experts in their own lives with increased agency & choice. More diverse families access more services to get their needs met.

#From ARACY: Blueprint 1.0 for improving wellbeing in the Early Years in Australia. Created by Early Years Summit 2020 Participants

QUESTION 5. What could the Commonwealth do to improve outcomes for children—particularly those who are born or raised in more vulnerable and/or disadvantaged circumstances?

- Prioritise reform in the identified key areas affecting ***families***:
- Homelessness
- Mental health
- Domestic violence
- Racism and discrimination
- Environmental degradation

- Practical indicators of success in achieving reform in these areas would be:
- Families are listened to – include family supports as a standard, rather than solely focusing on children.
- Families are accessing affordable or free assessments for children who are suspected of having disability/ support needs.
- Barriers to accessing early supports/ services are removed.
- Government departments universally use best practice approaches for effective communication. Information is presented in accessible formats with visual representation, translation, concise information and free of jargon.
- Family centred practice is implemented: Parent perspective and needs are prioritised in navigating service/s, rather than using a service/ government perspective.
- Roles are identified and funded to make links between systems and actively work across departments – reform to areas that are supposed to perform this function but get caught in silos e.g., National Disability Insurance Scheme (NDIS) Partners.

- Administration roles within early childhood spaces are recognised and expanded – allowing practitioners to focus on children and families rather than paperwork.
- Early years system mapping
- Public awareness campaign regarding reform, including increasing community knowledge of existing services.

QUESTION 6. What areas do you think the Commonwealth could focus on to improve coordination and collaboration in developing policies for children and families?

- Alignment across services and sectors as to what ages comprise "early years." e.g., NDIS will be transitioning to 0- 8 years, Early Years Strategy is up to 5 years, National Early Childhood Program caters for 0- 8 years, Department of Education identifies early years up to pre-school enrolment of children.
- Examine and rectify governmental history of losing continuity of well-established and effective programs due to changes in Government policy and funding which results in wasted resources, breakdown of well-developed referral pathways, loss of connections and relationships particularly with vulnerable and disadvantaged families e.g. Early Days Workshops replaced by National Early Childhood Program, cessation of Early Intervention Indigenous Liaison Officer program.
- Cultivate a genuine desire to break down silos; use information that has already been sourced through other departments and consultation processes. Please refer to attached NDIS consultation papers (Autism Intervention Consultation Paper response, Early Childhood Consultation Paper response, Independent Assessments Consultation Paper response) in addition to the consultation from various other organisations invested in improving outcomes for families and children.
- Staffing and recruitment of professional workforce in regional and remote areas to be prioritised – there is currently a consistent lack of services available due to lack of qualified workforce.

QUESTION 7. What principles should be included in the Strategy?

- Refer to the Autism CRC *'National Guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia'*[1]

Principles included are applicable to all children:

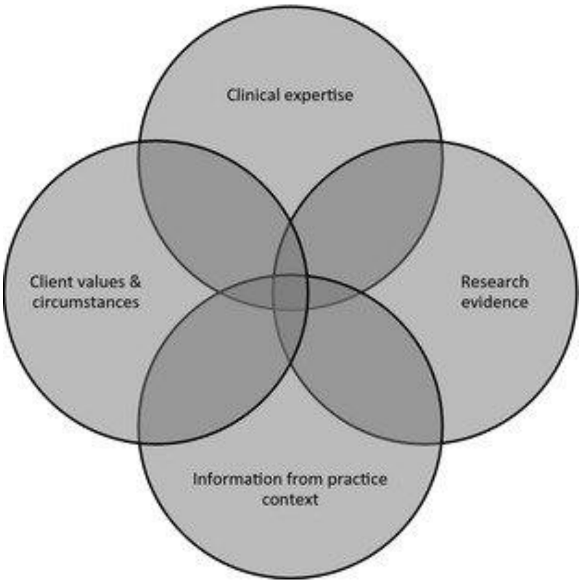
1. **Child and family-centred:** Supports should be child and family-centred, where individual goals, preferences, and circumstances are respected, valued, and supported through shared decision making.

2. **Individualised:** Supports should be individualised for each child and family.
3. **Strengths-focused:** Supports should build on each child’s and family’s strengths and interests.
4. **Holistic:** Supports should be holistic in terms of the goals that are targeted and the way they are achieved, considering all aspects of the child, family, and their community.
5. **Honour childhood:** Supports should honour the goals and activities of childhood including play, relationships, and personal discovery.
6. **Foundation for the future:** Supports should lay the foundation for a positive future, including optimum health, choice, learning, self-identity, participation, and wellbeing.
7. **Ethical:** Supports should be ethical to protect the rights of the child and family.
8. **Culturally safe:** Practitioners should acknowledge and respect the values, knowledge, preferences, and cultural perspectives of the child and family, and reflect on their own cultural knowledge and competency in delivering services.
9. **Respecting Australia's First Nations Peoples:** Supports should be culturally safe for Aboriginal and Torres Strait Islander Peoples, built on an acknowledgment of the barriers to accessing supports that they may experience; an understanding of current and historical truths and their enduring impact; and respect for deep connection to Country, language, customs, and traditions.
10. **Evidence-based:** Supports should reflect the best available research evidence, integrated with evidence from clinical practice and the lived experience of families, and the preferences and unique context of each child and family.
11. **Assent (children):** Each child has the right to say no to supports and their assent (expression of approval) should be sought and respected, whether they communicate using words or in other ways.
12. **Informed consent (parents):** Parents should have the information they need to make informed choices about supports and provide consent for any supports received.
13. **Qualified practitioners:** Practitioners should have relevant qualifications, be regulated, work within their scope of practice with appropriate supervision, and engage in continuing professional development.
14. **Neurodiversity-affirming:** Supports should be neurodiversity-affirming, embracing each child’s unique understanding of other people and the world around them.
15. **Parent and family affirming:** Supports should uphold the parents’ autonomy in raising their child, and ensure the natural roles of children, parents, siblings, and other family members are affirmed and preserved.
16. **Timely and accessible**: Each child and family should be able to access the supports they need, when they need them, and in ways they desire, regardless of who they are, where they live, or how much money they have.
17. **Coordinated:** Practitioners should engage in open and regular communication with other practitioners, the child’s educators, and other service providers, with appropriate consent, to ensure supports are coordinated.

Principles could also consider the needs of children and families across the service system and over time. The first 1000 days is particularly important to health and development; however, we would like to recognise that for autistic children and those with developmental delays or vulnerability, ongoing intervention and support needs to be extended across transition points of the early years, not just the first 1000 days.

QUESTION 8. Are there gaps in existing frameworks or other research or evidence that need to be considered for the development of the Strategy?

AQ proposes that the structure of the Strategy is reviewed to ensure that Evidence Based Practice (EBP) is represented as an underlying design element. Currently the reference to “evidence” does not include a robust evaluation of EBP for early childhood. Specifically, AQ submits the Hoffmann model[2] for consideration as a tool to promote best practice decision making.



In addition to existing frameworks that aim to tackle social determinants of disadvantage, outcomes for individual children and families must consider a decision-making process that pulls together the best available research evidence, knowledge from practitioners, and data and input from children and families, to identify and provide appropriate services that achieve positive outcomes for children and families. Image: Graham, Robertson & Anderson (2013)[3]

Yours sincerely

[redacted]

[1] Trembath, D., Varcin, K., Waddington, H., Sulek, R., Pillar, S., Allen, G., Annear, K., Eapen, V., Feary, J., Goodall, E., Pilbeam, T., Rose, F., Sadka, N., Silove, N., Whitehouse, A. (2022). National guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia. Autism CRC. Brisbane.

[2] Hoffmann, T., Bennett, S., & Del Mar, C. (2013). Evidence-based practice across the health professions. Elsevier Australia

[3] Graham, F., Robertson, L., & Anderson, J. (2013). New Zealand occupational therapists' views on evidence-based practice: A replicated survey of attitudes, confidence, and behaviours. Australian occupational therapy journal. 60. 120-8. 10.1111/1440-1630.12000.

AUTISM QUEENSLAND RESPONSE TO THE NDIS CONSULTATION PAPER: *ACCESS AND ELIGIBILITY POLICY WITH INDEPENDENT ASSESSMENTS*

Autism Queensland welcomes the opportunity to provide its feedback on the above Consultation Paper.

Autism Queensland has a number of significant concerns about the proposed introduction of Independent Assessments (IAs), as laid out in the Consultation Paper. We will provide feedback on these concerns in this submission, along with our responses, where relevant, to the questions posed at the end of the Consultation Paper.

However, most of our concerns boil down to three critical issues that this process will cause for people on the autism spectrum, along with their families and loved ones:

1. Undergoing an IA will be of great detriment to the emotional and mental health of the participant and the participant's carers:
   a. The requirement to engage with an unknown person will cause enormous stress and anxiety in many people on the spectrum.
   b. The requirement for the participant or their chosen representative to provide detailed information on the challenges they face will be extremely damaging to their self-esteem and will cause further anxiety and stress.

