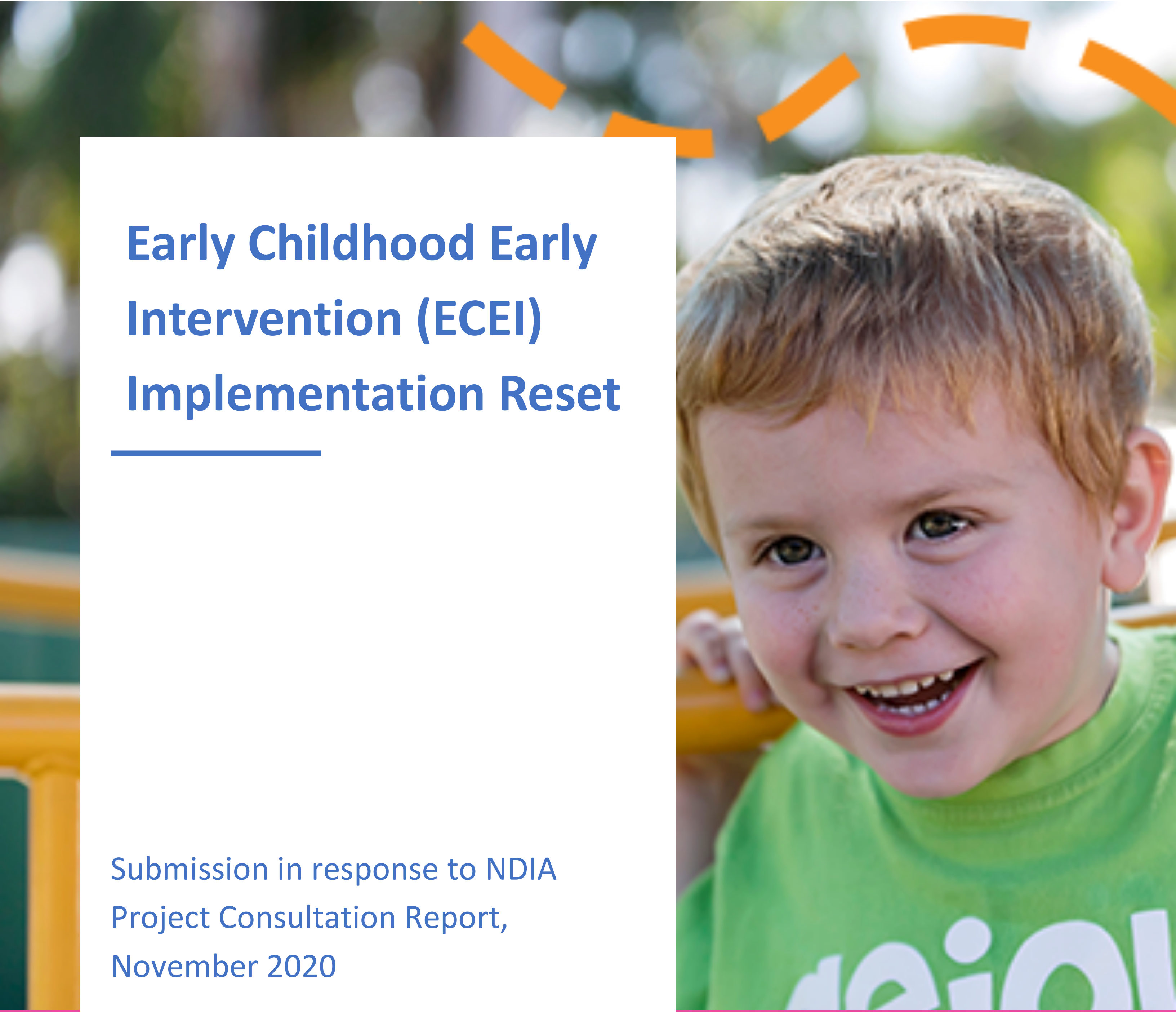


Early Childhood Early Intervention (ECEI) Implementation Reset

Submission in response to NDIA Project Consultation Report, November 2020

AEIOU Foundation for Children with Autism

Monday 22 February 2021
info@aeiou.org.au

aeiou
FOUNDATION
for children with autism

Contents

1.0) Introduction

Thank you for the opportunity to make a submission in response to the ECEI Implementation Reset Project Consultation Report.

AEIOU Foundation is one of Australia's largest providers of autism-specific early intervention, with 10 centres located across regional and south east Queensland and South Australia and another under construction in the ACT, opening July this year. Established in 2005, AEIOU enrols around 300 children aged 2-6 each year. Over the past 15 years, the service has supported thousands of children to develop life skills that support them to engage in everyday life, and participate at home, in the community, at school and in the workforce.

Children are supported by an expert team of clinicians and educators, who share the responsibility of assessing, planning, delivering and evaluating each child's individual plan. Teams are comprised of speech pathologists, occupational therapists, behaviour therapists, teachers and early educators.

Our mission is to enhance the lives of children with autism and their families, through evidence-based, successful early intervention programs and practical support.

We will be sharing this document with AEIOU families and stakeholders through our website and social media, with members of the Senate Select Committee on Autism, and with our fellow members of the Autism Alliance.

2.0) Executive Summary

AEIOU commends the agency for its commitment to continuous improvement as the NDIS matures; like many others in the sector, we support the decision to bring a dedicated approach to the ECEI space. We look forward to working further with the agency and partners in supporting families to help children develop the skills they need to take part in daily activities and achieve the best possible outcomes throughout their life. We appreciate this opportunity to allow our organisation's experience and expertise – and that of the parents and carers we work with – help refine the ECEI Reset in advance of changes being implemented. In this paper, we provide a response for eight of the twenty-three recommendations for your consideration.

We note that one of the issues the Reset seeks to address is that a higher volume of children than expected are progressing through to funded supports, and that children with autism comprise a large percentage of this cohort. We acknowledge the challenges of delivering funds within necessary budgetary constraints; however we also urge the Agency to ensure fairness and adherence to established medical science, in decision-making around access and eligibility.

Reducing spend on professionally delivered, early intervention for children with autism may help budgets to balance in the short term, but it will result in poorer outcomes for individuals and long term greater cost to the taxpayer.

Encouraging more supports to be delivered in a natural setting is a positive step, but it's not the only option in a family-centred approach. We encourage the Agency to consider the longer-term costs of reducing centre-based support as well as the benefits, notably forgone family labour productivity and the mental health implications of a lack of respite for families of children with autism.

We also urge the Agency to reconsider the role of diagnosis in this Reset. As with 'natural settings or clinics', 'IAs or diagnoses' are false binaries: both are helpful and beneficial – how they are balanced should depend on the individual family and their situation. Autism is a permanent condition, comprising both positive and disabling aspects, that will manifest differently in every individual. An autism diagnosis is a critical component in a family's journey of identifying and obtaining the most effective and suitable interventions and supports for their child.

AEIOU believes the single most effective thing the Agency could do to strengthen this important reform is to amend the NDIS Act to include social development in the Section 9 definition of Developmental Delay (b). This would ensure that a child's social skills be considered as part of a decision around developmental delay in accessing funded supports. For children with autism, that decision could literally change their life.

3.0) Response

In this response we shall address relevant Project Consultation Report recommendations individually. Underpinning these responses is a fundamental concern with how the proposed Reset approaches the social development of a child with autism.

3.1) Social development must not only be assessed but used to inform access and planning decisions.

In response to Report Recommendation(s) 13: Clarify the interpretation of the developmental delay criteria under Section 25 of the NDIS Act (2013) to improve the consistency and equity of Agency decision-making. Establish thresholds for key criteria using Independent Assessments.

Currently, children can enter the Scheme under Section 25 (Early Intervention) or s24 (Permanent Disability). The Reset proposes that children should enter the Scheme under s25 (Early Intervention) only. S25 for children has two entry points: through Developmental Delay or by providing a history of disability. This provision of 'disability history' may be impractical for very young children. AEIOU infers that under the proposed reforms, many children with autism will have to access the Scheme under the Developmental Delay criteria, regardless of diagnosis.

Under Section 25 1 (iii) National Disability Insurance Scheme Act 2013, children under 6 seeking access to the scheme under the Developmental Delay definition in the Act (Section 9) will need to be found to have developmental delay that:
…results in substantial reduction in functional capacity… in one or more of the following areas of major life activity:
i. self care;
ii. receptive and expressive language;
iii. cognitive development;
iv. motor development.

Under the Operational Guideline Section 8, children under 7 years seeking to enter under s24 (Disability) will need to first have met the s25 (Early Intervention) requirements before considering the disability requirements:
…substantially reduced functional capacity… in one or more of the following relevant activities:
1. communication;
2. social interaction;
3. learning/mobility;
4. self-care; or self-management (section 24(1)(c).

We draw attention to the fact that **social interaction is included under s24 Disability requirements (Becoming a participant) for substantially reduced functional capacity but not under s25, Furthermore it is not in the definitions in section 9 for Developmental Delay.** This means that if the Act stays as it is, and the current proposed Reset changes proceed, there will be no legal requirement for the social developmental abilities of a child aged 0-6 with autism to be considered as part of an NDIS access decision or level of supports in their plans.

For children with autism, not to have their capacity to develop socially be considered as part of their assessment would be a significant and unfortunate oversight. "ASD is the collective term for a group of neurodevelopmental disorders *characterised by persistent deficits in social communication and social interaction*, and by repetitive patterns of behaviour and restricted interests." (Autism CRC: *A National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorders in Australia*, October 2018).

Encouragingly, consideration of social capacity is included as part of the assessment tools proposed: Pedi-CAT ASD and Vinelands scales. Further information about the weighting of scores would help allay concerns that children with autism do not risk disadvantage under the proposed system.

Further, without an underpinning legal commitment to include the social major life activity area to determine access to the scheme and a plan value for a child with autism families have no assurance that supports will be provided to increase the functional capacity of their child in one of the most challenging features of Autism Spectrum Disorder.

The Productivity Commission's Inquiry Report: Disability Care and Support, 2011 noted:
*In addition to encompassing elements of self-care, communication and mobility, the assessment process should include aspects of learning and applying knowledge, and community and **social participation**. To do otherwise, might mean the support needs of some individuals were systematically overlooked (p 311).*

Should the proposed shift to s25 become the sole Scheme entry option for children, there is a real risk that thousands of children with autism will not receive the kind of supports that the NDIS was established to deliver.

