



AMAZE SUBMISSION

**Joint Standing Committee on the NDIS's
inquiry into the provision of services
under the NDIS Early Childhood Early
Intervention Approach.**



August 2017

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Summary of Recommendations

- I. The NDIA access and examine the existing Helping Children with Autism program data (2008 – 2016) held by the Department of Social Services to inform future modelling and planning of the NDIS ECEI approach.
- II. The NDIA consult and work in partnership with the autism community (individual autistic people, autism researchers and autism organisations) in its ongoing development and implementation of the NDIS ECEI approach.
- III. ECEI Access Partners build autism specific expertise relating to identification of early autism signs, diagnosis of autism, all evidence based clinical and therapeutic autism specific interventions and supporting families before and after diagnosis.
- IV. NDIA develop guidelines for NDIA, LAC and ECEI staff regarding the appropriate timing and facilitation of accessing an autism diagnosis for participants or ECEI participants presenting with precursory autism-like traits or autism-like traits.
- V. Ensure that children with an autism diagnosis (or demonstrating autism-like traits presenting to the ECEI) are able to access early intervention in line with evidence based best practice guidelines for autistic children, as soon as possible.
- VI. Removal of the KPI for ECEI providers that only 50% of entrants to the ECEI will be progressed to the NDIA to become a participant.
- VII. The NDIA review its use of PEDI-CAT for children 0 – 7 years of age, and seek sensitive and robust alternatives to the assessment of support needs in young children. If PEDI-CAT is to be the preferred assessment tool utilised by the NDIA, that it utilise the PEDI-CAT (ASD) to measure the adaptive behaviours and functional needs of all young children, particularly those aged 0-7.
- VIII. Development and distribution of accurate, detailed and accessible information on the NDIS ECEI and evidence based therapies, specifically in relation to autism. These resources should be developed for a number of different audiences, including autistic parents/carers, CALD communities and Aboriginal and Torres Strait Islander populations. The development of such resources should occur through co-design with autistic people.
- IX. Further investment in peer networks and pre-planning support, drawing on successful experiences funded through the DSO program.
- X. The NDIA ensure that ECEI participant packages of supports are developed in line with the current evidence base.
- XI. The NDIA access existing data from DSS and Autism Specific Early Learning Centres to build upon its evidence and inform its approach to determining the service needs of children accessing early intervention.
- XII. Australian governments and the NDIA consider block funding for services in regional areas, as well as innovative service delivery methods such as tele-health models, to mitigate potential market failure in the short term.

- XIII. Australian governments and the NDIA ensure all ECEI service providers have a strong knowledge of, and ongoing training in, autism and the support needs of autistic children and their families.
- XIV. The NDIA utilise HCWA and Better Start data to inform its market knowledge.
- XV. Australian governments fund selected DSO's to provide post planning support to participants of all ages and their families, as well as peer support.

What is autism?

“If you’ve only met one person with autism, you’ve only met one person with autism”.
Dr Stephen Shore

Autism Spectrum Disorder (or ASD) is a neurodevelopmental condition with symptoms that may appear early in life. Amaze uses the terms “the autism spectrum” and “autism” to refer to this group of conditions. The term “spectrum” is used to describe the range of characteristics and abilities found in autistic people, as well as developmental changes, such as improvement in language ability, which might occur over time in an autistic person.

Autism is not a disease. People are born autistic. It is a lifelong condition and there is no cure, but the way it affects people may change over time as a person grows and matures. Approximately 1% of the population is autistic. Currently, four times as many males are diagnosed than females, but the number of autistic females is increasing.

Every autistic individual is different, but these features are present in some form: challenges in communication and interaction; sharing interests and emotions; using and understanding non-verbal communication; making friends and adjusting behaviour to different social situations; repetitive speech and behaviour; interests that are very intense or narrow in focus; and a need for predictability and routine.

Autism may be present with other conditions and it is important to understand the implications of this for each person. For example, an autistic person may also be diagnosed with an intellectual disability, language delay, epilepsy, Attention Deficit Hyperactivity Disorder, anxiety, depression and/or other mental health conditions. Furthermore, no two autistic people are alike. In practical terms this translates into each person having diverse needs for support in different areas of daily life to enable them to participate and contribute meaningfully to their community.

Currently autism represents 28.3% of NDIS participants, the largest single diagnostic group within the Scheme.¹ Whilst autism impacts everyone differently, recent ABS data shows that 64.8% of autistic people have severe or profound disability that requires support.²

¹ NDIA 2nd Quarterly Report to COAG 2016-17 Q2, <https://www.ndis.gov.au/about-us/information-publications-and-reports/quarterly-reports>

² ABS (2017). Autism in Australia, 2015. Available at:

<http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0Main%20Features752015?opendocument&tabname=Summary&prodno=4430.0&issue=2015&num=&view=>

About Amaze

Amaze is the peak body in Victoria for autistic people and their supporters. Amaze is a member-based not-for-profit organisation established in 1967 that represents around 55,000 autistic Victorians.