   Families who engaged in recent consultation and information sessions were passionate and articulate in expressing their concern, in writing, on this issue:

   > How no earth can it be see (sic)as ethical to make children aged 7, to 17 sit and tell a complete stranger about their limitations - and many children aren't even AWARE of the issues they face> I certainly don't want to sit and speak about all of my child's challenges in front of her and she doesn't have enough awareness of some of her challenges to represent herself. the damage to her self esteem if I sit and tell someone in front of her face about all her social and other deficits etc would be hartbreaking (sic) for her. Self esteem destroying. And increase her anxiety. To me this can almost certainly will) cause HARM. So I do not understand how this is seen an a good process. Many families believe it is a way for NDIS to save money as families won't be prepared to put their kids through that due to the capacity for the process to cause harm to the child.
   >
   > My children already have assessments with their four therapists so that they can better plan their therapy for the year and know what to focus on for the year and try to improve/assist. They also attend school. They go through enough as it is, let alone another assessment where we are having to discuss all their negative qualities. This will destroy their self-esteem which we are working on daily to improve. Life is hard enough without having to jump through these hurdles.

2. There is great risk and likelihood that an IA will not accurately identify the true needs of a person on the autism spectrum.
   a. Assessments, particularly functional assessments, have been know for decades to be notoriously poor at picking up and appropriately identifying the needs of people on the spectrum.
   b. This situation is exacerbated if the person administering the assessment does not have a deep understanding of autism.

Again, families connected with Autism Queensland have expressed their fears and experiences on this:

The issue of children being able to adequately represent themself is a very important one. Please don't ignore it if it seems too hard. There is no way my child can give valid info but how will the assessor know that? Ask her - can you tie your shoelaces. Answer is - yes. Ask her - can you get your shoes onto your feet and tie your shoelaces so that they are tight and secure and you are able to walk around safely in them - answer is no - she can tie a bow now. But she can't put on shoes and tie laces so the shoes can be worn. Assessment tools are notorious for not being specific enough around these kinds of issues. Ask my daughter - can you make friendships - she will say yes. Ask her teachers, school, parents if she has capacity to independently make and maintain friendships -answer is no. Her self perception is different to reality.

How can a 3hr assessment with a stranger be beneficial for a person with ASD. Assessment needs to take into consideration the history of the child. A lot of ASD children camouflage, and cover up their anxiety. So they may look perfectly fine at the time of assessment, however they are not! You won't see their anxiety or their meltdowns or incapacity to function.

How can an Independent assessor make a report based on a few meetings, given this is key evidence, having time to know child, history, and functional impacts?

My teenager won't interact with anyone new and will need rapport built before any assessment could take place. I'm concerned a "cold" assessment will not get any information from my child directly and will cause problems.

People on the autism spectrum represent a very significant proportion of the total number of people accessing the NDIS. The introduction of any system needs to be designed for such individuals, rather than continue with the previous models that have served people on the spectrum so poorly.

Family members representing the functional capacity of a person on the spectrum may also be challenged to accurately respond to standardised “tick-the- box” questionnaire items which offer little opportunity to provide more nuanced or detailed information about the participant’s unique characteristics or contextual information related to their physical or social environment. For example, when asked if the person “*bathes or showers and dries self*”, the response may not convey to person’s reliance on frequent reminders and environmental cues or a tendency to completely neglect this task for prolonged periods if intensely engaged in a narrow interest area (an autistic trait). In terms of context, the capacity to perform this task in an unfamiliar environment when away from home or with unfamiliar carers can also not be conveyed in a single tick-the- box” questionnaire item.

Autism Queensland believes participants should have the right to engage their own AHPs to undertake the assessments. This will go some way to alleviating concerns about the stress associated with an assessment being performed by an unknown therapist. Experienced AHPs who are familiar with the participant will have gathered information from multiple sources including conducting a task-analysis of the person performing functional tasks in different contexts, gathering information from other settings (e.g., childcare, school or supported accommodation) and exploring the person’s typical participation in activities across their week. They are therefore better positioned to provide accurate information.

Autism Queensland also has concerns that the list of “disability-neutral” standardised assessment tools that the NDIS plans to use (as per the NDIS document released in September 2020 on “*Independent Assessment: Selection of Assessment Tools”*) may not adequately address the functional capacity on some adults on the autism spectrum. For example, these assessments are unlikely to be sensitive to the needs of people on the autism spectrum with university degrees, who struggle to find employment commensurate with their skills, and who are socially isolated, dependent on their aging parents and who frequently have both diagnosed and undiagnosed mental health issues. These adults need and deserve support to live an ordinary life and can make significant gains from targeted support. Furthermore, this support may ultimately reduce their dependence of social welfare and mental health services.

3. The lack of consultation with participants and providers around the most significant components of these changes, coupled with the lack of evidence for using assessment tools to determine financial outcomes for participants. The input that is being requested is relating to how to manage outcomes of a process that was not prepared in a consultative manner. Autism Queensland strongly requests that the implementation of IAs does not go ahead in the planned time-frame, but is re-considered, through a process of genuine consultation.

Other Autism Queensland comments on issues not covered by the Consultation Questions

THE IMPACT ON WORKFORCE

There is already a known shortage of allied health professionals (AHPs). Participants are having to wait for periods of over a year to gain access to AHPs, with this being especially challenging in regional and remote areas.

For IAs to be offered in a prompt and timely fashion, the number of AHPs required by the organisations granted the NDIS IA tender will be very large. The Consultation Paper and information sessions on IAs by NDIS staff have emphasised that Independent Assessors will be qualified and experienced. The most significant pool of such AHPs is with service providers, so it is expected that providers’ workforce challenges and participants’ lack of access to required supports will become a great deal more problematic.

This issue has been raised by all service providers during information sessions and also by parents attending participant-focused information sessions – for example:

> … taking these therapists from therapy work into purely assessment work is surely a step backwards. By diminishing an already difficult resource to engage I would think an NDIS goal would be to ensure there are the supports available that are so vital to help our children and adults to live their best life.

In each case, it has been acknowledged by the NDIA staff as a genuine concern but absolutely no information has been provided on how this is going to be managed or how the impact on participants is going to be ameliorated.

Additionally, it is also anticipated that the shortage of Allied Health Professional workforce will also impact Assessor availability, and significant waiting times for assessment are a distinct possibility. Has there been any consideration of how to manage this situation, should it eventuate?

A strategy that will create additional demand for an already limited resource seems ill conceived. Surely the focus now must be on building a competent AHP workforce to meet the support needs of participants.

HOW WILL IA RESULTS BE TRANSLATED INTO DOLLAR AMOUNTS?

A central feature of this process is that the data from an IA is used to identify the funding available in the individual's NDIS plan. Despite frequent requests to a range of NDIS staff and through various channels, no information whatsoever has been provided on the mechanism by which this will occur. Furthermore, we are not aware of any research that supports the use of these assessments as a tool for establishing funding. This is critical information that participants, providers and the community need to know and provide feedback on.

If that mechanism has not yet been determined, then that is of concern given the importance of this step and the close starting date for this new process.

If the mechanism has been determined but is not being disclosed, then the lack of transparency is adding to the general sense that the primary focus of this new process is to cut funds to participants.

DIAGNOSIS OR A SPECIALIST'S STATEMENT THAT THE PERSON'S DISABILITY IS PERMANENT IS STILL REQUIRED BEFORE THE PERSON CAN THEN PROGRESS TO AN INDEPENDENT ASSESSMENT

The Consultation Paper states: *The current access process requires people with disability to seek information about the impact of their disability from a variety of health professionals, including doctors and specialists. This can often involve long wait times. Appointments to see doctors and specialists can also cost a lot of money.*

From the perspective of the people on the autism spectrum, the long waiting times are for **diagnostic** assessments, not functional impairment assessments. As participants will still require a statement from an appropriate specialist that their disability is likely to be permanent before being able to progress to an Independent Assessment (IA), this change does not actually represent a great improvement in their situation – **a diagnosis is still required**. Diagnosis as a requirement for NDIS access has been the cause of incredible stress and distress for many people on the spectrum and their families, particularly those who already had a diagnosis but which was deemed not acceptable due to the period of time since the diagnosis was made. Most participants or their carers do not understand how the diagnosis of what is known to be a life-long condition is required to be made again.

In terms of the functional capacity information that was then needed for the planning process, a number – not all, certainly, but a considerable number – of participants who are on the autism spectrum would already have been accessing one or more allied health therapist and other appropriate professionals as a direct outcome of their diagnosis, meaning that relevant information about the person's functional capacity was already going to be available.

For those who did not have this information, a viable option at the planning meeting was to create a short-term plan with funding specifically for the purpose of gaining the necessary assessments and reports to then inform a longer plan. Whilst this option was not often spontaneously offered by Partners, when participants requested and received this in their planning meetings, it led to good outcomes for participants. Not only were they getting appropriate and comprehensive assessments but they were also able to commence ongoing therapy sessions with the professionals who conducted the assessments, which avoided the need for a new treating professional to also build a relationship with the participant and conduct some of their own assessments.