AEIOU Foundation recommends:

To avoid this systemic disadvantage and/or the perception of it, **we strongly urge the Agency to amend the NDIS Act 2013 to include an additional major life activity area - *social interactions* under Section 9 Definitions *developmental delay* (b).** The inclusion of emotional and behaviour aspects would further strengthen the section.

3.2) Independent Assessments and the removal of Lists

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

AEIOU recognises that disability Lists were intended as a temporary measure to facilitate the Scheme's rollout, and that the Agency is proposing a transition towards an ECEI Scheme that prioritises capacity over diagnosis. We believe that functional capacity and clinical diagnosis are *both* critical elements of a child's assessment. Together they provide a stronger picture of an individual's ability; removing the diagnosis component (performed by experts) results in a weaker set of information to inform access and a planning.

We are concerned that the tools proposed for assessment of young children with autism, and or autism symptoms, do not provide sufficient sophistication with which to gauge a child's challenges and progress. The Pedi-CAT measure may provide a baseline of skill as reported by a parent/carer on a given day, but a real risk exists that some children may fall through the gaps due to inconsistent reporting.

We acknowledge that the IA tools have acceptable levels of validity and reliability, in the context of population level research. However, further strengthening of this approach is required to ensure that partners can access high quality observational data and relevant training and development on how to interpret it.

Another area of concern is the potential burden on families in having their child repeatedly assessed for skill and behaviours that an autism diagnosis would negate the need for. Families have also expressed to AEIOU that having their children regularly assessed to determine ongoing eligibility through IAs would be stressful and time-consuming.

AEIOU posed the following question to all parents/carers with children currently enrolled at our centres.

> *"Do you think that young children with autism should undertake annual assessments to determine their eligibility for the NDIS?"*

101 families replied. Two thirds felt an annual assessment was appropriate, but that the assessment should inform progress – not eligibility. The following answers are indicative of their responses:

“I don’t think there needs to be an annual assessment to determine eligibility. It is a life long condition, unfortunately it is not going away. I understand annual funding may need to be reviewed as supports individuals require will vary as they make progress over time however I don't think families should have to prove their child has a life long disability every twelve months to ensure their child will receive the adequate supports.”

“I believe they should be monitored for progress, but I think a full assessment every year is quite overwhelming and invasive.”

“I think assessments are important to see how your child is progressing and improving. But shouldn't determine their eligibility for NDIS. Once they are diagnosed, this should prove eligibility for early intervention. And if they are assessed annually and are improving this shouldn’t stop them from continuing on.”

AEIOU Foundation recommends:

If IAs are to proceed, the disability Lists should remain. Diagnosis matters and is meaningful.

3.3) Independent Assessments, developmental delay and autism

In response to Report Recommendation(s) 13: Clarify the interpretation of the developmental delay criteria under Section 25 of the NDIS Act (2013) to improve the consistency and equity of Agency decision making. Establish thresholds for key criteria using Independent Assessments.

In the Reset, the Agency reflects that many more children than expected have accessed the Scheme through developmental delay and not exited. Subsequently, it proposes revising thresholds that would presumably reduce the numbers of children entering through this pathway. AEIOU seeks assurance for families that decision-making in this area will be based on the clinical diagnostic criteria which already exists for developmental delay. We acknowledge the challenges of economic management of such a large Scheme, but urge the Agency to base decisions on clinical expertise, equity for children, and the needs of families. For one group of children to be denied life-changing support because their disability is more common than another's, would be contrary to the established goals, not to mention the spirit, of the NDIS.

AEIOU seeks clarity around the timeframe of plans which are created through the developmental delay pathway. We are concerned about a scenario in which a family who cannot afford to get a diagnosis for an ASD child approaches their EC partner under the developmental delay criteria, meets the IA cut-off score for access, and then receives a plan with minimal support value and limited time (2 – 3 years?). It would be inappropriate (and potentially harmful) to classify a Level 3 undiagnosed child with autism as having developmental delay, until they can join the Scheme with a permanent disability plan at age 9. If they join the Scheme at age 4 and their plan runs for 3 years – what do they do between ages 7 and 9? Without encouragement for their family to seek a diagnosis, even through a delayed public system – or a record of their disability history over these 'in-between years' - many children on the spectrum could potentially miss out on gaining the right supports at the right time. They would lose the benefits that an early intervention approach is designed to provide.

At AEIOU over the past 24 months, many children have gained access to the NDIS under developmental delay. Using clinical observation, our trained team had determined a high likelihood of autism and commenced early childhood supports. Those children have all gone on to receive an autism diagnosis from paediatric specialists, which has further informed development of their individual plan. Enabling Scheme access through a developmental delay pathway based on current clinical definitions and having information about the child's needs further strengthened by a diagnosis, is a sound foundation for Scheme entry and participation.

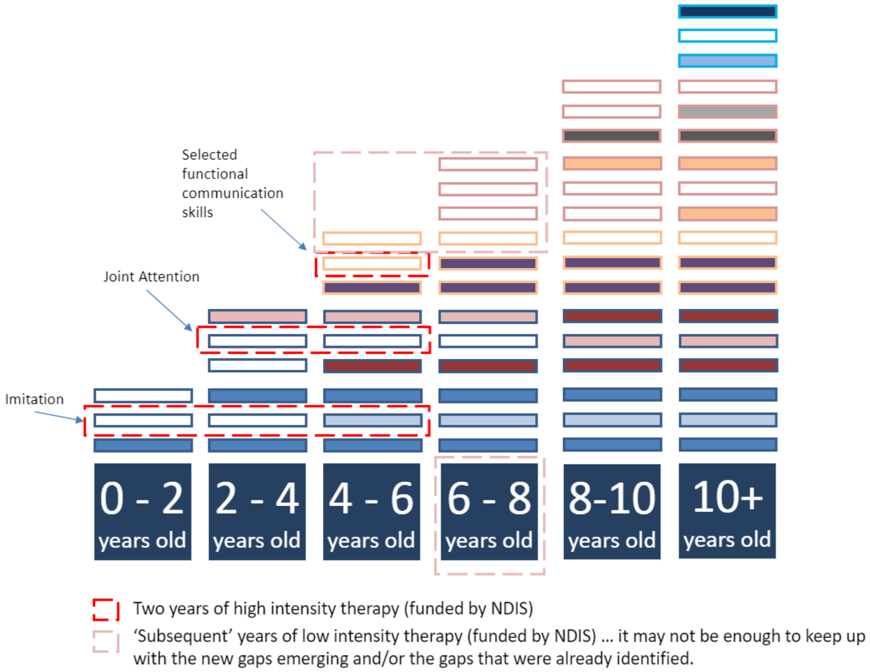
AEIOU Foundation recommends:

If IAs are to proceed, and developmental delay is to be further defined as part of that process, it is vital that diagnosis and other input from clinical professionals remain a valued part of decision-making.

3.4) Extending age range

In response to Report Recommendation(s) 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.

In principle, AEIOU supports lengthening the term that children spend under the Early Childhood Approach. However, we are concerned at the risk of children being on lower value plans during their early years, such as the example provided in the section above. This may create a situation where a child may not have access to funded supports throughout their formative years at school, only having another assessment (IA) at age 9 to enter the Scheme under S24. We seek assurances that children will not have time limits applied to plan lengths.



We also seek clarity around how it is determined that children are no longer eligible for the Scheme. Recommendation 23 suggests the Agency is seeking to transition out more children from the Scheme. Will this process be through IAs? Via a mandated plan length? How will clinical expertise factor into this process?

AEIOU Foundation recommends:

We ask the Agency to provide assurance that plan lengths and values will be based on clinical data, not pre-determined time limits.

3.5) Role of EC partners

In response to Report Recommendation(s) 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; and 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.

AEIOU commends the Agency for seeking to reduce the amount of time involved in commencing supports. However, as the Agency has itself identified, to have the organisation that determines plan value also be responsible for recommending providers – including itself – would be a conflict of interest.

This proposal would involve a concentration of power that sees EC partners acting as Support Coordinators, a referral body, conductors of IAs, decision-makers and implementers of STEIs. This would place the EC partner in an extremely influential position that could negatively affect the ECEI provider market. There is a real risk that EC partners would form partnerships with larger providers, over time monopolising the market with Agency backing, ultimately providing families with fewer choices due to stifled competition.

Families may lack trust in an EC partner who is recommending the optimal intervention for their child when the partner have the option to recommend (and receive payment for) their own services over those of competitors. A framework and process to alleviate this risk and promote transparency is insufficient; the proposal is open to manipulation and needs stronger safeguards for families.

AEIOU Foundation recommends:

While EC partners should be able to provide advice as to whether a provider employs a best practice approach, and connect families with service providers, as funding administrators EC partners should not deliver interventions themselves, due the risk of conflict of interest and longer term market viability, particularly in regional locations.

3.6) Natural settings

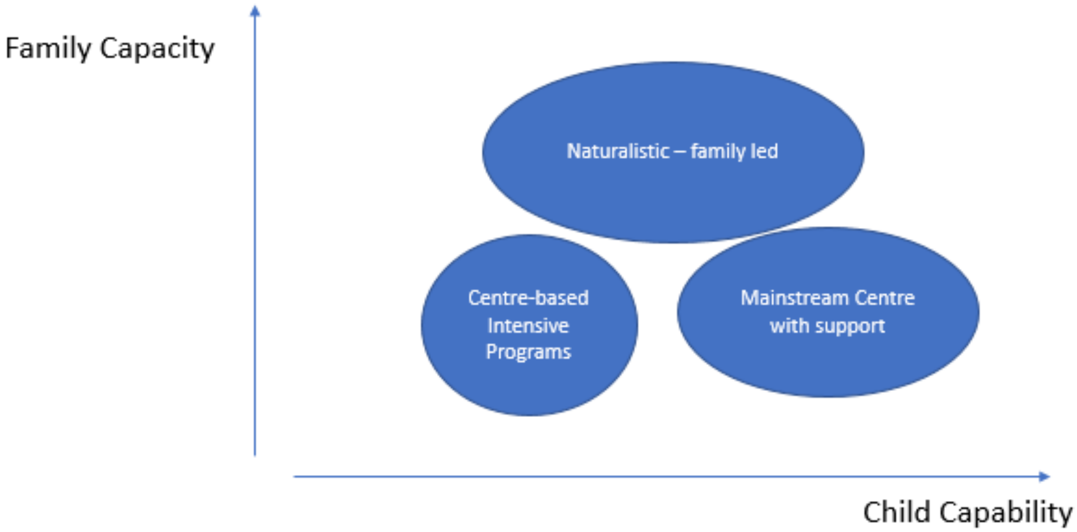
In response to Report Recommendation(s) 17: Introduce a 'capacity building support in natural settings' item in the NDIS Price Guide to encourage families and early childhood providers to prioritise supports delivered at home or other natural settings.