In 2015 Amaze launched its Strategic Directions to 2040 – a 25 year plan to achieve social impact where society respects every autistic person and they have real opportunities to participate and contribute. To achieve this, our three main goals are to:

- Increase community awareness and understanding of autism;
- Improve attitudes and behaviours towards people on the autism spectrum;
- Create more opportunities for people on the autism spectrum to participate and contribute to society in meaningful ways.

Amaze operates under a number of principles that guide our work and underpin our decision making. They are:

1. **Autistic People at the Centre** – We embody the motto “nothing about us without us”. We act as a facilitator to ensure the voices and needs of autistic people and their families/supporters are heard in the wider world. We actively engage with autistic people and their supporters to inform our priorities, how our organisation is governed and operates, and how we design and deliver our activities. We actively work to improve attitudes and behaviours towards autistic people and their families/supporters.
2. **Collaboration and Partnership.** We recognise that we cannot achieve our social impact goals alone and so we actively seek out like-minded people and organisations as partners.
3. **Courage and Independence** – We condemn any discrimination and ableism used to stigmatise or invalidate the life experience of autistic people. Whilst we adopt a practice of partnership, the needs of autistic people and their families will always come first, and we will speak out and challenge any government or organisation’s policy or practice that compromises autistic people.
4. **Evidence based** – We seek data and evidence to underpin decision making and we measure the outcomes of our work wherever possible. We advocate for greater collection of and accessibility to, data from public institutions that measure and track outcomes for autistic people and result in greater accountability.

Introduction

Amaze welcomes the opportunity to provide a submission to the Joint Standing Committee on the NDIS's inquiry into the provision of services under the NDIS Early Childhood Early Intervention (ECEI) approach. As the peak body for autistic people and their families in Victoria, this inquiry presents an important opportunity to highlight the current issues facing autistic children and their parents/carers as they transition to, and continue to access supports, through the NDIS ECEI pathway.

This submission demonstrates Amaze's support for the establishment of the NDIS ECEI approach to enable children to receive early intervention before decisions on eligibility to the broader scheme are made, ensuring immediate access to an NDIS plan for those with significant and long term disabilities such as autism. Given autism is a lifelong disability, Amaze is concerned to ensure that: autism is diagnosed as early as possible; autistic children are able to access evidence based early intervention in line with evidence based best practice guidelines for autistic children; and autistic ECEI participants can transition easily and without delay into the full scheme when appropriate.

The direct lived experience of autistic people and their families is at the centre of everything we do at Amaze. Our submission is therefore guided by our community's experience of the NDIS to date, and Amaze has proactively sought feedback from parents and carers of NDIS ECEI participants to inform this submission.

1. Consultation with the Victorian autism community

Amaze enjoys the benefits of an actively engaged Victorian autism community (individuals, families, careers, service providers and researchers) through which we directly communicate with more than 18,000 people fortnightly through our e-newsletter e-Spectrum, along with over 16,000 people daily through our social media outlets. The direct lived experience of autistic children, their families and carers is central to this submission.

To inform this submission, Amaze undertook a survey (26 July to 6 August 2017) of parents and carers of NDIS ECEI participants. This survey aimed to capture their experiences, hear directly about the issues they are facing and understand how they would like to see them to be addressed ("Amaze ECEI survey, 2017"). Taking into account the limited time available for consultation we received a response to our survey of 25 valid responses. A mix of qualitative and quantitative data was obtained through the survey which is documented throughout this submission.

Community feedback obtained through previous surveys of our community, our Autism Information Advisor service, Early Days workshops and work as a Disability Support Organisation (DSO) has also informed our response. In particular, in March 2017 we surveyed our community's broader experiences of the NDIS to inform our response to the Productivity Commission's NDIS Costs inquiry. We received 150 responses from autistic people and their families and the mix of qualitative and quantitative data obtained has also informed this submission.³

³ The results of this survey are outlined in detail in Amaze's submission to the Productivity Commission's NDIS Costs Inquiry – Issues Paper, available at http://www.pc.gov.au/_data/assets/pdf_file/0012/216030/sub0160-ndis-costs.pdf

Amaze is proud to have once again successfully engaged the Victorian autism community in the development of this submission. Giving voice to the views, opinions and experience of autistic people and their families and carers is central to our purpose.