So, overall, along with the concerns about the IAs and their impact on participants' eligibility and plans, this proposal does not improve the enormously problematic issue of waiting times and costs for participants to see specialists.

LACK OF CONSULTATION ON THE IMPLEMENTATION OF IAs

Autism Queensland notes that, despite the use of terms such as 'pilot', 'trial' and 'consultation', IAs are confirmed. This is concerning, particularly in light of many very serious and real issues that have been raised by participants, their families and providers representing their clients, not to mention the questionable data gained from the IA pilots (see next point). A parent participating in a recent information session said it very clearly:

I do find it disappointing that this appears to be so much change at a time when people are doing it tough enough especially given Covid has caused huge stress and upheaval for many too. 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 who this will just be yet another thing we need to advocate for and often we are already at breaking point and need support and by that means listening to the needs of the participants and carers.

CONCERNS REGARDING THE IA PILOT PROJECTS

1. Running a pilot during the COVID lockdown period seems likely to have led to skewed results
2. The data from the first IA pilot project is extremely small and not statistically valid.
3. Crucially, the first pilot did not use the IA results to determine the participants' budgets, so participants' rating of satisfaction was based purely on the actual process of having an IA. The most significant concern being raised by Autism Queensland staff and clients is how IA results will be interpreted into funding amounts and how it will change the planning process for participants. The pilot/trial projects have not tested this and yet the decision has been made to implement the process anyway. It is not known whether this step will be included in the second pilot.
4. Many parents of children and adults on the autism spectrum have chosen *not* to participate in the second pilot due to their grave concerns about the negative impact of this process – as highlighted in our introductory comments – on their sons and daughters. This means that the data from this pilot is missing input regarding a critical area of concern.

CONCERNS REGARDING PARTICIPANT/POTENTIAL PARTICIPANTS IN REGIONAL AND REMOTE LOCATIONS

Whilst the rationale for the introduction of IAs is for there to be equity and consistency for all, there are some troubling comments and gaps on exactly how this will be achieved for those in regional and remote areas. Suggested solutions to address the provision of IAs to those living in these areas all seem to consist of providing them with a service that is lower quality than those living in metropolitan areas would receive. The tender document for organisations to apply to become a provider of IAs says:

The NDIA expects that most Assessors will hold qualifications in one of the Assessor Categories described above, but may consider additional Assessor Categories in certain circumstances, for example in rural and remote regions. Tenderers wishing to tender for additional Assessor Categories must clearly indicate their proposed professions in the Tender Response Forms.

AND

The Supplier may only use a Telehealth service or other remote method to conduct an Assessment in limited circumstances where distance to a rural town or remote community would make face-to-face Assessment Services impractical.

The parents of Autism Queensland clients participating in a recent information session provided by the Queensland NDIS Community Engagement Team made the following comments:

Has the NDIA made comment on how they will ensure adequate assessors to implement timely IAs? Living regionally we struggle to find adequate support services and therapists – it's not likely local assessors will be available. And what qualifications do the assessors hold? - I have 4 to 5 separate qualified professionals informing the current plan.

In the case of regional towns, are assessors local or will they be flown in?

Living rural I have been on wait list for therapy assistance for 18months.

How will they assess someone over the phone? Especially if the person is a child?

Can you explain how assessments are to occur over the phone, how does that work, in regards to lack of observations,

In regards to independent assessors, will they be available in regional areas? e available to come to our home?

Autism Queensland acknowledges the challenges in providing services to those living in areas outside the metropolitan areas, especially to those in remote locations. However, people with disability in those areas are entitled to the same quality of service as those living anywhere else. Watering down, and accepting less than best practice, service provision is not acceptable. Other solutions need to be found.

Those in regional and remote areas are also going to be negatively impacted in the situations where an Independent Assessor requires additional information. The Consultation Paper states: *In some circumstances other information may be needed to determine if a person is eligible for the NDIS. If required, we will request this information. We will consider all evidence provided in relation to impairment and the permanence, or likely permanence, of that impairment. Where appropriate, this information can be provided by the applicant's treating health professional.*

Clinical information and reports from the applicant's usual treating health professional can provide an understanding of the supports or interventions that have and have not worked in the past, as well as any barriers and proposed supports for the future. Independent assessments provide a holistic view of functional capacity at a point in time, and do not replace the clinical relationship and expertise that are important for achieving outcomes and supporting a participant throughout their life.

Accessing this kind of additional information is going to be challenging and, in some cases, impossible to achieve for those in regional and remote areas due to lack of availability of AHPs and specialists. How is this additional disadvantage going to be addressed?

LACK OF INFORMATION ON HOW IAs WILL IMPROVE OUTCOMES FOR CURRENTLY DISADVANTAGED COHORTS

A focus of the rationale for the introduction of IAs is to overcome the current inequalities as evidenced by the variability in funding amounts received by participants from the lowest socio-economic category compared with those in the highest socio-economic bracket, and other inequities for those from CALD or indigenous backgrounds. Autism Queensland completely endorses the importance of addressing these issues. However, there is no information provided on how this IA process is going to be more accessible for those people. IAs are still a process that the person has to know about, engage with, understand and navigate. What is being proposed in order to achieve the stated desired outcome?

Autism Queensland responses to the Consultation Questions

1. What will people who apply for the NDIS need to know about the independent assessments process? How is this information best provided?

   - They need to know that preliminary eligibility is required before an IA can take place.
   - They need to know specifically, that preliminary eligibility requires an appropriate professional to determine that the person's disability is likely to be permanent – and that this means that a diagnosis is required before an IA can take place.
   - They need to know how recent such information needs to be – current requirements state a diagnosis must be less than 2 years old. Given that the majority of diagnoses prior to the commencement of the NDIS in any area would not have included the specific wording that the disability is life-long as that was considered to be implicit in the diagnostic label itself, will all those who are attempting to enter the NDIS who only have a diagnosis from more than 2 years ago all need to go back to a specialist to get an updated diagnosis / inclusion of the statement that the disability is life-long? As raised at the start of this submission, this has been a huge issue for many Autism Queensland clients in terms of access to a specialist, waiting times and costs.
   - Information is best provided in a simple step-by-step format – more straightforward but also more detailed than the example in the Consultation Paper. For example, Step 1: go to https://www.ndis.gov.au/how-apply-ndis/what-access-request-form#access-request-form to download Access Request Form (ARF) or to organise how to get it sent to you; Step 2: complete ARF and attach proof of address (bill for electricity, rates, library card), proof of age (birth certificate, passport, driver's licence), proof of diagnosis (letter from medical specialist); etc.

   What should we consider in removing the access lists?

   - One of the reasons for the Access Lists was that there are many disabilities that are known to be life-long and where the person is clearly going to need support throughout their life. Requiring this to be individually stated by a health professional for each person is inefficient.

2. How can we clarify evidence requirements from health professionals about a person's disability and whether or not it is or is likely to be permanent and life long?

   - There should be recognition of health professionals' expertise in making this determination.
   - There should be recognition that there are many disabilities that are known to be life long and that the diagnosis alone is sufficient to communicate this. Requiring a person to provide evidence that their amputation, Down syndrome, autism, cerebral palsy, etc., is going to be permanent is offensive and unnecessary.
   - Training for the NDIS staff who are reviewing this documentation in their knowledge of disabilities.

3. How should we make the distinction between disability and chronic, acute or palliative conditions clearer?

- Clearer for whom?
- Consult with medical specialists with this expertise. These terms exist because they have meaning within their relevant sector and definitions / explanations would already exist.
- The question itself indicates that the NDIA considers there to be a distinction so does the criteria for this not already exist? If the NDIA itself cannot make this distinction, then it should not be in the process.
- Training for the NDIS staff who are reviewing this documentation, in their knowledge of disabilities.