AEIOU recognises the benefits of capacity building and delivering interventions in natural settings. Alongside these benefits, we encourage consideration of the economic and social costs of this approach also. While some interventions can be delivered at home as part of daily interactions that occur around work and education (meals, bathing), others require dedicated time during which the parent/carer cannot do anything else. The foregone labour productivity involved in prioritisation of home and community-based delivered by parents/carers should not be discounted. Equally relevant are the mental health implications for parents/carers and other children and family members, due to a of lack of respite.

A recent report quantified the potential loss for families under the proposed reform as up to $23,000 a year per household. There are approximately 2100 young children diagnosed with autism each year. If all were provided with recommended levels of intervention under a parent-led/mediated model, the annual productivity loss would amount to $48.3 million per cohort *(see Appendix i: Economic cost of parent-led and parent-mediated interventions, February 2021, Synergies Economic Consulting).*

There is absolutely a role for intervention to occur in the home with family – but it shouldn't be the only option. Family life often involves trade-offs: in this case, how much time and emotional energy a parent/carer should dedicate to one child, as opposed to other responsibilities (other children, spouses, aging parents, work, faith, community, their own mental health). Schools/mainstream childcare settings vary greatly in their attitudes toward inclusion and their capacity to accommodate support delivery alongside their usual programs. The families of children at schools/centres who are still in the early stages of understanding autism and inclusion face the additional burdens of advocacy and educating others.

A truly family-centred approach would recognise that different families have different levels of capacity, different financial and transport situations, different cultural beliefs around autism and caregiving, and a multitude of other family obligations to balance.



AEIOU posed the following question to all parents/carers with children currently enrolled at our centres.

"Keeping your current personal, family and financial resources in mind, if you had to coordinate all of your child's therapies yourself at home or via clinics, and learn how to deliver more of their therapy yourself, the impact would be…"

101 families replied and the following answers are indicative of their responses. The rest of the responses can be found in *Appendix iii: AEIOU NDIS ECEI Reset survey, Qualitative, February 2021.*

"The impact would be I would suffer extreme mental, emotional and physical exhaustion that would eventually lead to resentment and possibly breakdown of relationships, depression and anxiety. Eventually I would have just sacrificed my health and wellbeing and will still probably not have gotten anywhere with my child's progress. I know this because I had to co-ordinate clinics appointments with Speech & OT before coming to AEIOU, unknowingly it was straining me mentally. Emotionally and mentally I was having so much trouble switching from being a therapist to being just a Mum, I had nothing to give at the end of the day to my partner because I've just spent all day giving everything to my child, I was always doubtful, full of guilt and always questioning if I was doing the right therapy, if my child was progressing, I had so much parenting insecurity."

"Absolutely detrimental to our current family environment. Not only financially but from an emotional and mental health point of view as well. It is invaluable to have access to professionals who are able to provide the types of therapies required. I would not feel I could provide a sufficient level of therapy to my child at home and such this would cause immense stress and strain on myself and the family unit as a whole."

“Completely detrimental to the physical, mental, emotional, financial health to myself, my husband, my son and especially my son with ASD. It would break us.”

This proposal also runs the risk that participants’ plans may be locked to a line item that the market may not be able to respond to. Interventions delivered by providers that take place in the community, education settings, or a family’s home, are likely to incur additional costs due to risk management. For example, two employees may be needed per home visit for personal safety reasons. It would need to be determined how such increased costs of delivery would be funded in order to develop the market.

AEIOU Foundation recommends:

An alternative method to encourage delivery of interventions in natural settings should be considered instead of a dedicated line item in the Price Guide. Each family should be assessed based on their individual situation before determining how interventions in natural settings can best be integrated into their child’s support, and their family life as a whole.

3.7) Exiting children from the scheme

In response to Report Recommendation(s) 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; and 23: Offer families of young children a 'transition out' plan for up to three months' duration, to support them to transition to the next stage of their lives, if they are no longer eligible for the NDIS.

AEIOU seeks assurance that families will be supported to celebrate the achievement of reaching their goals and outcomes, and transition out of NDIS supports, *only* when clinical assessment has determined that such a transition is appropriate. This assessment should consider functional ability, diagnosis, and recommendations from trained and suitably qualified ECEI providers (not just EC partners).

While most of our engagement with EC partners around children's plans is collaborative and positive, we have also witnessed planners who transparently demonstrate that their decision-making is based on subjective perceptions of value, not clinical advice, and family input. Our concern is that families will feel pressured to leave the Scheme by EC partners who are themselves pressured to meet targets and budgets.

AEIOU also seeks assurance families will only be offered a 'transition out' plan for up to three months *only* when clinical assessment has determined that such a transition is appropriate. Again, this assessment should consider functional ability, diagnosis, and recommendations from trained and suitably qualified ECEI providers (not just EC partners).

We are concerned about a scenario in which a family who cannot afford to get a diagnosis for their 3 year old child with autism approaches their EC partner under the developmental delay criteria, meets the IA cutoff score for access, and then receives a plan with minimal support value and limited time (2 – 3 years?). If the child receives no formal autism diagnosis, and EC partners are not compelled to incorporate social functioning under s24 (Early Intervention) when creating plans, there is a risk that the child will be provided with a 3 month 'transition out' plan at age 5 or 6. We are fearful for children and families who may fall through the gap between the end of short term plan, and being able to approach the NDIS again at age 9, through s24 (Disability).

We recognise that many children with developmental delay will indeed make progress within two years and this should be celebrated; for children with the lifelong condition of autism, especially Levels 2 and 3, support will be required throughout early childhood and beyond.

AEIOU Foundation recommends:

We ask the Agency to provide assurance that Scheme exits will based on clinical data: a combination of functional ability, diagnosis, and recommendations from trained and suitably qualified ECEI providers – not a previously determined plan length or value.

4.0) Recommendation summary

- We strongly urge the Agency to amend the Act to include the domain of social interaction under the list of s25 (Early Intervention) requirements for developmental delay.

- If IAs are to proceed, and developmental delay is to be further defined as part of that process, it is vital that diagnosis and other input from clinical professionals remain a valued part of decision-making.

- We ask the Agency to provide assurance that plan lengths and values will be based on clinical data: a combination of functional ability, diagnosis, and recommendations from trained and suitably qualified ECEI providers - not pre-determined time limits.

- While EC partners should be able to provide advice as to whether a provider employs a best practice approach, and connect families with service providers, as funding administrators EC partners should not deliver interventions themselves, due the risk of conflict of interest.

- An alternative method to encourage delivery of interventions in natural settings should be considered instead of a dedicated line item in the Price Guide. Each family should be assessed based on their individual situation before determining how interventions in natural settings can best be integrated into their child's support, and their family life as a whole.

- We ask the Agency to provide assurance that Scheme exits will based on clinical data: a combination of functional ability, diagnosis, and recommendations from trained and suitably qualified ECEI providers – not a previously determined plan length or value.

Appendix I: Economic cost of parent-led and parent-mediated interventions, February 2021, Synergies Economic Consulting).

Briefing note

AEIOU

Economic cost of parent-led and parent-mediated interventions

High-level assessment of economic cost of parent-led and parent-mediated interventions models
18 February 2021

Summary

Children with autism benefit greatly from early intervention and studies have shown these benefits can be delivered through not just one type of intervention. However, each intervention model will have both advantages and disadvantages.

In its recent report on early childhood early intervention,[1] the NDIS is encouraging the provision of interventions, including parent-led interventions, in natural settings such as the child's home. While studies acknowledge that parent-led intervention can be beneficial (e.g., gains in self-help and social skills), there is a lack of acknowledgement of the full costs, including non-monetary costs (e.g., loss of respite care) under this model.

This paper assesses the potential costs and risks associated with this approach to intervention, particularly for children with moderate to severe autism, focusing on those costs that may not be immediately apparent to policy makers. The following key economic costs of a parent-led model were identified and assessed:

- The additional costs to professional intervention staff and organisations to prepare materials and train parents to provide the intervention that normally would be provided by the training professionals. Particularly for children with moderate to severe autism, there are special skills required by the intervention provider to support children with physical and behavioural challenges in order for the intervention to be effective. This is a significant responsibility for parents. In addition, the home needs to be set up in a way to facilitate the intervention including a designated space equipped with a laptop, internet connection, etc.

---

[1] NDIA (2020). Early Childhood Early Intervention (ECEI) Implementation Reset. Consultation Report.

- In many cases, the demand of the child and hours of intervention (typically 15 to 25 hours per week) will result in one parent foregoing their employment to a significant extent. This loss of productivity is a cost to the family in form of lost income and a loss to the wider economy.
- Centre-based intervention also provides valuable respite care for families. Families with children with autism can experience higher levels of stress than those whose children have other impairments. Further, appropriate respite care can provide both social and educational opportunities, enabling the children to generalise existing skills and learn new ones, as well as taking steps towards greater independence and adulthood. Without the respite care that centre-based intervention provides, there is a significant economic cost of poor mental, physical, and emotional health and welcoming outcomes for parents and families.
- Though there is no 'one size fits all' approach to intervention for children with autism, there are benefits of providing care and education services within an education-based setting which would be foregone under a parent-led intervention model. Studies have shown particular developmental gains are associated with centre-based intervention. Without these skills, children may be at risk of not achieving positive lifetime outcomes such as living independence and employment which can have a significant negative economic impact.