2. The eligibility criteria for accessing the NDIS ECEI pathway

(a) Autism and the ECEI pathway

Autism is the largest single diagnostic group of NDIS participants (28.3%), with this being significantly skewed towards 0 – 7 years olds, as shown from data gathered from South Australia (47%) since 2013 and the Nepean Blue Mountains (49%) since 2015.⁴

There has been significant public discussion over the past 18 months led by certain media outlets, about the higher than expected number of autistic participants entering the scheme, including younger participants entering via the ECEI pathway. The quantum of autistic participants into the scheme has not been of surprise to Amaze, especially in the 0-7 age cohort for a number of factors; global trends in autism prevalence rates have been increasing over the past decade (and Australia is aligned with these increases) and our experience in delivering the Autism Adviser service for the Helping Children with Autism (HCWA) program has seen similar numbers access this program since 2008.⁵

We are concerned that there has been a lack of consultation by the NDIA with the autism community, autism experts and the Department of Social Services in the development and implementation of the NDIS ECEI gateway. Amaze is Victoria's peak autism body, yet it was not consulted. Furthermore, data collected from the HCWA program by the Commonwealth Department of Social Services (DSS) has not been analysed and incorporated to forecast anticipated participant's numbers for the NDIS ECEI approach. For example, the ECEI tender documents released on behalf of the NDIA in August 2016 contained projected numbers of children likely to enter the NDIS ECEI pathway, disaggregated by NDIS regions. These projections were extremely low, when compared to our analysis of DSS HCWA data. For example, HCWA data analysis shows that when the NDIS rolls out in the Inner East Melbourne region there will likely be 973 existing HCWA participants ready to be transitioned into the NDIS ECEI in that region. Yet projections in the ECEI tender documents were that only 1,736 participants would enter the NDIS ECEI in the Inner East Melbourne region between October 2017 and June 2018. Existing HCWA participants alone equate almost 50% of this projection. Taking into account children with new diagnosis of autism not yet accessing HCWA, children requiring early intervention whilst awaiting diagnostic assessment, children with developmental delays and children with other disabilities, this projection is clearly too low and leads to broader concerns about the funded capacity of the ECEI to meet demand now and into the future.

We therefore urge the NDIA and DSS to have strong regard to the HCWA data, collected since 2008, as it provides a significant opportunity to develop baseline data of children diagnosed with autism under 7 across Australia and for the scheme to plan appropriately, for both the purpose of scheme transition to ascertain the current level of 'stock', along with identifying the level of newly diagnosed children who will enter the scheme, or 'flow'. This will provide greater insights for the NDIA to establish anticipated costs associated with autism.

⁴ NDIA 12th Quarterly Report to COAG 2015-16 Q4, <https://www.ndis.gov.au/about-us/information-publications-and-reports/quarterly-reports>

⁵ Randall M, Sciberras E, Brignell A, Ihsen E, Efron D, Dissanayake C, Williams K. Autism spectrum disorder: Presentation and prevalence in a nationally representative Australian sample. *Australian & New Zealand Journal of Psychiatry*. 2016 Mar;50(3):243-53

We also encourage the NDIA to consult and work in partnership with the autism community, including autism peak bodies and experts, autistic people and their families/carers and the broader community into the future.

Recommendation:

- The NDIA access and examine the existing Helping Children with Autism program data (2008 – 2016) held by the Department of Social Services to inform future modelling and planning.
- The NDIA consult and work in partnership with the autism community (individual autistic people, autism researchers and autism organisations) in its ongoing development and implementation of the NDIS ECEI approach.

(b) Eligibility criteria and autism diagnosis

We understand that the NDIS ECEI approach is intended to provide a ‘gateway’ for children aged 0 – 6 to the NDIS, so that only children that meet the NDIS eligibility criteria eventually become participants of the scheme.

Amaze is satisfied that the early intervention entry requirements within the *NDIS Act 2013* and List D of the *NDIS Operation Guidelines* are adequate to ensure eligibility for those children, either with a formal diagnosis of autism or showing the initial signs of autism. The application of List D reduces the burden of assessments for families and recognises the individual and community wide benefits of early intervention for children experiencing the 130 identified conditions, including autism and global developmental delay. List D ensures that children are able to enter the scheme as soon as possible and receive supports immediately from an ECEI Partner.

There are clear benefits for children who are showing signs of developmental delay entering ECEI and receiving services that previously weren’t available to them. However, if a child is also presenting with obvious precursory autism-like traits or autism-like traits it will be critical to seek a diagnosis of autism, either prior to, or after, entry into the Scheme, to ensure that an autism specific package of supports is put in place quickly so intensive early intervention is not delayed.

Given the high number of children in the 0-7 age cohort with an autism diagnosis (average of 50% of participants in the South Australian and Nepean Blue Mountains 0-7 aged based trial sites), along with Amaze’s access to the HCWA data for Victoria as outlined above, it is reasonable to anticipate that a significant percentage of children entering the ECEI will have a diagnosis of autism, precursory autism-like traits or autism-like traits without a formal diagnosis.