4. What are the traits and skills that you most want in an assessor?

- The inclusion criteria state that the assessment tools should be able to be used by AHPs of any discipline without the need for extensive or specialised training. The assessment process would be more rigorous if completed by a multidisciplinary team integrating knowledge from different disciplines. From the perspective of autism, assessment is complex and it is important that the AHPs have training and experience in working in the autism field; undoubtedly this is true for other disabilities.
- Assessors and the process need to be mindful of the need to build rapport, and of the additional barriers for many people on the autism spectrum. The assessment process is likely to be highly stressful (unknown therapist, change in routine, high importance to funding outcome).
- An assessor needs to be skilled enough to probe further rather than accept answers at face value.
- Feedback from NDIS staff during information sessions has mentioned the likelihood of assessors who are ‘skills-tagged’, that is, have expertise specific to a particular disability and therefore appropriate to do the assessments of people with that disability. Autism Queensland supports this suggestion.
- However, it needs to be recognised that if a professional moves into a position that focuses solely on carrying out assessments rather than working therapeutically with people over time, their skills and understanding of the complex nuances of that disability will erode.
- Parents of children on the autism spectrum have had this to say about this aspect:

> My child currently see's (sic) 4 therapists, how will one assessor cover all those different types of skilled therapists? I.e. A physio does not have the skills that a OT has and can't accurately assess what an OT can assess etc.
>
> My children already have assessments with their four therapists so that they can better plan their therapy for the year and know what to focus on for the year and try to improve/assist. They also attend school. They go through enough as it is, let alone another assessment where we are having to discuss all their negative qualities. This will destroy their self-esteem which we are working on daily to improve. Life is hard enough without having to jump through these hurdles.
>
> This also applies to adults with ASD as well not coping well with new people asking them questions

> My ASD children like routine and consistency, so a independent /stranger assessing them isn't appropriate.
>
> Why does the NDIA believe that one person with a set questionnaire can replace the years of specialist training that OTs, speechies, psychologists, developmental pediatricians etc undergo? I note that an allied health professional will conduct the assessments - however never in the past has my daughter's psychologist thought she had capacity to assess my child's OT or physiotherapy needs? And vice versa. Professionals undergo training for a reason, To think a checklist can replace that seems extraordinarily strange logic.
>
> I'm concerned about the assessors. If they are just part of an organisation that does assessments and they have certain skills (sic) tags, they aren't going to be professionals practicing in autism say on an everyday basis. Therefore, they aren't going to be up with the latest research or know the nature of the disability (sic) as well as a professional that practices in it in the real world everyday.

5. What makes this process the most accessible that it can be? For example, is it by holding the assessment in your home?

- Ensuring that the time is taken to develop rapport and make the person as comfortable as possible during the process.
- Enabling the person's treating professional to attend and be able to charge for this time. If the treating professional's time is not funded by the NDIS, there is a significant risk of inequity, as families who have the capacity to pay for a private therapist will likely have better access to NDIS funding than those who are unable to pay for this assistance.
- The estimation of an average 3-hour time frame may be unrealistic – there is likely to be a requirement to observe the person in more than one environment, as well as the time needed to settle the person in and build rapport.
- Will participants in remote areas have access to the same array of accessibility options as those elsewhere – e.g. holding the assessment at their home?
- Accessibility should not be at the expense of validity – a person on the autism spectrum may consider an assessment over the phone to be accessible in that it reduces stress around travel and organisation but may not be indicative of that person's capacity to function under different circumstances.
- There should be a pre-assessment risk assessment to identify any factors that need to be taken into consideration to protect the participant, carers and/or staff member.

6. How can we ensure that independent assessments are delivered in a way that considers and promotes cultural safety and inclusion?

- Consultation with relevant cultural groups to define training and arrangements needed.
- This would be easier to achieve if the assessments were administered by AHPs known to the participant.

7. What are the limited circumstances which may lead to a person not needing to complete an independent assessment?

    - Information already available demonstrates the supports required.
    - Recently conducted functional assessment through another channel.
    - High levels of anxiety.
    - Risks to participant, family and/or assessor due to behaviours of concern – this also needs to take into consideration the risks to the family and participant *after* the assessment as some people on the autism spectrum will mask their stress and anxiety during the appointment and then experience an extreme melt-down, including aggression to others and self-harm, once the session has concluded.
    - What if the person refuses to participate in an independent assessment? There are a number of people on the autism spectrum who will not undertake such an activity because they are experiencing high levels of anxiety and depression and their response is to refuse to engage; or who are in denial of their diagnosis and difficulties and will not engage in any activity that references this; or the diagnosis itself compromises their self-awareness of their own challenges. These responses are in no way indicative that the person does not have substantial support needs. Comments from parents include:

        > Good luck if you can even get an ASD child out of their bedroom to see an independent assessor!
        >
        > Or to get them to actually answer any questions from a person they aren't comfortable with!

8. How can we best monitor the quality of independent assessments being delivered and ensure the process is meeting participant expectations?

    - The interplay between the compulsory participation in an IA, the funding outcome that is determined by the IA and the fact that IA results cannot be challenged is causing many participants and their families to be cautious and deeply suspicious of the overall process:
        - More receptiveness to information that participants already have from their own AHPs and specialists is needed.
        - Transparent communication on exactly how IA results are converted to the participant's funding is critical.
    - IA providers need to be subject to a rigorous audit process through the NDIS Quality & Safeguard Commission similar to that for registered providers.

Submitted: 23 February 2021

AUTISM QUEENSLAND RESPONSE TO THE NDIS CONSULTATION PAPER: *SUPPORTING YOUNG CHILDREN AND THEIR FAMILIES EARLY, TO REACH THEIR FULL POTENTIAL*

Autism Queensland welcomes the opportunity to provide its feedback on the above Consultation Paper. Our organisation recognizes and appreciates the investigation and work that has gone into preparing both the Consultation Paper and ECEI Implementation Reset – Project Consultation Report. The acknowledgement by the NDIS that there are components of the Scheme that need changes and its commitment to continuous improvement are highly valued by Autism Queensland and we endorse the stated objectives of the ECEI Implementation Reset.

Autism Queensland responses to the ‘Improving the NDIS’ section

In response to the section in the Paper entitled “Improving the NDIS”, our organisation makes the below suggestions and comments:

- The Early Childhood (EC) Approach needs to reconnect with and better communicate the original clear vision for ECEI, and should be more adequately differentiated from the general, more adult-centric, Scheme.
- There needs to be a well-articulated, visible, easy-to-understand and comprehensive process for those children who will be moving from the EC Approach to the general scheme, regardless of what age it is finally determined is the end point for the EC approach.
- There needs to be a more clearly articulated Agency position on what constitutes best practice in Early Childhood Intervention (ECI).
- The Agency needs improved processes and tools to enable more consistent, fair and equitable decision making around access and planning, with far more significant oversight by the Agency of the Early Childhood Partners – the number of different organisations delivering EC Partner services across the country, and the large number of individual offices and staff members within these EC Partner organisations is causing significant differences in outcomes for children and their parents.
- School-aged children are currently overlooked by both the EC Approach and the general Scheme. As school-aged children also have very particular needs and circumstances that are different from early childhood and from adulthood, an Approach specifically for this age cohort would be valid.
- Autism Queensland is extremely concerned about the impact of this EC reset from the perspective that most of the recommendations will require a vastly increased number of allied health professionals. There is already a critical shortage of these professionals, particularly those with experience, and no information has been provided by the NDIS on how this issue – which is being voiced by all in the sector, including participants and parents – will be overcome. A lack of appropriately qualified service providers will drastically reduce the positive impact of the NDIS for participants. We would like to have information on the analysis that the NDIS has done on the impact of this model on the AHP workforce and the planned responses to it.
- In conjunction with the above point, Autism Queensland is concerned that the format and focus of the NDIS EC Approach continues to steer participants’ and providers’ perceptions of necessary service delivery along the lines of a medical model – individual sessions over long periods with multiple different therapists. Autism Queensland’s experience with EC Partners is that any other form of service delivery (e.g. group therapy, short intensive blocks of therapy, transdisciplinary service) is viewed with suspicion and often proves difficult, if not impossible, for parents to receive funding for. This is despite all these models being supported by research and meeting criteria for innovative service delivery. The static model most commonly funded in EC Plans adds to the issues of therapist capacity and availability. Autism Queensland recommends that the NDIS carry out further analysis of how it has impacted the AHP workforce in terms of what is driving the demand and patterns of accessing therapy supports.

Autism Queensland responses to the Recommendations proposed in the Consultation Paper

We have not made responses to every Recommendation, only those where we have something to say.

Overarching recommendations

Recommendation 1: Explain, rename and promote the NDIS Early Childhood Approach – and stop using the term "gateway" – so families understand and follow a clear pathway with a mix of early childhood support options available.

Autism Queensland response: As highlighted above, this action should include attention to how children who will continue to require and be eligible for NDIS support once they are over the EC age, are supported to transition to the general Scheme. At present, there can be confusion and stress experienced by parents about this process, especially if their child gains entry to the Early Childhood pathway only shortly before they will turn 7.

Recommendation 2: Clearly and consistently, communicate the intent of the new Early Childhood approach and the Agency's support for best practice, so families understand how the approach informs positive outcomes for young children.

Autism Queensland response: Better communication and assistance to understand the EC Approach and the NDIS is required as the complexity and, at times, contradictory nature of the information provided significantly adds to the stress parents experience. Work in this area needs to particularly target how to engage with and communicate effectively with families from Culturally and Linguistically Diverse (CALD) backgrounds, families where the parent/carer also has a disability or additional needs (such as low literacy skills, or mental health challenges). Autism Queensland would highly value more detailed, consultative and clarified information on 'the Agency's support for best practice', as this currently is contentious. Many young children's NDIS Plans and the NDIS Price Guide, along with comments from and decisions by EC Partners, do not allow for some best practice supports to be provided.