Introduction

In November 2020, the National Disability Insurance Agency (NDIA) released their 'Early Childhood Early Intervention (ECEI) Implementation Reset – Project Consultation Report'. Specifically, the NDIA report recommends the introduction of a 'capacity building support in natural settings' item be introduced in the NDIS Price Guide to encourage the provision of interventions, including parent-led interventions, in natural settings (e.g., mainstream childcare, home-based settings). The report highlights evidence from the literature as presented in the Autism CRC 2020 Report regarding the positive intervention effects of parent-led and parent-mediated interventions for children with autism.

This paper assesses the potential costs and risks associated with this approach to intervention, particularly for children with moderate to severe autism, focusing on those costs that may not be immediately apparent to policy makers. This paper focuses on the following cost components:

1) **Costs associated with facilitating provision of parent-led or parent-mediated intervention in a natural setting, including parental training costs; preparation of intervention material; and other costs to prepare an environment appropriate for the provision of intervention.**

2) **Opportunity cost of foregone labour attributable to parents of children with autism having to participate in intervention, as opposed to participating in the workforce.**

3) **Loss of benefits of respite care provided to parents under the AEIOU intervention model (noting the flow-on adverse impacts for the family unit).**

4) **Loss of benefits from child participation in education-based settings and adverse consequences for children in mainstream settings (i.e., disruption costs).**

Economic cost of parent-led and mediated interventions

Cost of training and material preparation

The delivery of effective EI to children with autism requires a multidisciplinary approach.[2] This approach is extremely valuable in creating a comprehensive treatment plan that allows for coordinated interventions and ongoing assessments that accurately gauge a child's progress.[3] Hence, the positive intervention effects of parent-led and parent-mediated interventions, as reported in the literature cited in the Autism CRC 2020 report, are contingent upon parents having the capabilities to effectively lead and/or participate in intervention.

For example, a parent may be unable to manage behaviours during the learning session, such as absconding during the session, the child's inability to attend to tasks, or destruction of material. These behaviours are particularly significant to manage for children with moderate to severe autism.

For parent-led or parent-mediated intervention to achieve the beneficial results reported in the literature, it is therefore necessary for parents to be provided with significant training across several capabilities that would otherwise be provided by trained professionals across several disciplines (i.e., speech pathology, occupational therapy, behavioural therapy, and child psychology). This requires significant investment of resources, given most parents lack of capabilities and experience necessary for the delivery of effective intervention to children with autism.

There are also significant costs associated with the development and adaptation of material for the effective delivery of parent-led or parent-mediated intervention. The model requires the adaptation of materials to enable them to be understood and implemented by parents with limited training or experience. Further, expertise is also required to develop the parent-led program. This type of program requires regular maintenance and customisation for greater impact.

The AEIOU@Home program provides an example of the significant costs associated with delivering intervention under a model where parents are involved in the provision of intervention. The program was developed in response to the closure of childcare facilities due to the COVID-19 pandemic in 2020. AEIOU@Home consists of one-to-one consultations and virtual classroom sessions with children and their families.

To deliver AEIOU@Home, the therapy team was required to create resources for learning sessions to keep the children engaged through this mode of learning. This was an ongoing task and use of resources

---

[2] Strunk, Julie; Leisen, Melissa; Schubert, Carolyn (2017). Using a multidisciplinary approach with children diagnosed with autism spectrum disorder. Journal of Interprofessional Education & Practice.

[3] Cartwright, C. (2009) Assessing Young Children with ASD: A Multidisciplinary Approach.

as contents of the lessons changed every fortnight to support the learning of skill through different activities.

Another key learning from the implementation of the AEIOU@Home program was a general lack of understanding from parents on how to support children with their learning e.g., prompting, reinforcement, following the schedule, maintaining attendance (training required) during the sessions.

Ultimately, there will be parents who are simply not able to deliver the intervention effectively, regardless of the resources allocated to training and material preparation. This is the reason a 'one size fits all' approach is not tenable, even if all costs were adequately accounted for.

Opportunity cost of foregone labour

Another key cost component is the lost labour productivity as a result of parental involvement in the provision of intervention to children with autism as parents are no longer able to participate in the labour market. This opportunity cost attributable to the parent-led and parent-mediated intervention model is incurred by both individuals directly and the wider economy through a loss of labour productivity.

Under the current circumstances, families with children with autism already endure significant productivity losses. A 2014 study distributed a questionnaire to 3,723 families with children under 18 years old registered as having autism to assess the cost of autism for families. One question asked how much their child's diagnosis affected the employment status of their household. Results showed that of the total annual family cost of autism, 90 per cent was due to loss of income from employment.[4]

The traditional method for estimating productivity losses has been the human capital approach, which measures lost productivity as the amount of time by which working life is reduced.[5] This work time lost is then valued at the market wage; which economists assume, in a competitive market, reflects the value of that labour to society. The resulting productivity loss should be adjusted to account for labour force participation[6] and unemployment.

Thus, to calculate the opportunity cost attributable to the parent-led/mediated intervention model, the following lost productivity equation is applied:

$$\begin{aligned}&(Work\ time\ lost * average\ wage\ rate)\\&\qquad * labour\ force\ participation\ rate * (1\\&\qquad - unemployment\ rate)\end{aligned}$$

---

[4] Horlin C, Falkmer M, Parsons R, Albrecht MA, Falkmer T (2014) The Cost of Autism Spectrum Disorders. PLoS ONE 9(9): e106552. https://doi.org/10.1371/journal.pone.0106552

[5] Cancer Research Economics Support Team (2016) 'Productivity losses and how they are calculated', November 2016.

[6] The proportion of the population who wish to be employed.

This can be quantified based on Australian Bureau of Statistics (ABS) data:

- Median hourly earnings - $36 (as at August 2020)
- Labour force participation rate – 64.8% (as at September 2020)
- Unemployment rate – 5.3% (as at September 2019[7]).

According to the literature, 15 to 25 hours per week is generally recommended for autism early intervention in the research literature (Roberts & Prior, 2006) with some programs recommending as much as 40 hours per week.

Assuming that parent-led/mediated intervention requires 20 hours of parental involvement per week, the opportunity cost of foregone labour productivity equates to $442 per week, or around $23,000 a year for one household. There are approximately 2,100 young children[8] diagnosed with autism each year. If all of these were to be provided with intervention under the parent-led/mediated model, the annual productivity loss would amount to $48.3 million per cohort.

Loss of respite care benefits

The provision of intervention to children with autism under centre-based models provide respite care to parents and caregivers. Respite care provides significant benefits to families given the intense care requirements for children autism.

There is extensive literature providing evidence on the significant benefits of respite care for parents of children with a developmental disability. A lack of sufficient respite care can have significant negative impacts on parents' mental health and wellbeing, stress, physical health (fatigue) and quality of life. Further, it can also add stress to the family in terms of marital quality and on siblings. Importantly, appropriate respite care can also give children with autism positive experiences, such as social and educational opportunities, enabling the children to generalise existing skills and learn new ones, as well as taking steps towards greater independence and adulthood.

Table 1 summarises key findings of the benefits of respite care and the impacts in absence of respite care.

Table 1 Benefits of respite care (and costs of insufficient respite care)

Study	Findings
The Impacts of short break provision on families with a	• Short breaks appear to have the potential to positively impact on not only the well-being of carers, but also the children receiving short breaks and their families as a whole.

---

[7] Given the impact of COVID on employment rates, the unemployment rate from pre-COVID is used to provide a 'business as usual' value.

[8] Based on ABS 2018 'Autism in Australia' prevalence rate of 0.7% for ages 0-4 and average number of births a year in Australia.

Study	Findings
disabled child: an international literature review (Robertson et al 2010)	
Respite Care, Marital Quality, and Stress in Parents of Children with Autism Spectrum Disorders (Harper et al 2013)	• Results indicated that the number of hours of respite care is related to marital quality for both husbands and wives who have a child diagnosed with ASD. Respite care helps reduce stress, which in turn affects marital quality. • The paper concluded policymakers should consider establishing guidelines for providing respite care, as it affects the quality of family life for those who have a child diagnosed with ASD.
Anxiety and Depression Association of America ‘Caregiver Mental Health’	• Around 40 to 70 per cent of caregivers show symptoms of depression with approximately a quarter to half of these caregivers meet the diagnostic criteria for major depression.
A pre-test and post-test study of the physical and psychological effects of out-of-home respite care on caregivers of children with life-threatening conditions. (Remedios et al 2015).	• Caregivers had below-standard levels of quality of life compared to normative populations. • Caregivers' average psychological adjustment scores, fatigue score and mental health/quality of life scores significantly improved from pre-respite to post-respite. • Qualitative data showed caregivers sought respite for relief from intensive care provision and believed this was essential to their well-being.
Parents’ experiences of accessing respite care for children with Autism Spectrum Disorder (ASD) at the acute and primary care interface: a systematic review. (Cooke et al 2020).	• In the absence of appropriate services and defined pathways to support services such as respite care, overwhelmed parents and community providers of mental health resources may not be able to meet the specific needs of children with an ASD and their families which may be contributing to a direct increase in hospitalisations.

Study	Findings
The Impact of Respite Programming on Caregiver Resilience in Dementia Care: A Qualitative Examination of Family Caregiver Perspectives (Roberts 2018)	• Without supportive services at each transition in the continuum of care, family caregivers risk poor health outcomes as their resilience and stamina may wear down, making it harder to bounce back with each new set of caregiving responsibilities and circumstances.
Respite care for families with children with autism spectrum disorders (Preece 2011)	• Respite care has long been identified as important for families with children with ASD as families with children with ASD can experience higher levels of stress than those whose children have other impairments. • Respite care can help reduce stress in families, as well as provide them with the chance to have a break from caring and doing things that they cannot do while the child with ASD is at home. • Appropriate respite care can also give children with ASD positive experiences. Such services can provide both social and educational opportunities, enabling the children to generalise existing skills and learn new ones, as well as taking steps towards greater independence and adulthood.
Measuring the benefits of respite care use by children with disabilities and their families (Otsuki et al 2019)	• Children receiving respite care are exposed to new life experiences that can enhance their communication skills and help improve life skills. • During respite care, children are encouraged to form their own self-concepts and promote psychosocial development apart from their family caregivers. • Caregivers have high levels of anxiety regarding their children's future and such anxiety is related to their adverse physical and mental quality of life. However, respite care is associated with positive family quality of life.
Parents' Experiences of Caring for a Child With Autism Spectrum Disorder (DePape et al 2015)	• Parents felt frustrated by the lack of time they had for themselves and their family and felt overwhelmed by family demands and some felt apprehensive, such that they were always waiting for the next crisis to occur. • Others experienced a range of behaviour problems with their child, such as tantrums, that they were unsure how to manage.