It is therefore vital that ECEI Access Partners have a significant level of autism specific experience relating to identification of early autism signs, diagnosis of autism, all evidence based clinical and therapeutic autism specific interventions and have the capacity to support families before and after diagnosis. Once the signs of autism are apparent to skilled and trained ECEI staff, there should be no delay in a diagnosis being facilitated with assistance from their ECEI partner and specific interventions and supports being accessed to maximise the child’s developmental trajectory.

In addition, there should be no delay of entry into the NDIS for children who require a higher level of support than can be provided by the ECEI. The potential for this delay was identified

in the ECEI tender documents, which outlined a number of KPI's that ECEI partners must report against. The KPI's included a monthly target that 50% of children would have an NDIS plan approved – it is concerning that a target would be set within an entitlement based scheme, and we are concerned about how this will affect practices of ECEI partners.

In the case for autistic children, delay in accessing a full suite of evidence based interventions specific for that child can severely limit their developmental trajectory – and therefore increase lifetime costs for the NDIS.⁶ We therefore recommend that the NDIA remove the KPI for ECEI providers that only 50% of entrants to the ECEI will be progressed to the NDIA to become a participant.

Recommendations:

- ECEI Access Partners build autism specific expertise relating to identification of early autism signs, diagnosis of autism, all evidence based clinical and therapeutic autism specific interventions and supporting families before and after diagnosis.
- NDIA develop guidelines for NDIA, LAC and ECEI staff regarding the appropriate timing and facilitation of accessing an autism diagnosis for participants or ECEI participants presenting with precursory autism-like traits or autism-like traits.
- Ensure that children with an autism diagnosis or demonstrating autism-like traits presenting to the ECEI are able to access early intervention in line with evidence based best practice guidelines for autistic children as soon as possible.
- Removal of the KPI for ECEI providers that only 50% of entrants to the ECEI will be progressed to the NDIA to become a participant.

⁶ Prior M, Roberts J, Roger S, Williams, K & Sutherland R (2011). A review of the research to identify the most effective models of practice in early intervention of children with autism spectrum disorders. Australian Government Department of Families, Housing, Community Services and Indigenous Affairs, Australia; Roberts J, Williams K (2016). Autism Spectrum Disorder: Evidence-based/evidence-informed good practice for supports provided to preschool children, their families and carers. Commissioned and funded by the NDIA. February 2016

3. The service needs of autistic participants receiving support under the ECEI pathway.

(a) The importance of intensive early intervention for autistic children.

As emphasised by the Victorian Parliament in its recent Final Report on ASD, the NDIA must ensure that children with an autism diagnosis or demonstrating autism-like traits presenting to the ECEI are able to access early intervention in line with evidence based best practice guidelines for autistic children, and as soon as possible.⁷

Autism, at its very core, impacts every autistic child differently. However, as autism currently accounts for almost 1 in 3 NDIS participants, there is merit in the Scheme having an 'autism specific' response to provide efficiencies in how the scheme works for autistic individuals and provide for their specific needs.

Systematic reviews of the evidence clearly demonstrate that intensive early intervention support for autistic children is key to increasing their developmental trajectory over their lifetime, allowing them to be as independent as possible and participate to their full potential in education, employment and their community.⁸ By providing autistic NDIS ECEI participants with evidence based supports as early as possible in their life time, the long term support costs for the NDIS (and via other government supports) will also be significantly decreased. Scarce resources must not be wasted on supports that will not produce optimal outcomes.

The evidence demonstrates the importance of ensuring that a participant accesses not only the most appropriate types of therapies, but also the most appropriate frequency/intensity of therapies (20 hours per week), in line with evidence based best practice guidelines for autistic children. For example, see:

- Roberts J, Williams K (2016). Autism Spectrum Disorder: Evidence-based/evidence-informed good practice for supports provided to preschool children, their families and carers. Commissioned and funded by the NDIA. February 2016; and
- National Guidelines, Best Practice in Early Childhood Intervention, Early Childhood Intervention Australia. April 2016.

Adherence to these guidelines is also essential to ensuring that the quality of services provided meet the necessary standards for services delivering early intervention. We also want to ensure that those providing early intervention to autistic children have autism specific experience.

As discussed below in section 4(b) of this submission, we are concerned that many NDIS ECEI participant are not receiving packages of supports in line with the evidence of best practice.

⁷ Victorian Parliament 2017. Inquiry into Services for People with Autism Spectrum Disorder - Final Report. Family and Community Development Committee. Available at <https://www.parliament.vic.gov.au/fcdc/article/2588>.