Recommendation 4: Create a distinct delegate/planner workforce that is exclusively focused on young children and their families, to improve the way families are supported.

Autism Queensland response: We find it difficult to make a response to this Recommendation without a great deal more information about what it would look like. How delegates and planners currently work in this space is not information that is easily available, therefore how it could or should change is not able to be commented on.

Recommendation 5: Continue to work with federal, state and territory governments to identify gaps and strengthen the role of mainstream services, so all young children receive support from the appropriate system when they need it.

Autism Queensland response: We would see more effective cross-government interaction as being one of the most significant factors for improved outcomes for all NDIS participants, regardless of their age. Many opportunities for genuinely responsive, wrap-around supports that would enable participants to achieve goals more promptly and effectively are lost due to representatives from NDIS and other government departments responding simply that the particular assistance the person requires is not their responsibility. The time taken for the participant or parent to then find and engage with the sector that is appropriate (and many times, the overall result is that no one will provide the support), then to wrangle the interface between the two departments detracts significantly from the efficacy of the support and is often too challenging for parents to take on. Attitudes by government sectors such as 'NDIS stops at the [school] gate' have added to this silo effect. Autism Queensland would highly value more detailed information on what work has been going on up to this point and what is proposed as a strategy to achieve this recommendation.

Recommendation 6: Consider a range of mechanisms that will enhance compliance of providers with the *NDIS Practice Standards on Early Childhood Supports* and increase awareness by families of providers that adopt that best practice framework.

Autism Queensland response: Please see our responses to Consultation Question 4.5.

Recommendation 9: Implement a tailored Independent Assessments (IAs) approach for young children to support consistent access and planning decisions.

Autism Queensland response: Please see our responses to Consultation Question 4.4.

Recommendations for early support (including NDIS access)

Recommendation 10: Increase Early Childhood partner capacity to identify and help young children and families from hard-to-reach communities or those experiencing disadvantage or vulnerability, so they can connect to – and benefit from – early intervention supports.

Recommendation 11: Increase Early Childhood partner capacity to connect families and young children to local support networks and services in their community.

Recommendation 12: Increase Early Childhood partner capacity to provide Short Term Early Intervention (STEI) support to eligible young children and families for longer.

Autism Queensland response: The above 3 requirements were all part of original role of EC Partners. Further information on the mechanisms that have been in place to carry these tasks out and detail on why EC Partners have been unable to achieve them so far would seem to be very necessary. Simply increasing the capacity of the EC Partners – which we interpret as primarily being increasing the *number* of EC Partners, may not be the most effective response. More staff who still do not have the skills to engage with hard-to-reach communities is not a solution.

One factor at play in particular for Recommendation 11 is the high turnover of staff within EC Partner organisations. Developing a useful knowledge of local networks and services takes time and each new staff member will have to start from scratch to obtain this. Data on staff turnover and confirmed reasons for this is required so that these issues can be addressed.

Recommendation 14: Increase the age limit for children supported under the Early Childhood Approach from 'under 7' to 'under 9' years of age, to help children and families receive family centred support throughout the transition to primary school.

Autism Queensland response: Please see our responses to Consultation Question 4.1.

Recommendations for planning and implementation

Recommendation 16: Increase Early Childhood partner capacity and flexibility to tailor the level of support provided to families to implement a child's plan and more quickly connect to the right supports and services.

Autism Queensland response: Is there information available that details how this would be done and what the barriers are to the Early Childhood partners working in this way up to now?

Recommendation 17: Introduce a ‘capacity building support in natural settings’ item in the NDIS Price Guide to encourage families and early childhood providers to prioritise supports delivered at home or other natural settings.

Autism Queensland response: We do not feel clear on what is being suggested here – a higher price cap? Autism Queensland requires further detail on how this would overcome the barriers that currently cause supports to not be offered in natural settings. The barriers we experience are:

- Settings such as schools and child care centres not allowing access for service providers.
- Travel costs for staff.
- Individual staff in the mainstream setting not engaging with the service provider, e.g. not being in agreement with an evidence-based strategy and therefore not implementing it or simply seeing presence of service provider as meaning they (the mainstream staff) do not need to be engaged with the child at that time.
- Parents not being present when supports are delivered at school/child care.
- ‘Silos’ seem to have become more pronounced since the commencement of the NDIS rather than less – this becomes even more evident once the child reaches school age - 'the money' drives the system so every system puts up boundaries; in the end children and families fall between the gaps; many disability providers feel they have less and less capacity to help bridge those gaps as they have lost block funding and billable hours do not allow for this kind of support.

Recommendation 18: Publish new guidance about what is considered ‘reasonable and necessary’ when making decisions around support for children on the autism spectrum, based on evidence found in the Autism Cooperative Research Centre (CRC) 2020 report.

Autism Queensland response: We look forward to the imminent release of the Consultation Paper on this topic.

It is important to note that there were many questions that the Autism CRC umbrella review (meta-review of other systematic reviews) was unable to answer (see page 97 of the report on *Interventions for children on the autism spectrum: A Synthesis of research evidence*). Rather than being a reflection on the quality of the umbrella review provided by the Autism CRC, this issue related to the lack of available evidence and/or inconsistences in the available evidence for some research questions. These gaps in current knowledge point to the need for more high-quality research focusing on the range of early intervention approaches required to address the high level of heterogeneity among young children on the spectrum.

For example, the review was unable to provide information on which interventions have a positive effect on which outcomes, for which children. As there is a high level of variability in the outcomes of interventions, there is a need for autism-informed expertise in clinical decision-making for each child (as discussed on page 101 of the report).

Similarly, there was a lack of consistency in how the total amount of intervention was measured and reported on within and between the systematic reviews included in this umbrella review. As a result, it is not currently possibly to draw firm conclusions about the number of hours of intervention required for each child. Again, more research is required to determine the intensity of intervention needed by children on the spectrum with different clinical presentations.

Likewise, based on current evidence, conclusions were unable to be drawn on the best intervention setting (e.g. clinical, home or educational), intervention format (e.g. group or individual) or intervention agent (e.g. delivered by therapists or parents, or peer-mediated delivery).

The clinical decision-making involved in selecting an intervention that will best meet the needs of an individual child and family is a complex process. Service providers with a high level of clinical expertise in autism are needed to apply the best available scientific evidence to an appraisal of factors such as parental and child preferences and priorities, and the context in which the intervention is to be delivered.

Recommendation 19: Empower Early Childhood partners to provide families with clear advice about the best providers for their child and situation so families can make more informed choices.

Autism Queensland response: We have concerns about this based on our experience so far. Specific providers were recommended or deemed to automatically meet 'reasonable and necessary' requirements whilst others were not, without any engagement by the partners with either the recommended or not recommended provider. The Helping Children with Autism (HCWA) model is worth reviewing in that providers had to be registered, therefore it was known that all providers met key criteria. The Autism Advisors, whose role was to provide information about autism, mainstream services available and the services that could be purchased with their HCWA funding, needed to have in-depth understanding of the various evidence-based approaches for ASD and would then discuss the practical differences between providers that would help the family choose – mobile service delivery compared with only centre-based; the different (but evidence-based) approaches used by different providers; transdisciplinary practice provided compared with single discipline, etc. The families were assisted towards a decision without being told "this one is better for your child than that one". Many families would like to be told very clearly which support or provider to access – in a manner similar to consulting a specialist medical professional for a physical illness – but to do so disempowers them and dismisses the value each provider may have to the family. Additionally, as Early Childhood Partners are generalists not specialists, it would be inappropriate to believe that such a Partner would have an in-depth understanding of each service provider's supports.

Recommendations for transitions

Recommendation 21: Improve the existing annual progress review process for young children, to support families to celebrate the achievement of reaching their goals and outcomes, and transition out of NDIS supports to the next stage of their lives.
Recommendation 22: Ensure providers are using the recently introduced 'provider outcomes report', as a mandatory measure to evaluate the effectiveness of their supports and services.
Recommendation 23: Offer families of young children a 'transition out' plan for up to 3 months' duration, to support them to transition to the next stage of their lives, if they are no longer eligible for the NDIS.

Autism Queensland response: Please see our responses to Consultation Question 4.1.

Autism Queensland responses to the Consultation Questions

4.1 GENERAL QUESTIONS

Feedback in relation to the increased focus on Short-term Early Intervention (STEI) outside of access to the Scheme:

- Evidence is required of the positive outcomes for STEI – there are no outcomes measured or reported for the benefits or shortcomings of STEI.
- We are concerned that increased focus on STEI will delay access, at a critical time, to specialist early childhood supports for those children who require this. How will decisions on which child is directed to STEI and which to full Scheme be made?
- This proposal seems to be a return to the state systems that were recently dismantled, e.g. the Queensland Family and Early Childhood Services (FECS) – problems experienced were minimal intervention sessions due to high demand, lack of continuity due to staff turnover, lack of disability-specific expertise, delays in accessing appropriate specialist support.
- Furthermore this model removes choice of provider for these children and their parents
- The level of upskilling required for EC Partners would be immense, particularly given the current shortage of experience early childhood intervention practitioners.
- The requirement for an increased number of experienced allied health professionals will severely negatively impact on service providers in all services (not just NDIS providers).