Study	Findings
	• Other parents had to quit their job because the demands of caregiving were too great, and this produced mixed emotions among them. • Some parents suffered health problems, including high blood pressure. • Caring for a child with ASD affected the relationship that parents had with their other children. Parents reported their other children feeling they were not treated the same as their brother or sister with ASD.

While quantification of the economic cost of the loss of respite care provided by centre-based intervention models would require extensive analysis (beyond the scope of this assessment), the adverse impact on families of children with autism is likely to be significant. A minimum estimate for the value of respite care can be inferred from the NDIS Price Guide 2020-21,[9] which provides price limits[10] for respite care.[11] On average, the NDIA provides support of $104 per hour for respite care.

It is important to note that this estimate, which implies a community willingness to pay for respite care of at least $104 per hour, is a lower bound estimate. This provides an indicative estimate of the economic benefit derived from the respite provided to parents as a result of the provision of EI in a centre-based environment.[12]

Adverse consequences of providing intervention in a mainstream setting

The parent-led/mediated intervention model may involve intervention being provided in the home setting however would not be limited to the home setting and would also include intervention provision in mainstream education-based settings such as a childcare centre or early learning centre. Under this scenario, where children with autism are not receiving intervention from therapists in a designated learning centre, children with autism are receiving special learning alongside their typically developing peers in mainstream settings.

When intervention is being provided to children with autism in this environment, their peers are likely to receive less care and assistance in their education due to the high needs children included in the learning group. This is because it places additional stress on a teacher not specifically trained to provide

---

[9] NDIS, Price Guide 2020-21 Version 2.0.

[10] The price limits detailed in the NDIS Price Guide are the maximum prices that Registered Providers are permitted to charge NDIS participants for specific supports.

[11] Termed by the NDIS as 'Assistance with self-care activities in a Short Term Accommodation'.

[12] Noting that to some extent, the value of respite care may overlap with lost labour productivity, as part of the value of respite care may be enabling parents of children with autism to participate in the labour force (when they would not be able to under the scenario in which they were required to participate in the provision of intervention). As such, it is not appropriate to consider this estimate as additive to the lost productivity costs quantified in the previous section.

special needs learning to cater to the different learning abilities of a child with autism. Studies noted that teachers of children with autism in mainstream settings are vulnerable to burnout due to the unique characteristics of these children particularly if their training and preparation to support these children is inadequate.[13]

There is significant evidence in the literature[14] that teachers struggle with the tension between accommodating the special needs of some students and disadvantaging other students due to their lack of appropriate teacher preparation and resourcing, in which case children with and without disabilities would both miss out on educational benefits. For example:[15]

> It has been reported that teachers have expressed concerns about having students with autism and emotional behavioural disorder in the general education setting because of the children's lack of social skills, behavioural outbursts, modifications made to the curriculum, and lack of training and supports. Many instructors do not believe they are able to teach these populations effectively while simultaneously teaching a large group of typically developing students.

---

[13] Emam, M. & Farrell, P. (2009) Tensions experienced by teachers and their views of support for pupils with autism spectrum disorders in mainstream schools.

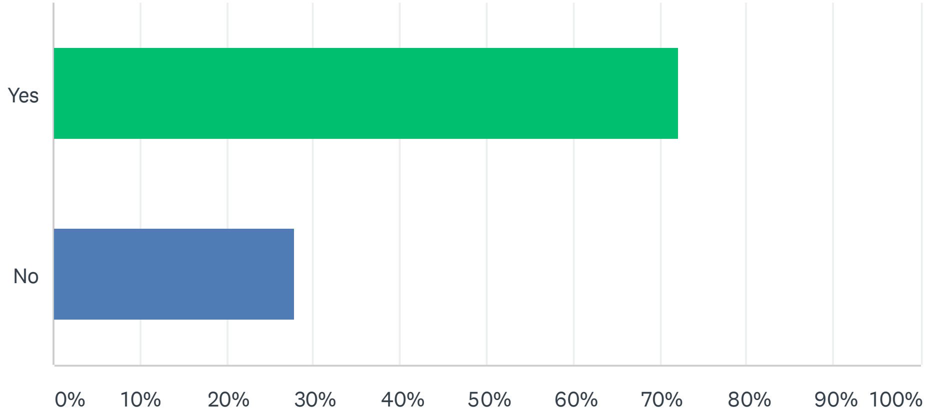
[14] Konza, B. (2008) Inclusion of students with disabilities in new times: responding to the challenge.

[15] Cassady, J. M. (2011). Teachers' Attitudes Toward the Inclusion of Students with Autism and Emotional Behavioral Disorder, Electronic Journal for Inclusive Education, 2 (7).

Appendix II: AEIOU NDIS ECEI Reset survey, Quantitative, February 2021.

Q1 Prior to AEIOU, was your child enrolled in a mainstream environment (i.e. childcare, kindergarten)?

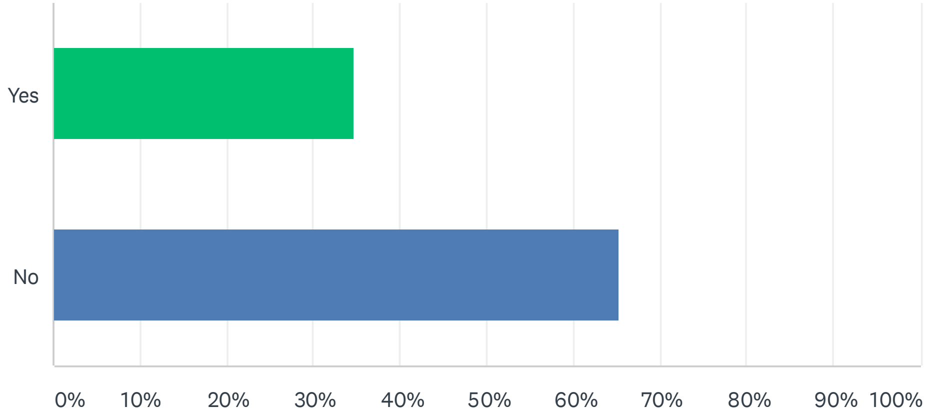
Answered: 108 Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes	72.22%	78
No	27.78%	30
TOTAL		108

Q2 Did you feel included and welcomed?

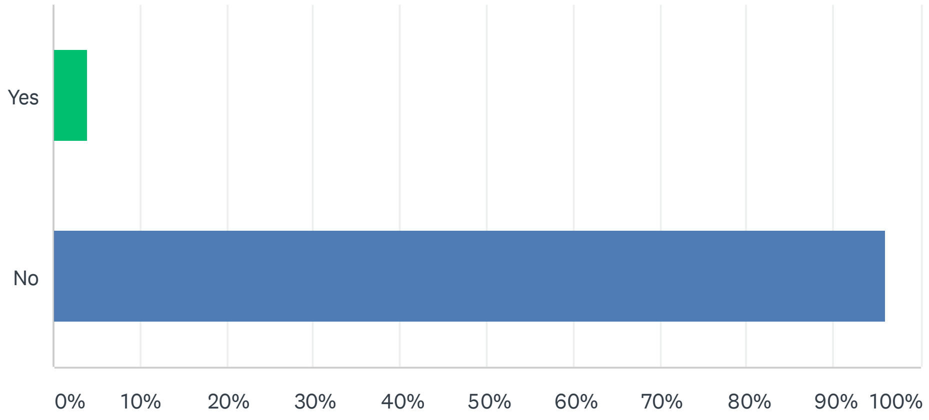
Answered: 75 Skipped: 33



ANSWER CHOICES	RESPONSES	
Yes	34.67%	26
No	65.33%	49
TOTAL		75

Q3 Did you feel your child was able to participate in the group activities / with their peers?

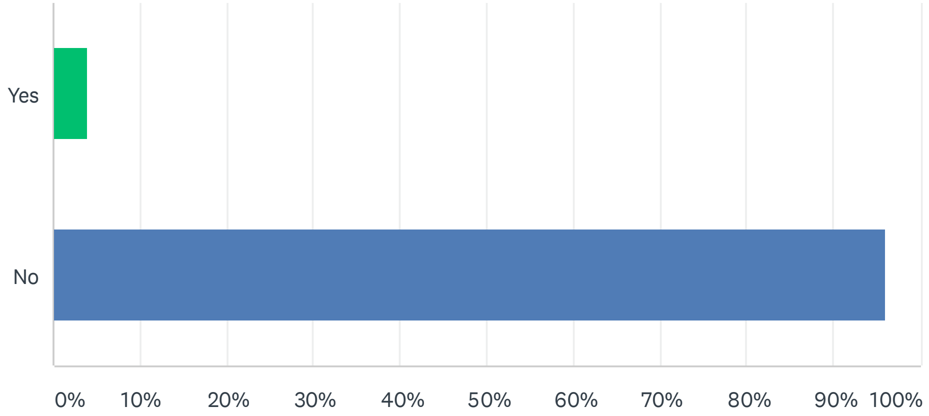
Answered: 75 Skipped: 33



ANSWER CHOICES	RESPONSES	
Yes	4.00%	3
No	96.00%	72
TOTAL		75

Q4 Did you feel your child was able to learn in this environment?