⁸ Prior M, Roberts J, Roger S, Williams, K & Sutherland R (2011). A review of the research to identify the most effective models of practice in early intervention of children with autism spectrum disorders. Australian Government Department of Families, Housing, Community Services and Indigenous Affairs, Australia; Roberts J, Williams K (2016). Autism Spectrum Disorder: Evidence-based/evidence-informed good practice for supports provided to preschool children, their families and carers. Commissioned and funded by the NDIA. February 2016

(b) Functional assessment tools

Assessment tools used to measure the adaptive behaviours and functional needs of NDIS ECEI participants must be valid, reliable, accurate and efficient. There is evidence that the commonly used assessment tools, such as the Paediatric Evaluation of Disability Inventory - Computer Adaptive Test (PEDI-CAT) and World Health Organization Disability Assessment Schedule 2.0 (WHODAS), may not be providing a valid, reliable or accurate measure of the nature, frequency and intensity of young autistic children's diverse support needs (particularly between the ages of 0 to 5) and indeed, may be providing a barrier to young autistic children accessing the levels and types of early intervention they require, via the ECEI pathway.⁹ As recognised by the Productivity Commission in its NDIS Costs Position Paper 2017, these tools may also be skewing the NDIA's data and wrongly suggesting that 40% of children entering the scheme do not have substantial functional deficit relative to their peers.

If PEDI-CAT continues to be the NDIA's recommended assessment tool, in order to mitigate against the tool's flaws in functional assessment in young autistic children, research suggests that the PEDI-CAT, modified for autism spectrum disorder (PEDI-CAT (ASD)), is likely to be a more efficient and sound assessment tool for this group.¹⁰ The PEDI-CAT (ASD) is yet to be validated, however, particularly in our Australian population. We propose that no single functional measure captures the range of difficulties that young autistic children can present with now, or in the future, and thus caution should be taken with usage of any assessment tool to measure support needs.

Recommendations: The NDIA review its use of PEDI-CAT for children 0 – 7 years of age, and seek sensitive and robust alternatives to the assessment of support needs in young children. If PEDI-CAT is to be the preferred assessment tool utilised by the NDIA, that it utilise the PEDI-CAT (ASD) to measure the adaptive behaviours and functional needs of all young children, particularly those aged 0-7.

⁹ Coster W et al 2016. Evaluating the appropriateness of a new computer-administered measure of adaptive function for children and youth with autism spectrum disorders. *Autism*. Vol. 20(1), 14 – 25; Kao YC et al 2012. Comparing the functional performance of children and youth with autism, developmental disabilities, and without disabilities using the revised Paediatric Evaluation of Disability Inventory (PEDI) Item Banks. *Am J Occupational Therapy*. 2012; 66(5): 607 – 616.

¹⁰ Ibid. For further information, see www.pedicat.com.

4. Experiences of autistic participants and their families/carers, accessing the ECEI pathway

"The planner that was assigned to us was great. Her understanding of my son's ASD needs and supports was great. I felt very lucky that we were assigned to her. Other families we know with similar ASD needs to my son had different experiences which was sad to hear. There should be consistency across all applications"

"Communication from planners is lacking. Education for parents is lacking. The whole process is massively overwhelming".

"I have no idea where we even are in the process. We have been assessed as suitable months ago and that's it."

Responses to Amaze's ECEI Survey, 2017

A quality NDIS ECEI gateway and planning process is key to achieving short and long term positive outcomes for young autistic participants. By investing in a quality NDIS ECEI gateway and planning process now and ensuring autistic children receive cost-effective supports, their lifetime outcomes will be significantly improved, together with the financial stability of the scheme. The social and economic costs of autism will also be reduced, and unlock greater economic return through improved workforce participation and greater independent living.

The feedback we have received from the autism community regarding their experiences in accessing the NDIS ECEI pathway varies greatly, with many parents and carers reporting that the pathway was easy to navigate and that they are satisfied with their child's plan. Many describe it as life changing. However we equally hear from many parents and carers of NDIS ECEI participants who are frustrated by the system, have experienced significant delays in accessing the scheme and/or a plan, have experienced gaps in accessing ECIS services and/or who are highly dissatisfied with the planning process and/or their child's plan.