Feedback in relation to the proposed increase in age range for the EC Approach from under 7 to under 9 years of age:

- We would like to have access to detailed and research-driven information on what the benefits of this change would be.
- We see this suggestion as creating a further diminishing of targeted support for those children who would then fall between the EC Approach and the NDIS full scheme.
- This change prolongs the period when families do not have choice and control over who provides their services if they are directed to Short-Term Early Intervention, as this is provided by the EC Partners *only.*
- It would further increase the number of EC partners required, once again drawing from the already too small number of experienced allied health providers.
- The current EC Approach age range already covers the period of children transitioning into school. Widening the age range to include the first 3 to 4 years of schooling into the EC Approach is bringing in a period that is very different from before school age needs and would be spreading the required skill-set of EC Partners much more widely.
- The value of EC Partner support for children transitioning to school is dependent on collaboration between the NDIS and education systems, which has been problematic up to this point, due to the NDIS position on funding not able to support education and school systems' position on 'NDIS stopping at the school gate'. For this change to be actively helpful, there first needs to significant work in the area of collaborative interactions between sectors. This should happen and be effective before any change to the age range for EC Approach is implemented.
- Another major transition for children is the move to secondary school, which is not being accounted for or acknowledged in this model.
- As stated in our introductory statement about additional improvements, we believe that a specific NDIS Approach for school-aged children would be more valuable. Within the autism cohort, parents consistently experience and reference huge challenges during their child's school life. This would also allow more concentrated effort by partners on address the current silos between NDIS and education.

- Autism Queensland's *Have Your Say* survey captured this data. In response to this survey question, "*Has your child/have you ever had to change schools because the school wasn't the right fit for him/her*?", 34% of 403 parents of primary school-age students on the spectrum and 53% of 175 parents of secondary school-aged students on the spectrum said that they had changed schools because the school was not a good fit. Of those who had changed schools, 30% had changed more than once. Parents gave many different reasons for changing schools, but the top 5 reasons were (1) lack of appropriate support, (2) bullying by other students (3) lack of understanding of the student's autism, (4) unfair or inappropriate treatment by teachers and (5) lack of academic progress. Parents were also asked "*What are your preferences regarding your child's school placement?*". Although regular mainstream school classrooms placements were the most preferred placements, around half of the parents identified an option other than a regular mainstream classroom as their preferred option. The most notable differences between parent-preferred school placement options and current school placements were that many parents preferred autism-specific classes in mainstream schools rather than special education classes that were not autism-specific, and autism-specific schools rather than special schools. Together these findings suggest that mainstream education systems are currently struggling to successfully include many students on the spectrum, and that parents are seeking educators who have a good understanding of the needs of students on the spectrum.

- The comment below made during recent information sessions on these Consultation Papers for our clients expresses this clearly:

  > What support is out there for children in schools? I've heard so many mothers including myself, where the schooling system completely fails their child. Can NDIS support them somehow in their education journey?

  Having Partners who are specifically informed and dedicated to the needs of children at school seems more relevant than extending the expected tasks and skills of those with expertise in very young children to also include school-aged children.

Feedback in relation to the desire to see more successful transitions from the Scheme to the next stage of life:

- It is counter-productive and contradictory for there to be an emphasis on needing people to exit the Scheme when gaining access to it in the first place required evidence of permanent impairment. As commented by parents in the recent information sessions:

  > Leave NDIS meaning somehow the person no longer needs support? From a lifelong condition that requires ongoing supports? How can you no longer be eligible if you have a lifelong disability?

  > How does a person become "no longer eligible for the NDIS" if their condition is permanent?

- 'Early intervention' leads to *improved* outcomes, not a cure; children who meet the criteria for NDIS early intervention support will do so because they have significant disabilities and their functional capacity will be reduced, compared with same age peers, long-term. The financial requirements may **reduce** but there should not be the expectation that early intervention will lead to large numbers of children no longer meeting the criteria for NDIS support. It is stated in the consultation paper that the NDIS takes 'a lifetime approach'; an emphasis on moving people out of the Scheme as soon as possible is counter to this message. Section 25 of the NDIS Act states "likely to benefit the person by reducing the person's future needs for supports in relation to disability", 'likely' means that the future cannot be foretold for any child – how much improvement they will show is not known at the start of the intervention; 'reducing' is not the same as 'removing'.

- The focus on transitioning out seems to reflect an overall lack of understanding of the true impact of disability as suggested by the Social Model of Disability. The Social Model of Disability sees ‘disability’ as the result of the interaction between people living with impairments and an environment filled with physical, attitudinal, communication and social barriers. Children with disabilities encounter many new environments as they mature (e.g. transition to school, transition to secondary school, transition to post-school options). They often need support to overcome different sets of barriers associated with different environments in order to ensure that they can successfully participate in each new environment. Although the child may have received effective early intervention services that led to improved outcomes, it is therefore likely that further supports will be needed during these times of transition.
- If too much focus is placed on 'celebrating' transitioning out of the Scheme, a future need to re-enter – which is extremely likely for life-long disabilities – will be seen as a failure. Furthermore, this position seems to suggest failure for those children that do not transition out. Celebrating achievement of our goals should not mean we did not aspire to more.
- This focus also seems likely to perpetuate families’ interpretation of the need to focus on their child’s deficits in order to stay the scheme as they are so fearful of losing this access. There needs to be consideration of the capacity for participants to come and go from the Scheme – or have funding to use when they need it, without the sense that if they don’t use it now, they will lose all access forever.
- We suggest turning this around and making it clear that the child is an NDIS participant for life, just not accessing funding unless it is needed. Check-ins, as per one of the proposals in the Plan Flexibility Consultation Paper, would occur throughout life, including when the person was not actively using NDIS funding.

Feedback in relation to how can we help families and carers better understand some of the terms the NDIA, and Early Childhood partners use such as:

  - best practice
  - capacity building
  - natural settings, and/or
  - evidence.

- Minimise use of sector-specific jargon – this is particularly important for those families from CALD backgrounds, those with their own disability and/or those who are otherwise already disconnected with systems and supports. Over-use of these and other terms will alienate.
- Use the already existing resource (for those on the autism spectrum) of the Early Days Parent and Carer workshops which have been in place since the commencement of the Helping Children with Autism initiative and came about due to the already recognized need to improve understanding of such terms. These workshops have a strong focus on achieving this.
- The understanding and/or the ability to convey the meaning of these terms seems inconsistent amongst current EC partners, therefore further training of these partners is needed. For example, an EC partner recently made reference to evidence in response to a support being requested by a parent but was then unable to provide that evidence.

4.2 SUPPORT WITH ACHIEVING GOALS

What is the best way for us to check with families and carers on how their child is tracking to meet the goals for their child?

- Improve the goal statements in the first place. If they are not SMART goals, how is anybody to know if they are on track?

- Consider meetings with the parent and child whilst services are being delivered – EC Partner makes observations and asks questions based on what is actually occurring. This would also assist the development of truly collaborative 3- or 4-way relationships between the parent, the EC partner, the service provider and, where relevant, the mainstream support.

Would a mandatory early childhood provider report developed between families and their provider be useful for tracking against their goals?

- It would be expected that any provider of early childhood supports (or any other supports) would already have a process for establishing and recording goals, along with tracking progress. A specific template is helpful in ensuring that information is being provided in the way that the NDIS needs it – we believe this is in place already.

How can we better support families to connect with services that are either funded or available to everyone in the community?

- Regular engagement with providers in the community – currently capacity and high staff turn-over make it difficult for Partners to stay informed about these supports.
- EC Partners need to be proactive in gaining information and have as part of their role that they go and look at such services so that they can informatively and supportively convey to families what they can expect and how such services are appropriate.
- More work with those medical / health professionals who may be the first contact that the family has – GPs, General Practice nurses, paediatricians – who often operate outside of the relevant systems and are unfamiliar with (e.g.) inclusion support in child care, state specialist early childhood services, government funded workshops, etc – so that families are directed to those services as a matter of course when first consulting about their child.

4.3 TARGETED SUPPORT

If you live in a remote or very remote part of Australia, what are some ideas you have on how we can get early childhood supports to work in your community or communities like yours?

- Provide a base level of block funding to support providers to establish and maintain services – may include a combination of travel to communities and online focussing on coaching models.
- Allow for connection for provider and participant initially, (face to face), move to graded supports – towards more online/less frequent support. A study that the NDIS commissioned Autism Queensland to conduct demonstrated that online support is more effective if there is an initial face-to-face contact in order to understand the child within his or her local environment (Ashburner, Vickerstaff, Beetge & Copley, 2016).
- Provide support for families to travel to specialist providers (e.g. over holidays) where intensive support can be provided and then maintained less intensively through online and less frequent face-to-face contacts.
- Supporting and facilitating links with existing cultural connections in community that promote children’s development and family knowledge.
- Building the connectedness and communication between local teams and visiting providers.
- The Indigenous Liaison Officer (ILO) program has been very successful in assisting families across the country – funding ceases 31 March 2021.