Answered: 74 Skipped: 34



ANSWER CHOICES	RESPONSES	
Yes	4.05%	3
No	95.95%	71
TOTAL		74

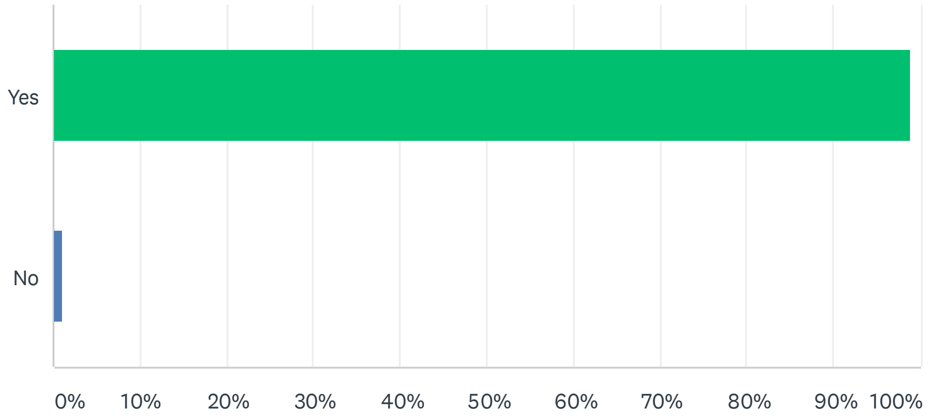
#	YOU MAY SHARE MORE ABOUT YOUR CHILD'S EXPERIENCE HERE, IF YOU LIKE.	DATE
1	Although there was a support person, Harry was often left to his own devices and I regularly found him on his own when attending the kindergarten. He made little to no progress in that environment.	2/17/2021 10:33 AM
2	His resistance to social situations/group learning was allowed to continue	2/14/2021 4:37 PM
3	Because of Sonny's autism and the ratios of teachers to students 1 to 8. Sonny would be left on his own and would not participate in the class activities.	2/13/2021 7:11 AM
4	He did learn to clear his plate after each meals and to wash his hands. He did some painting. But he still did not speak and it was difficult for him to be understood by others and to express himself which frustrated him a lot.	2/12/2021 4:27 PM
5	In main stream kindy there was not enough support or people to watch over my child. He does not learn like the other children, and takes longer and different styles of learning to achieve any type of progress.my child can not focus and pay attention long enough to acknowledge or process learnings. Meaning that he was left out From the groups and it was to difficult for them to try, and would rather him be by himself than learn with he’s peers. He’s behaviours worsen due to this ,acting out with biting and hitting. He’s speech and toileting was none existent and he did not understand. He was expelled from one school because of he’s behaviours and the other daycare he started to attend would call every day for me to pick him up due to the fact they could not calm him down or were worried for the safety of the other children. He did not learn in this environment.	2/12/2021 2:31 PM
6	There was too many children in his class and not enough support staff to manage all the children. Daniel seemed to miss out on most activities. He did 1 painting in twelve months. This I found very sad.	2/12/2021 2:24 PM
7	The environment was not set up for Children with Sensory and Social and Emotional challenges/barriers. The staff also did not have the appropriate training to support my child.	2/12/2021 10:19 AM
8	Our boys were often left out of activities and were left on their own while staff interacted with other children	2/12/2021 9:31 AM
9	the expectation of what she can do was too overwhelming for her as she was expected to perform in the same skill level with her peers which of course, was not the case.	2/12/2021 9:22 AM
10	Lack of social and communication skills	2/12/2021 8:58 AM
11	left alone to run around the play area by him self	2/11/2021 11:39 PM
12	Whilst the mainstream childcare centre was wonderful, our child needed more specialist care (which she receives at AEIOU) to allow her to grow and return to a mainstream environment.	2/11/2021 10:30 PM
13	The change we have seen in comparison to main stream kindy is remarkable. AEIOU Has an amazing program for our children and caters to our child’s needs and assists with there learning and helping to prepare for the future	2/11/2021 9:41 PM
14	Drastic difference in that he is super happy to come to AEIOU and has no separation anxiety / tantrum. I can see that he is well supported by the staff and always involved in activities.	2/11/2021 9:38 PM
15	Wouldn't like playing or associating with other children daycare said they couldn't help him any more and recommended aeiou	2/11/2021 6:17 PM
16	Even though he learns few things, still excluded some activities and not had enough support to be encouraged to be part of them.	2/11/2021 5:33 PM
17	My child was considered high maintenance and they told me they needed extra help as he would try and escape, climb things and wasn’t able to follow what other children were doing for his age level. It was very stressful and my son did not show any signs of progress in this setting.	2/11/2021 2:13 PM
18	My daughter who was a little over 2yo at the time was going to a well known well regarded childcare here in Brisbane for 2 days a week (she had inclusion support). She was always crying and had anxiety at drop offs and on pick up she would not let me go. She would wander all day not really interacting with any of her peers and she gave minimal interactions with her care givers. As soon as she started AEIOU within day 2 or 3 she was happily walking into the building and that's when I realised that there was this huge gap that mainstream childcare wasn't able to provide that AEIOU did - call it inclusion, recognition or understanding or all of it but whatever it is her needs were met and she no longer cried and displayed signs of anxiety. I think deep down I've always known this but the change in	2/11/2021 2:04 PM

	behaviour solidified my suspicion. Couple that with the fact that my daughter learnt more social and communication skills in weeks attending AEIOU than she ever did attending mainstream childcare. I honestly wished I found AEIOU earlier.	
19	The daycare was locally very well thought of but we had a dreadful experience where the staff constantly ignored her (our child is very quiet and did not seek attention as other kids do). We felt That to some degree the staff had dehumanised her, for example asking if it was ok not to apply sunscreen as she cried…we live in QLD, our child has the right not to get burned or increased chances of later life melanoma, same as every other child!	2/11/2021 1:13 PM
20	The mainstream teaching environment didn’t work for my son because they would teach the general curriculum that he wasn’t interested in, and they aren’t able to adapt the teaching to help assist in his learning.	2/11/2021 12:57 PM
21	No one really had the necessary skills for dealing with my twin ASD 3 boys on a daily basis in mainstream childcare which caused a lot of daily issues and unwarranted distress for the boys, myself & my partner.	2/11/2021 12:39 PM
22	My child was always left to his own devices because the educators didn't know how to help him. 4years of my child's daycare life I never once new about what he was doing or how he was progressing. There is 100% zero support for parents with autistic children in a mainstream environment. And if funding changes like suggested then there will be no hope for the future for our kids and that scares me.	2/11/2021 12:38 PM
23	The reason why my child was recommended to attend childcare is for him to at least interact with other kids while waiting for funding from NDIS and while waiting for a placement to a centre that can help address his needs in all aspects in his life. He managed to tolerate being with other people not familiar to him but not really learn how to interact with other kids.	2/11/2021 12:38 PM
24	The inclusion staff at daycare always just let my son sit in the corner. Came home end of year with no artworks	2/11/2021 12:17 PM
25	There are too.many children for the carers to be able to handle an autistic child, plus they aren't trained in how to deal with them.	2/11/2021 12:13 PM
26	At mainstream kindy our daughter was ostracized and neglected physically and intellectually	2/11/2021 12:08 PM
27	The educators did not understand my daughter condition and when she was having meltdowns due to sensory overload they thought she had health issues . So each time they would call me and ask me to pick her up and go to see our GP.	2/11/2021 12:03 PM
28	It was a really traumatic time for my son. He would sit in a corner and bang his head on the wall. There was nothing we or the daycare educators could do yet we were told he had to "socialise" there. I understand he used to strike out at the educators too and many refused to deal with him. They were understanding but severely limited in what they could do to help him.	2/11/2021 11:39 AM
29	My child used to sit in a corner the whole time and didn’t eat anything the whole day. He lost 6 kilograms in 2 months. Started to have grey hair and dark circles. Moreover, he didn’t learn anything there.	2/11/2021 11:34 AM
30	He seemed 'lost' in mainstream. Sort of just wandering about aimlessly not participating in anything.	2/11/2021 11:25 AM
31	He struggled to interact with his peers because of his difficulty to communicate	2/11/2021 11:20 AM
32	My son did not fit into the mainstream environment. He was nearly kicked out from the kindergarten numerous times as his needs were too high for them.	2/11/2021 11:16 AM
33	Only on a very basic level. Routine etc.	2/11/2021 10:55 AM
34	My son was only able to engage in a limited way because of his limited communication skills.	2/11/2021 10:40 AM
35	At the previous day care, my son often didn't participate in group activities, they would let him go off all day and do his own thing. They didn't try to get him involved or help him communicate. I would often pick him up and he had no pants on. While they were lovely and approachable, they could not give my son the attention and help he needed. My son has been at AEIOU for 3 weeks and we have already noticed significant progress. We need the funding to give our son the best chance of attending mainstream schooling and living an independent life when he is older.	2/11/2021 10:38 AM
36	Felt he was brushed to the side and let to just wonder around	2/11/2021 10:27 AM

37	Whilst our child was younger, the mainstream system was sufficient, however as she got older and it became apparent she would require additional therapies to assist with some of her learning challenges and bring her into line with her peers. The intensive therapy environment at AEIOU has proven invaluable, it has provided the right supports and learning environment that we are unable to provide in the home or that is unable to be provided in mainstream setting.	2/11/2021 10:26 AM
38	Harrison was put into classes well below his peers and could not Futher his development. He was put with children that were 2-3 years below his age. This was due to his many faceted developmental delays and also his personal care development.	2/11/2021 10:24 AM
39	The staff were not trained to deal with autistic children, Finn spent alot of time playing on his own	2/11/2021 10:19 AM
40	My child was left to do her own thing so I felt like it was just a baby sitting service. I felt like they didn't have the skills or experience to get her involved in activities.	2/11/2021 10:12 AM
41	We were told to look somewhere else as my child was not being accepted with how he was behaving at the time.	2/11/2021 10:08 AM
42	My son was discriminated against and there were several instances I observed where they were unwilling to recognise his needs, despite knowing I was searching for a diagnosis.	2/11/2021 10:00 AM
43	The staff were unable to address basic safety and care for out child and as a result he sustained a serious head injury. The not only did not have the knowledge to know how to help him then had no idea how to keep him and the other children safe.	2/11/2021 9:59 AM
44	Elijah and Christian both pulled away from peers and became isolated	2/11/2021 9:57 AM
45	The carers in his room were nice people who cared about him, but whom did not the time or resources to really do anything more than ensure he ate, had clean clothes and didn;t hurt himself or others to a signficant degree. The center manager was not at all welcoming of a child with additional needs (although was quick to say they would never exclude such a child), and we were certainly made to feel by herself that we were in the wrong place. There was also huge despair as the "sparks" that came home and the "what happened this week" that came home was always FAR beyond Andy and he was never mentioned as particpating and he never made it in the photos as someone participating and it was very depressing, and certainly highlighted his disability with no real development of his ability	2/11/2021 9:56 AM
46	My child is still traumatised by the experience. We cant walk past the block without crying. I saw significant regression in learning, behavioral and feeding	2/11/2021 9:53 AM
47	She was being excluded in certain group activities because she couldn’t handle some social aspects and therefore put alone while the group done the activity	2/11/2021 9:52 AM
48	It was good from a perspective of building social skills, however the actual learning was limited.	2/11/2021 9:51 AM
49	They never helped her by getting her to engage with others	2/11/2021 9:51 AM
50	Connal was lost in a mainstream centre. We saw very little verbal or social development during that time. The staff were wonderful and caring but they simply could not support his learning needs.	2/11/2021 9:50 AM

Q5 Do you feel your child has made more progress at AEIOU than their previous setting?