Responses to Amaze's ECEI survey 2017 demonstrate this divergence in experiences. For example:

- 60% of respondents rated their experience of accessing the NDIS via the ECEI pathway as neutral, difficult or very difficult, while 44% rated their experience as easy or very easy (12% rated it is "other");
- 46% rated their planner's understanding of autism as moderate to low and 31% rated their understanding as high to very high (with the remainder unsure/not applicable);
- Of the respondents that had met with an Early Childhood Partner when accessing the NDIS ECIA pathway, 50% identified their Early Childhood Partner's knowledge of autism as high and 50% identified their Early Childhood Partner's knowledge of autism as moderate to low;
- 36% of respondents reported incurring costs to access the NDIS ECEI pathway (i.e. costs in relation to initial diagnosis, providing evidence of reasonable and necessary supports.). One respondent reported incurring a total of \$1200 of paediatrician reports;

- 9% of respondents reported that the timeframe between lodging an application to access the NDIS ECEI pathway and eventually receiving a plan was 1 to 2 weeks, 27% of respondents reported this timeframe was 3 – 4 weeks, a further 27% reported 1 to 2 months followed by another 27% that reported 3 to 6 months, with the final 9% reporting that the timeframe was more than 6 months.

This divergence in views suggests a lack of consistency across regions, Early Childhood Planners and planners. It also suggests that while parents and carers capable of navigating the system and providing evidence of their child's disability and functional needs may achieve a positive outcome through the NDIS ECEI pathway, those that do not have the resources or capacity to navigate the system are often left confused and wanting.

The results of Amaze's ECEI survey 2017 largely reflect those of Amaze's broader survey of NDIS participants (n=150), conducted in March 2017, to inform our response to the Productivity Commission's NDIS Costs inquiry. This survey demonstrated participants frustration with inconsistent approaches to planning and information provision, as well as the amount and types of services funded.¹¹

(a) The adequacy of information for potential ECEI participants and other stakeholders

"The support received from Amaze (Pam Gatos) prior to the NDIS planning meeting was really helpful and made the process much smoother. I was well prepared with all the necessary information so that the planner could understand my son's situation better right from the start of the meeting"

"...It appears that if you are a good advocate, you can get a lot more NDIS funding for your child (as per my discussion with other parents at my child's school). I feel strongly that this is unfair, not every family or carer has the ability to advocate"

"I was overwhelmed by the NDIS roll out..."

"I sought my own advice sessions"

Responses to Amaze's ECEI survey, 2017.

In response to Amaze's ECEI survey, 2017, 52% of respondents reported that they found the information for families and carers of potential NDIS ECEI participants to be inadequate.

Parents and carers of ECEI participants need consistent, clear and accessible information about the NDIS ECEI pathway and the planning process, including how to prepare for it, the questions that will be asked, the criteria for supports and plan implementation. The level of advice provided prior to planning meetings by Early Childhood Partners can depend on their knowledge of both the NDIS and autism. The information provided during planning meetings can be inconsistent and/or (particularly in the case of autistic parents of ECEI participants) difficult to process quickly in that environment. Similarly, for people from non-English speaking backgrounds there is a lack of culturally or language appropriate information.

¹¹ For more information, see Amaze's submission to the Productivity Commission's NDIS Costs Inquiry – Issues Paper, available at http://www.pc.gov.au/data/assets/pdf_file/0012/216030/sub0160-ndis-costs.pdf

While a well-resourced parent or carer may be able to seek out information on-line, this information is not always clear and concise, nor is it presented in an “autism-friendly” way for autistic parents. It is very general and does not provide clear and specific advice about what to expect during a planning meeting or how the NDIA will determine whether a support requested will be considered “reasonable and necessary”. Common experiences reported to Amaze involve the use of bureaucratic or jargonistic language and the need to search through large amounts of information.

Consistent and relevant information should be provided to all parents and carers prior to planning meetings to enable them to read it, process it and be prepared to ask questions. Not only would this maximise the validity and reliability of information given during a planning meeting, and the plan subsequently developed, it would also increase the efficiency of a meeting, enabling parents and carers to focus on the individual needs of their children rather than being overwhelmed by new information. As recognised by the Victorian Parliament in its Final report on autism services, clear information is also required on evidence based therapies, particularly in the ECEI pathway.¹²

To support autistic parents to navigate the system, autism specific information, delivered in an “autism friendly” way is also required. A trusted, independent and experienced organisation should be commissioned to develop these resources for the autism community – in partnership with government and the NDIA to ensure accuracy of information, and also utilising a methodology of co-design with autistic people to ensure the utility of the end products. Ongoing investment in information that is accessible to culturally and linguistically diverse communities and Aboriginal and Torres Strait Islander populations will also be required.

However, it must be emphasised that information resources on their own will not be enough, many parents and carers will be better supported through face to face pre planning workshops where they can engage in active conversations and be guided by peers and experts. Ongoing funding is therefore required for Disability Support Organisations (DSO) to provide pre-planning support, including specialised and peer support for autistic parents and carers.

Through Amaze’s work as a DSO over the last 24 months, we have observed the significant benefits our facilitated pre-planning sessions provide to autistic people and their families. The overwhelming feedback from workshop participants is that our workshops have been vital in enabling them to meaningfully participate in their child’s planning meeting. Having support from peers through these workshops, including those who were further along in the planning process, was also considered extremely valuable.