How can our Early Childhood partners and mainstream services best support peer-to-peer connections?

- Keeping up-to-date information on all the peer-to-peer support groups that are in their vicinity and passing that on.

- Being a central point for such information to be maintained and passing on information on changes, new groups, upcoming events.
- Offer to attend sessions to provide information to the group and/or to conduct brief consultations with individual group members who are in need.

Are you interested in helping us co-design an approach that would make peer-to-peer networks easier to find and join for people?

- Gaining the necessary information about such groups and keeping it up-to-date is extremely time-consuming and demanding; the implementation of the NDIS has made it too difficult for many organisations to do this due to not being funded to do so and the emphasis on billable hours for clients.

How can we better reach and get support to young children and families who experience vulnerability and remove barriers so they can receive outcomes in line with other children and families?

- Commit to serious staff training in the relevant areas – these families and children are hard-to-reach for a variety of reasons, which makes proper understanding and access to specialised knowledge of how to engage essential.
- Consider all other suggestions made regarding reduction of the ‘silo’ effect, improved cross-government interaction, promotion of positive and open working relationships between providers and partners and block funding for some services so that there can be a flexible and fluid response.

4.4 TAILORED INDEPENDENT ASSESSMENTS (IAs) APPROACH

Do you have any feedback on this recommendation and/or any suggestions on how this proposed approach would work best for young children and their families/carers?

- How are they *independent* if the NDIS Early Childhood partners are administering the assessments and, in many cases, determining access? This is of serious concern to Autism Queensland and seems to be in direct contradiction to reasons put forward for many other NDIS decisions, processes and changes, where avoidance of conflict of interest, concern about service providers inappropriately funnelling clients to themselves, choice and control, best practice and more are highlighted.
- There are many concerns about IAs in general, for all age groups, which we cover in more detail in our submission to the Consultation Paper on this topic.

4.5 GREATER TRANSPARENCY ON PROVIDERS OF BEST PRACTICE

What mechanisms do you think could help achieve this?

- All providers of professional ECI services should be registered and audited. This is listed by the NDIS as an option as a dot point as part of this Consultation Question (see below) and yet information presented at an information session held by the NDIS on the topic of the Early Childhood Implementation Reset stated that this will not happen, which is confusing and extremely concerning. If ensuring that best practice is delivered to all children is genuinely a priority, then the delivery of services needs to be closely monitored and controlled. The registration process and renewal of registration audits are gruelling and thorough, which ensure adherence by registered providers to the NDIS requirements. If a provider is not registered, there are no mechanisms for categorically ensuring the quality of the service provided. It has apparently

been commented that to require all Early Childhood service providers to be registered with the NDIS would "reduce a parent's/carer's 'choice and control'" and yet if that child is deemed to require STEI, there is no choice possible; similarly for the EC Partners are proposed to conduct the child's IA (once IAs are introduced), and also determine the amount of funding the child will receive – absolutely no choice or control are available to families.
Please note we find it particularly concerning that this mechanism is proposed in this document but has apparently already been pre-determined within the NDIS to be not an option, which begs the question of why have it as a Consultation Question and creates concern that many other decisions have already been made, regardless of feedback.

- It is suggested that Early Childhood partners engage in more contact with Early Childhood service providers to gain understanding of services delivered and whether they meet best practice, and so that they can provide useful information to families about these services. Early Childhood partners are still seen to be discriminating between service providers eg. suggesting individual therapy but never small group or intensive supports

Who would be best placed to lead the development of, and manage, any additional complementary mechanisms?

- The Agency.

What do you think of the following ideas for potential mechanisms? What are the benefits or concerns with these potential mechanisms?

- Provide greater information to families about the benefits of using providers registered by the NDIS Commission.
  - Extremely beneficial – families would be in a better position to make an informed choice and be fully aware of the difference between registered and unregistered providers.

- Establish an industry-led 'best practice accreditation system'.
  - In theory this sounds good, but Autism Queensland has concerns for the additional workload for providers it seems likely to represent.
  - Such a system would need to recognise best practice disability specific intervention /approaches as well as generic EI best practice.
  - This seems as though it would take considerable time to set up.
  - Would this be managed by the Commission?

- Establish a 'quality feedback/rating system'.
  - If managed well, this kind of system can create value for participants and providers, BUT must be managed well, as there is a high risk of fraudulent reviews by providers and participants and of selection bias.
  - Additionally, people are more likely to leave reviews if their experience was very good or very poor and you are less likely to hear about anything in between.

- Make registration with the NDIS Commission mandatory for all providers operating in the EC space.
  - As stated above, Autism Queensland considers this to be the most effective way of ensuring quality of service to participants.

- Require self and plan-managed participants in the new Early Childhood approach to use only registered providers.
  - As above.

Submitted: 23 February 2021

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 75th 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.

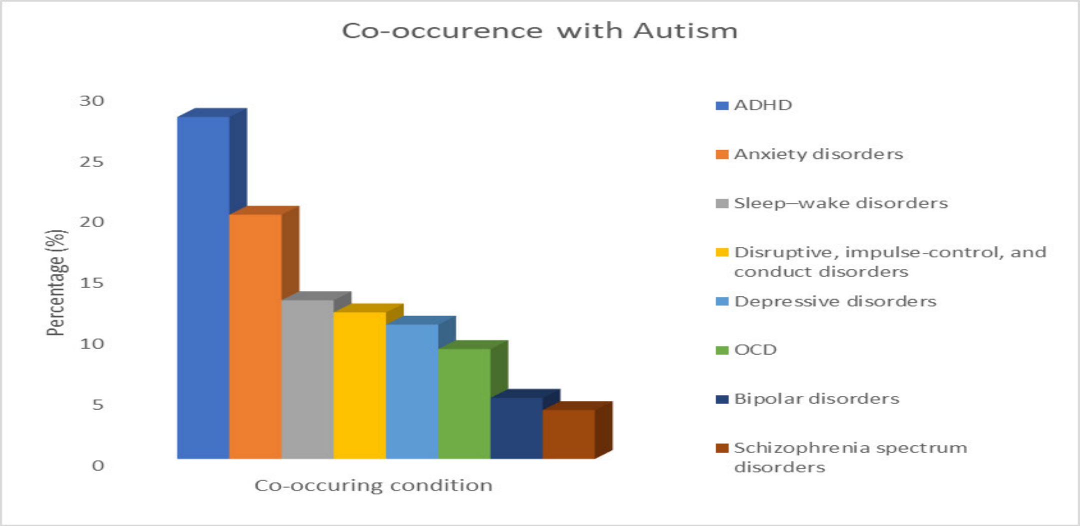
Respecting research findings

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.**

1

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."

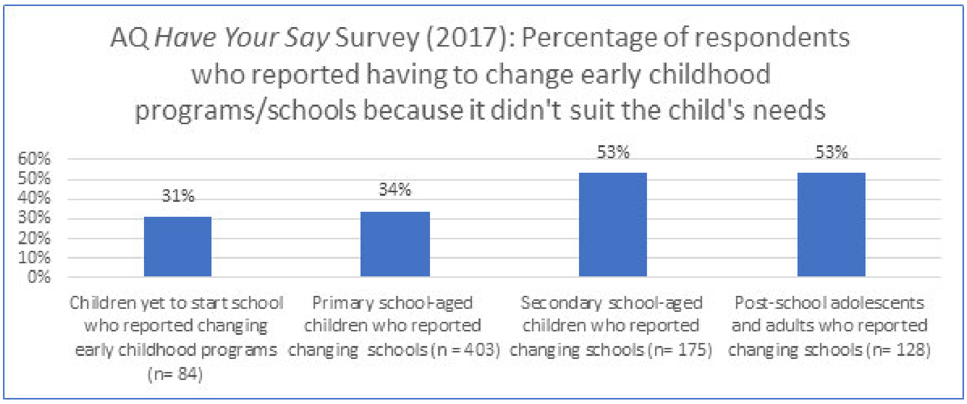
"I'm finding mine (child) needs MORE support the older she gets as life gets more complex."