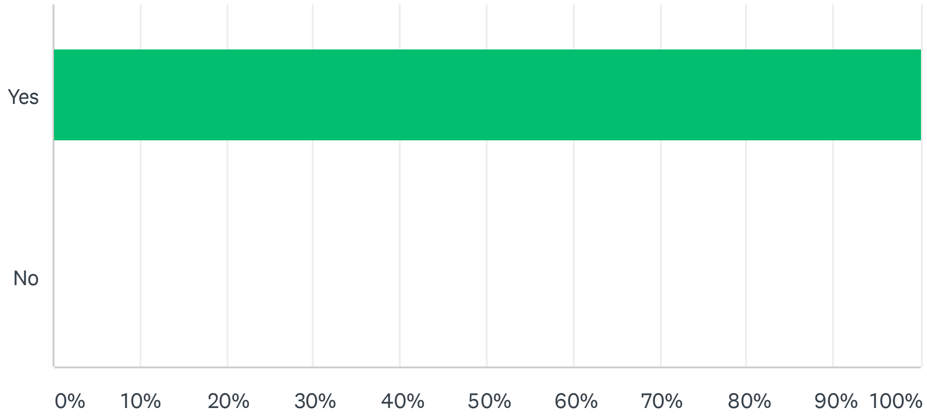
Answered: 104 Skipped: 4



ANSWER CHOICES	RESPONSES	
Yes	99.04%	103
No	0.96%	1
TOTAL		104

Q6 Do you think your child would be disadvantaged if they had no option but to receive therapy supports at home or through the home (e.g. virtually)?

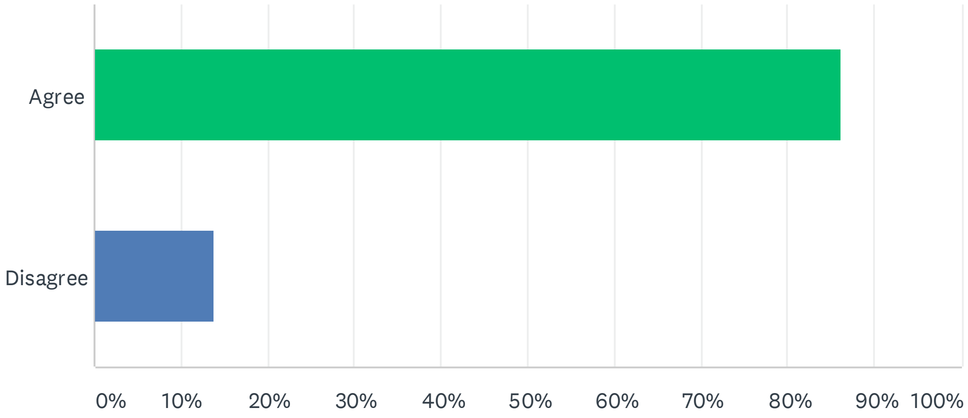
Answered: 104 Skipped: 4



ANSWER CHOICES	RESPONSES	
Yes	100.00%	104
No	0.00%	0
TOTAL		104

Q7 Do you agree or disagree with the following statement?"The best peer support you can have is found among other parents who have children with autism."

Answered: 101 Skipped: 7



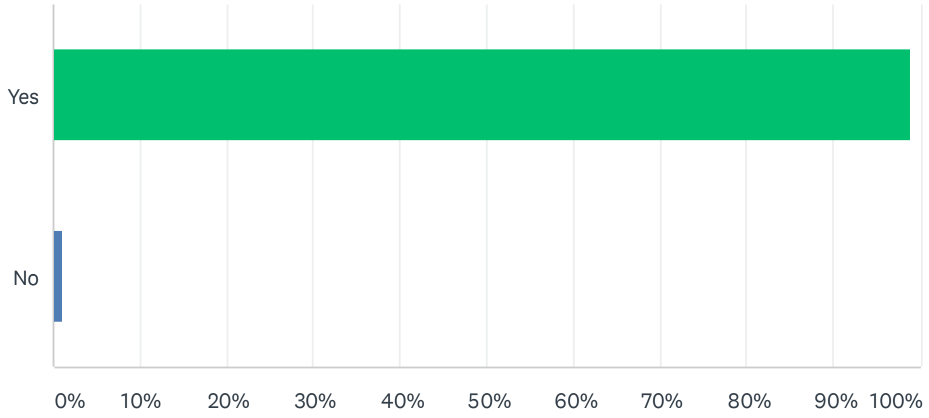
ANSWER CHOICES	RESPONSES	
Agree	86.14%	87
Disagree	13.86%	14
TOTAL		101

#	IF YOU LIKE, YOU CAN SHARE MORE ON THIS IN THE SPACE PROVIDED BELOW.	DATE
1	Children with autism need intensive therapy at an early age, as they tend to have learnt behaviour from other autistic peers and that behaviour is not always in the best interests of the child.	2/15/2021 9:50 AM
2	Making connections with families with similar values has been difficult until joining aeiou	2/14/2021 4:53 PM
3	I agree that it can help with play dates and our sanity, but the real support for me is the therapists at AEIOU.	2/12/2021 4:35 PM
4	It helps to talk to other parents to know your not alone.	2/12/2021 2:41 PM
5	Accessing AEIOU is is inclusive and allows our family to be part of a larger community of parents/peers/therapists/educators who understand the needs & challenges we experience.	2/12/2021 10:26 AM
6	neither agree or disagree	2/12/2021 9:30 AM
7	It is imperative that, as a parent of a child with severe autism, there are other parents in my village that understand the journey of a neurodivergent child. They are not typical. The journey is not typical. It can feel lonely. By having appropriate peer support, this can make the world of difference.	2/11/2021 10:45 PM
8	It’s not easy to share what you are going through with a autism kid. The pain can only be understood by someone who is sailing in the same boat	2/11/2021 9:44 PM
9	It is always good to be able to talk to other people that are in the same situation as you as they understand more	2/11/2021 6:22 PM
10	As a single mother of twins, one of whom has Autism, I rely heavily on AEIOU to provide intensive therapy to my 3 yo son, which is also more convenient for me, as I do not have any family support where I live. Engaging with other parents of Autistic children, helps me to put things in perspective and gives me encouragement to persevere on those days when things are not going so well. Having access to that social support with other parents is crucial for one's own mental health I think.	2/11/2021 3:28 PM
11	I think any parent with a child with Autism would feel this way - I have peers within the autism community and peers outside with neuro-typical children and they just don't understand, everything you do when raising a child with Autism has to be well thought off, intentional. You can't just wing it because the after effects will be met differently by an autistic child and compared to a neuro-typical child. There is plenty of facebook supports group who find comfort and advice from each other than you just can not get from people who is not going through a similar situation to you.	2/11/2021 2:53 PM
12	I feel like I am able to ask the other parents for advice and see how they cope with different situations and I in turn am also able to let them know different tips that worked for my child. I don’t feel as alone in my circumstances.	2/11/2021 2:26 PM
13	I	2/11/2021 2:25 PM
14	Other parents will understand the true challenges that come with children’s who have autism. They will also be able to provide advice and life lesson experiences that will be valuable for other peers.	2/11/2021 1:18 PM
15	N/A	2/11/2021 1:00 PM
16	Experiencing the same thing with regards to having kids on the spectrum makes a big difference in terms of support, understanding and acceptance. We share our thoughts about certain topics, we also learn from each others experiences.	2/11/2021 12:50 PM
17	Parents without autistic kids just don't get it and can't relate to what we go through. In there perfect worlds we just have and I quote "weird or naughty kids".	2/11/2021 12:42 PM
18	I don't know about peer support so I can't really answer this - our son needs a proper environment with trained professionals and intensive support to help him develop as fully as possible	2/11/2021 12:25 PM
19	Its a better social learning for my son an gets to have all therapies in one place so less intrusive. An I get to have friendly conversation with other parents	2/11/2021 12:21 PM
20	The teachers at AEIOU bring together the parents who share solutions about kids	2/11/2021 12:13 PM
21	We have wonderful friends who support us.	2/11/2021 11:58 AM
22	To have people who understand your situation makes a world of difference. We got to the point (pre-AEIOU) where we stayed at home all the time as we were too embarrassed by our	2/11/2021 11:45 AM

	son's behaviour or have parents in a park (who didn't understand) accusing us of being bad parents due to his behaviour.	
23	We stopped socialising completely for 2 years until our son went to AEIOU and due to his therapy, now he is much better and our life has started to get better with support from other families at AEIOU who have kids with autism.	2/11/2021 11:45 AM
24	It was very hard for others even friends and family to understand our child's needs. It wasn't until AEIOU did we meet others who understood our child and what its like to be a parent of a child with autism. Positives and negatives.	2/11/2021 11:03 AM
25	NO! You need professional help.	2/11/2021 10:54 AM
26	Best support is from therapists who know how to help children with autism	2/11/2021 10:49 AM
27	Support is more effective from all stakeholders - not just other parents of autistic children.	2/11/2021 10:46 AM
28	The best peer support is from other parents who understand the limitations and frustrations we experience as a family with an autistic child. Parents of neurotypical children don't experience many of the same issues we do. A Support network is essential.	2/11/2021 10:46 AM
29	Absolutely agree. We understand each other experience and accept that each other's experiences are also unique. We support all the challenges we face and also share the wins. We problem solve together too.	2/11/2021 10:32 AM
30	Being amongst others who have autism you don't feel as judged and they know the challenges you go through in life	2/11/2021 10:25 AM
31	I don’t have any friendships with other parents who have kids with autism	2/11/2021 10:11 AM
32	Being able to connect with other parents who go through the same struggles that we do on a daily basis has significantly improved my own mental health.	2/11/2021 10:11 AM
33	Our child went to five different kindergartens before she went to Aeiou . The reception we had from the other parents was that of having a child who distresses their own children. That of contempt whenever we went to pick our child	2/11/2021 10:09 AM
34	No one I know goes through the challenges I have at home; and the only ones who have any understanding is asd parents and I have only met them through AEIOU.	2/11/2021 10:02 AM
35	We have just had a small holiday weekend with other AEIOU families and all felt comfortable as we were underatood	2/11/2021 9:59 AM
36	I have learned so much from othet parents and has helped ensure my child florishes	2/11/2021 9:57 AM

Q8 Would you experience financial, physical or mental burden on yourself or spousal relationships if you were the long-term and primary provider of therapy supports for your child?