Recommendation:

- Development and distribution of accurate, detailed and accessible information on the NDIS ECEI and evidence based therapies, specifically in relation to autism. These resources should be developed for a number of different audiences, including autistic parents/carers, CALD communities and Aboriginal and Torres Strait Islander populations. The development of such resources should occur through co-design with autistic people.

¹² Victorian Parliament 2017. Inquiry into Services for People with Autism Spectrum Disorder - Final Report. Family and Community Development Committee. Available at <https://www.parliament.vic.gov.au/fcdc/article/2588>. P. 126

- Further investment in peer networks and pre-planning support, drawing on successful experiences funded through the DSO program.

(b) The adequacy of services funded under the ECEI pathway;

"The NDIS plan has made the most amazing difference to our family. My son is very well supported and has taken enormous leaps this year, I (his mother) have been able to increase my working time and am now starting my own business in the disability sector. It has been truly life changing for us".

"We wanted to join a small group but plan only allowed individual therapy"

"Need dietician related to my child's disability. Need sensory equipment which is not funded by NDIS"

"I estimate that the funding is 40% to 50% below requirements"

"Not really flexible. The planners only represent NDIA, they are not ECEI who know my child better"

"The Planner does not respond to queries about my child's plan, the NDIA refuses to fund sensory equipment that would make a big difference to my child's behaviour. Planner informed that NDIS would not cover dietician, however other parents who have children on the spectrum have told me that have managed to get dietician funded through NDIS!"

Responses to Amaze's ECEI Survey, 2017

In response to Amaze's ECEI survey, 2017, only 57% of respondents reported that they were satisfied that their plan allowed access to the *types of services* necessary to meet the early intervention support needs of their child. Similarly, only 54% of respondents felt satisfied that the *amount of funding* provided was adequate to meet their child's early intervention support needs.

We are concerned by feedback that there are vast inconsistencies in the amount and types of services funded for NDIS ECEI participants with similar needs. We are also concerned that in order to curb total package size, certain intensive, yet evidence based therapies are not being considered for inclusion in participant's plans. As above, we acknowledge that every autistic child has varied needs and requires an individualised package of supports – but this should not rule out certain evidence based interventions given their sizable cost. Furthermore, this practice is contrary to the foundational insurance principles that underpin the scheme of investing early to increase a participants economic, social and community participation along with increasing long term scheme costs.

As raised above, we are concerned that existing data and evidence gained from DSS funded early intervention services in recent years has not informed the NDIA's approach. For example, the DSS has been funding Autism Specific Early Learning Centres around the country since 2010 and these centres have undertaken significant research and recorded and analysed a substantial amount of data on the outcomes of children attending these centres. We would query the extent to which the NDIA has sought to utilise this data or applied the vast learnings and research in the development and implementation of the NDIS ECEI approach.

Recommendations:

- The NDIA ensure that ECEI participant packages of supports are developed in line with the current evidence base.

- The NDIA access existing data from DSS and Autism Specific Early Learning Centres to build upon its evidence and inform its approach to determining the service needs of children accessing early intervention.

(c) Choice, control and access to services via the NDIS ECEI pathway

“It has been difficult to access service providers due to so many other families needing these services as well”

“Just started looking, most (service providers) have wait lists”

“We went with Melbourne City Mission who put us on a waitlist for services for each service”

“No one knows what’s going on.. my nonverbal severely autistic son went 2 years with no ECIS as on NDIS wait list yet NDIS say they don’t know ECIS put us on their list? We broke a family - went bankrupt and now being treated for depression and can barely leave the house anymore, The system failed us big time and has caused heaps of damage”

Responses to Amaze’s ECEI survey, 2017.

In response to Amaze’s ECEI survey 2017:

- 60% of respondents reported that they felt confident they could implement their plan in the 12 month period, while 30% reported feeling slightly confident or not confident, and 10% unsure.
- 10% of respondents reported that their child’s plan enabled them to increase their choice and control over supports to “a great extent”, with 55% reporting that the plan would increase their choice and control “somewhat” and 30% reporting that it would increase their choice and control very little or not at all.
- 76% of respondents reported they had been able to find service providers to deliver services and supports under their plan, while 14% of respondents reported they could not.

Significant growth in the disability service sector will be necessary to meet anticipated demand of ECEI services if the fundamental NDIS principle of choice and control of services by people with disability to be achieved. Given the rapid intake of NDIA ECEI participants over the next few years as full roll out is achieved, there is a need for a concentrated effort by Government to stimulate growth in the skilled disability workforce.