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

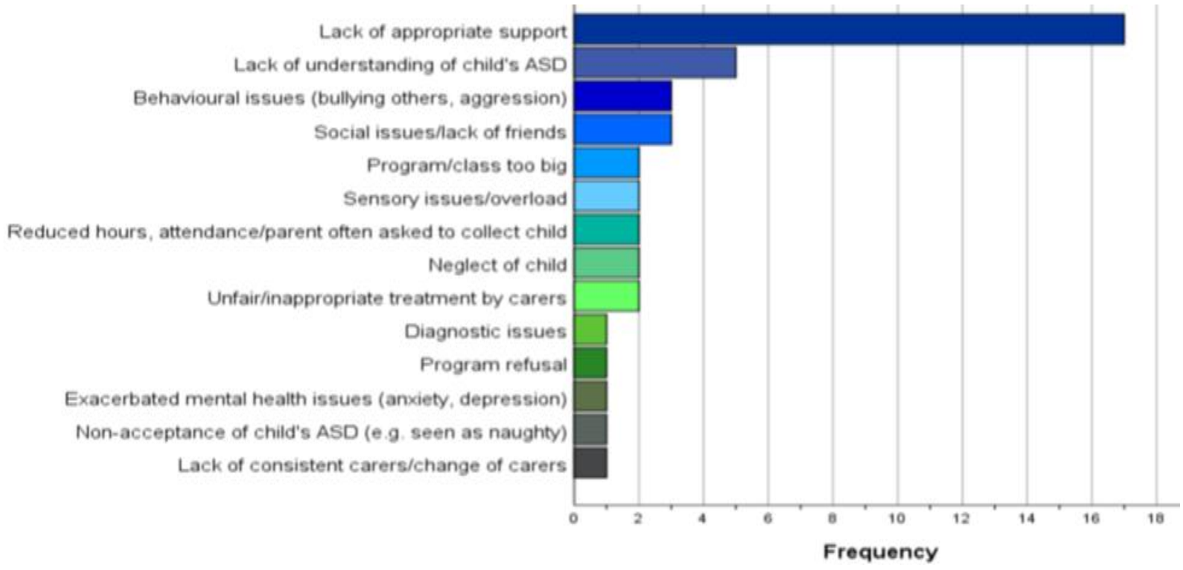
"My son needs more support as his needs change and become more complex due to the gap in his skill set widening as he gets older."

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:



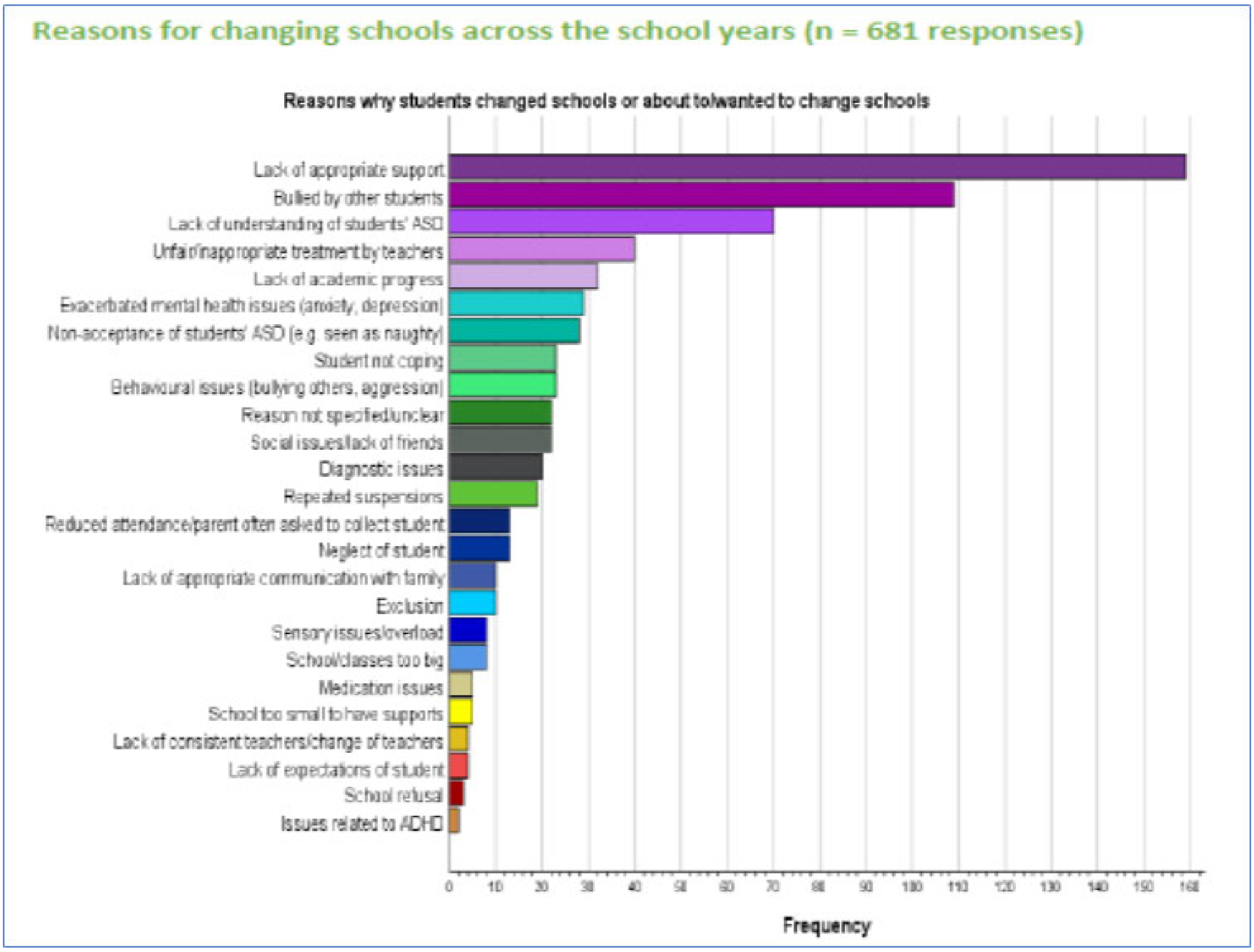
Examples of parents' comments regarding changing early childhood programs:

"[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:

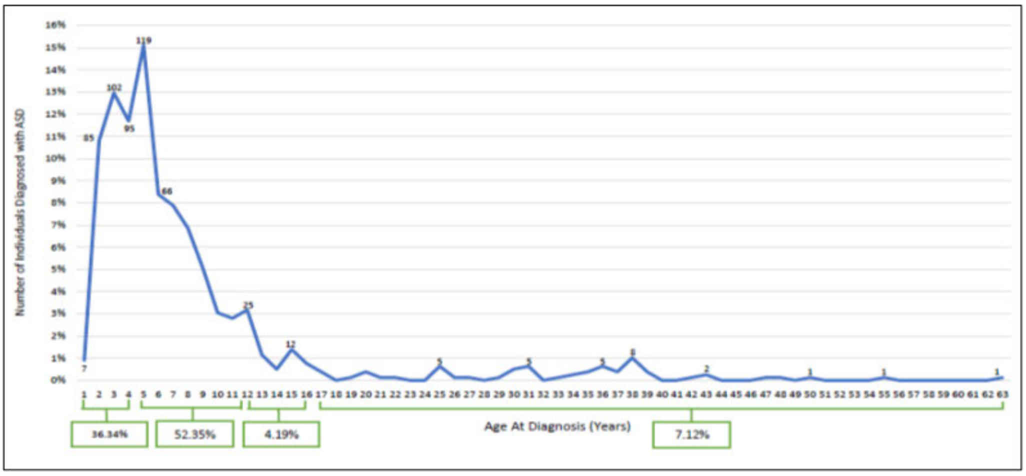

Reasons for changing schools across the school years (n = 681 responses)

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.

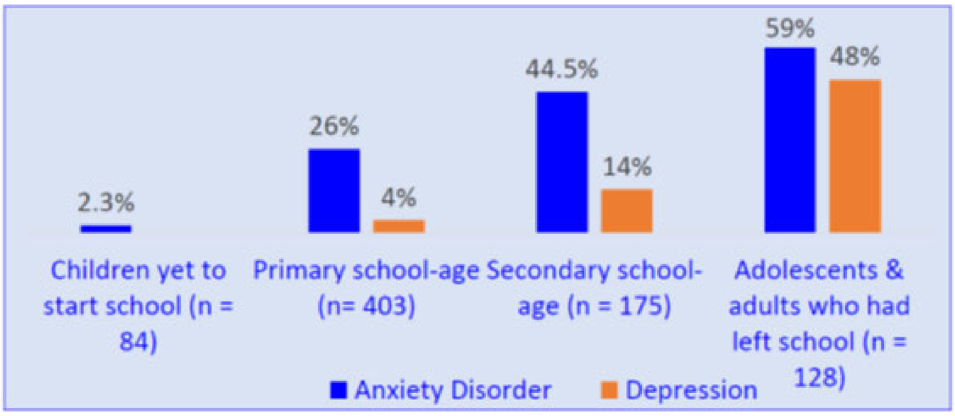
The graph below from Autism Queensland's 2017 *Have Your Say* survey of 790 children and adults on the spectrum, the age of diagnosis peaked at 5 years.



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 Lunsky (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 [redacted]

- ASD level 2
- [redacted]
- [redacted]
- 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 [redacted]

- ASD Level 3
- Speech and language delay with echolalic and learnt scripts as expressive langue.
- 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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