In particular, accessing services in regional and remote locations for autistic children is very difficult, with people often reporting to Amaze having to travel many hours to access specialist services, and often only if they have the means to pay for them privately. This issue will be exacerbated within the NDIS in a purely market based model, especially for highly skilled staff such as early intervention practitioners in regional locations, with the clear potential for market failure leaving autistic people without services. This is a major issue and Amaze recommends that the Victorian Government and the NDIA investigate alternative methods, such as an element of block funding for services in regional areas, to mitigate potential market failure in the short term.

Emerging research supports the efficacy of delivery of therapeutic services to remote locations via videoconferencing facilities that can be accessed within people’s homes.

Amaze recommends further investigation into the potential of these innovative service delivery methods, such as utilising telehealth models.

There is also a need to ensure a level of quality in ECEI Partners and service providers that will provide ECEI services through the NDIS. The provision of a wide range of early intervention support requires a skilled workforce that has a specific understanding of autism and the support needs of autistic children and their families. Autism specific training and capacity building should be available to all registered providers of supports. Not only will this enhance the quality of services received by autistic children through the ECEI approach, but within a market based system of disability supports, it will provide a competitive advantage to disability service organisations that undertake this training.

Finally, it is clear that the NDIA has not utilised HCWA or Better Start data analysis to inform its market knowledge, i.e. to develop a picture of services that were available and utilised under these models and any identify gaps in services across regions. Where ECEI packages are not being fully utilised, this data could help inform the NDIA's understanding of services available in relevant regions. Urgent steps are also required to ensure that no child falls through the gap or loses access to ECIS services while waiting for NDIS services in their region.

Recommendations:

- Australian governments and the NDIA consider block funding for services in regional areas, as well as innovative service delivery methods such as telehealth models, to mitigate potential market failure in the short term.
- Australian governments and the NDIA ensure all ECEI service providers have a strong knowledge of, and ongoing training in, autism and the support needs of autistic children and their families.
- The NDIA utilise HCWA and Better Start data to inform its market knowledge.

(d) Post planning support for parents and carers of NDIS ECEI participants.

Amaze regularly receives inquiries from parents and carers that have an NDIS or NDIS ECIS plan and do not know what to do next. Many do not understand their plan, the services they may access or how to find an appropriate service provider. Many are frustrated that they have been unable to obtain adequate post planning support from the NDIA, their planner, their Early Childhood Planner or plan manager and are seeking independent advice.

Accordingly, we are of the view that significant benefits could flow from DSOs and private intermediaries providing ongoing support to participants if they can demonstrate that they have a strong understanding of the NDIS and its scope, as well a strong awareness of appropriate services in a participant's area. DSO's and private intermediaries would also need to be adequately funded to do this work.

Through its Autism Adviser service, Amaze has demonstrated its ability to provide sound, consistent and evidenced based information and support to HCWA recipients in Victoria. A DSO such as Amaze that engages with members of the autism community on a day to day basis could be well placed to provide post planning support, specifically meeting the information and support needs of autistic participants (of all ages) and their families. It could also facilitate valuable autism peer support groups to enable the sharing of plan

implementation experiences, including how to find and arrange supports and how to connect with inclusive community organisations.

Recommendations:

- Australian governments fund selected DSO's to provide post planning support to participants of all ages and their families, as well as peer support.

5. Measuring the effectiveness of the ECEI Approach.

We agree with the observations of the Productivity Commission in its recent NDIS Costs Position Paper that it is too early to tell if the ECEI approach has been successful in upholding the eligibility criteria of the NDIS or contributed to beneficial outcomes for participants. We also agree that its success will be dependent on services outside of the NDIS being available and the management of family expectations about how children's needs may be better met.¹³

We understand that the NDIA has developed an evaluation and monitoring framework for the ECEI approach and that this is aimed at monitoring entry and exit from the NDIS via the ECEI pathway and evaluating the effectiveness of the ECEI approach. As discussed above, outcomes will be maximised for autistic children if provided in line with evidence based best practice guidelines for autistic children. Short, medium and long term goals with frequent assessment of progress will be vital, as will an adequate and well trained workforce to support participants to achieve their goals.¹⁴

Conclusion

We thank you again for the opportunity to respond to the Terms of Reference of your inquiry and look forward to reviewing your findings and recommendations.

If you have any questions arising out of our submission or we can provide further information, please contact Braedan Hogan, Amaze's Manager, Public Affairs and NDIS Transition on (03) 9657 1650 or via email at braedan.hogan@amaze.org.au.

10 August 2017

¹³ Productivity Commission 2017, NDIS Costs – Productivity Commission Position Paper. June 2017. Commonwealth of Australia. Available at <http://www.pc.gov.au/inquiries/current/ndis-costs/position/ndis-costs-position.pdf>

¹⁴ Ibid.