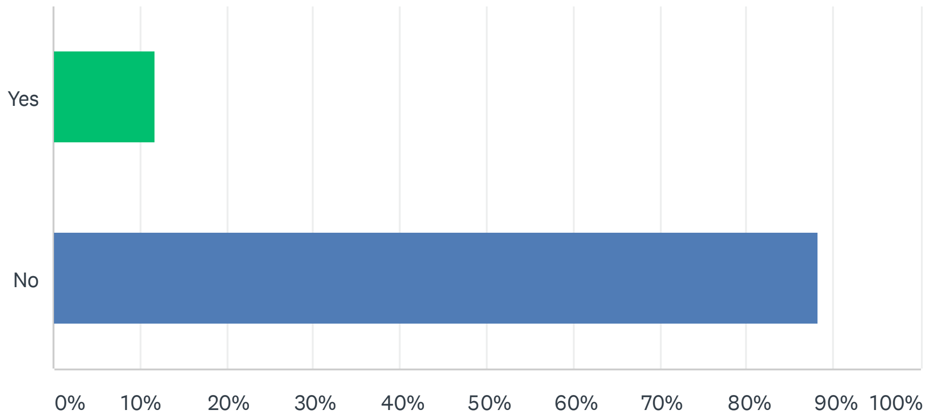
Answered: 103 Skipped: 5



ANSWER CHOICES	RESPONSES	
Yes	99.03%	102
No	0.97%	1
TOTAL		103

Q11 Do you think it would be fair if children with disability had to wait until they were 9 years old to access permanent disability supports via the NDIS?

Answered: 102 Skipped: 6



ANSWER CHOICES	RESPONSES	
Yes	11.76%	12
No	88.24%	90
TOTAL		102

#	WE INVITE YOU TO SHARE ANY THOUGHTS YOU HAVE ON THIS CONCEPT IN THE SPACE BELOW.	DATE
1	Harry has been making real and measurable progress since attending AEIOU. I firmly believe early intervention is going to help enormously in later years. Waiting until 9 years old would mean a burden of challenges in later years it would be difficult to overcome.	2/17/2021 10:40 AM
2	Seriously this question is fucked. How dare you even ask this question. Early intervention for kids is the best thing for them at an early age. If you assess them at 9, they will cost the NDIS alot more money in the long term. You need to help these kids early on so that they can receive help to navigate this world. Starting at 9 is too late.	2/15/2021 9:55 AM
3	Neuroplasticity in areas important to children with autism reduces greatly after 6 years old. The chances of great improvements are diminished after this age, especially if this age is the time they're to transition to school and are often outcast as "idiots" by there peers and experience in inclusion by teachers is not consistent	2/14/2021 4:57 PM
4	Early intervention is crucial to ensuring kids with autism being able to integrate into mainstream education.	2/13/2021 7:50 AM
5	It would get harder for them the longer we wait for them to get the help they need. They learn better and faster the younger they are.	2/12/2021 4:37 PM
6	The early years for an autistic child are crucial for therapy to help them as early as possible	2/12/2021 2:49 PM
7	My child was diagnosed at 2 years old. Before he was diagnosed the day cares would call every day to complain and ask for me to pick him up, or he was expelled due to behaviours. The daycares wanted proof of he diagnosis and even then they could not handle or cope with a child with autism. Early intervention is key. My child has been attending AEIOU for a short period of time and I can already see small improvements. Due to them understanding autism The costing would be the other problem. I would not be able to afford OT, behaviour and speech therapy’s. Meaning my child would fall behind and fall behind further. The mental burden on parents would be horrendous, knowing your trying but no one cares because there would be no diagnosis	2/12/2021 2:49 PM
8	Every bit of early intervention will help children the later you leave their therapy the harder it will become	2/12/2021 2:33 PM
9	As parents and full time carers, we have already endured a great deal of stress, burnout and anxiety in an attempt to access, appropriate, adequate and intensive supports for our children. We are finally beginning to see progress and momentum in terms of the social/emotional/behavioral areas and minimal funding or a complete lack of access to the NDIS would see our young people regress and have decreased opportunity to live their best lives, with fewer barriers and greater coping mechanisms. Furthermore I know my family, as well as many others, will potentially have so much added stress and anxiety without intensive supports, that are own mental health will decline and create martial pressures that may not withstand this added stress. NDIS needs to recognise Austism as a permanent disability and understand that greater early intervention supports under the NDIS will hopefully mean a decrease in funding over the lifespan. It is ignorant and a breach of human right to not allow our young people with Autism access to the funding and supports that require for a better quality of life.	2/12/2021 10:34 AM
10	Children respond better to therapy when they young. Leaving until they are 9 to access funding is stupid. Parents are already stressed and struggling and don't need this burden.	2/12/2021 9:49 AM
11	Studies show that early intervention is the most effective way in being able to assist children cope with everyday life with their disability. This is going agaisnt evidence based studies.	2/12/2021 9:32 AM
12	Ridiculous notion, every interventions have proven to be extremely beneficial	2/12/2021 9:21 AM
13	This is not fair to wait until the age of 9	2/12/2021 7:31 AM
14	I have two children with severe autism. They are both non-verbal with complex needs beyond autism. My daughter was signed off as having permanent severe autism just after her 7th birthday by her paediatrician. No question. Her brother, aged 5, is currently in his 3rd year at AEIOU, and could be signed off permanently for lifelong autism now. I understand that some cases are not as clear cut, but many are. Children who attend AEIOU are children with the more severe levels of autism, who require intensive intervention. They require this early in their lives for the greatest chance at assisting them to lead more functional lives. Waiting until they are 9 is too late. They are already developed significantly, and the AEIOU early intervention program currently only runs until the child's 6th birthday, making it too late for them to receive this important level of support.	2/11/2021 11:04 PM

15	Austism at early stages and intervention can make kids normal.. I don’t think to wait for 9 years for PERMANENT DISABILITY when we can make kids normal with early intervention.. This will make kids Disabled for life long.. Please don’t spoil their future let them become normal by 6-7 years rather than making permanently disable at 9	2/11/2021 10:04 PM
16	Early intensive interventions have been proven to be effective and will allow the best outcome for the individual. It is vital this is facilitated for these children to have the best outcome so that they have a chance to live a fulfilling life.	2/11/2021 10:02 PM
17	I don’t think it’s fair to play with someone’s bright future by not providing them with the essential supports. The early we intervene greater are the chances for the child to have a typical childhood	2/11/2021 9:50 PM
18	Its not fair early intervention is needed for these children ndis should support families early	2/11/2021 7:02 PM
19	You can tell that things aint right with your child from very early on and when you take them to see a peadatrician they can pick it up straight away as well and getting to them and helping them from a early age is the best thing that can happen for them	2/11/2021 6:25 PM
20	Evidence based research recommends that autistic child should have intensive therapy for at least a couple of years before they turn 6 yrs old. My hope is that with intensive therapy for the next 2 yrs, my 3 yo son will have the best possible chance of starting school when he is 5 yrs old, and that he will have the best chance of learning at school from Day 1. Waiting until he is 9 yrs old to access disability supports will put him at a significant disadvantage in terms of his capacity to learn, and by that age…it may well be too late. He is significantly speech delayed, so communication therapy is key for his ability to learn and form relationships.	2/11/2021 3:34 PM
21	I just don't understand the reasoning behind this. Every research in children's development points to early intervention will give you the best outcome. Why not do intensive therapy now while their brains are developing rather than waiting until they are 9yo when half of those therapies would no longer work. The way I see it and my goal for my daughter is if we did all the hard work now and give her the best most intensive therapy you can get as she gets older she can rely less and less on NDIS. I would want her to be a productive member of the society. You don't wait until until the pipe has burst to do something about it, you fix it when it's just a leak!	2/11/2021 3:02 PM
22	I knew when my child was 12months old that there was something not quite right with how he engaged and also with his speech. If we were not able to access the help he needed as early as we were able I believe my son would be a very different little boy today. He has made huge progress in self care and people skills and is learning daily with AEIOU. Without NDIS funding supports there is no way possible we could have afforded the therapy my son needed. Early intervention is the key to helping children with Autism have a brighter future, without funding this is type of intervention is NOT possible. These children need support 5 days a week and need continuous support for not just them but their families too during this period of their life. If we had to wait until he was 9 years of age (year 4 of schooling) he would have fallen so far behind his peers that he may never catch up in all areas, social skills, playing skills, self care and communication. Families need support from as early as posssible... it is too hard to navigate independently. AEIOU is life changing for children with Autism and has given my family hope for my sons future.	2/11/2021 2:42 PM
23	Until these people making these decisions have an autistic child themselves and understand the struggle and the loss of power we have as parents because we can not take away this burden on them and really help them ourselves they need to stop making these life altering decisions	2/11/2021 2:28 PM
24	With any issues, sickness, challenging behaviours or disabilities in life, its always better to treat it as early as you can. To have to wait until 9 years old is like saying we have given up on you already. It is extremely painful to have to see your own children go through all the challenges to fit in with ‘normal’ day life.	2/11/2021 1:26 PM
25	My daughter is 4 and cannot communicate verbally, this makes life incredibly difficult. The sooner we can improve her communication the less she will fall behind in traditional development trajectories. To wait until she was 9 seems arbitrary and cruel when she was diagnosed at 2 and research tells us early intervention is imperative	2/11/2021 1:23 PM
26	He needs it now, while he is young.	2/11/2021 1:02 PM
27	We always say that early intervention makes a big difference and bases on alot of studies most kids improve if early intervention is done. Waiting until the child is 9 year old will only lessen our chances for our kids to reach their full potentials and may not be a useful member of the community.	2/11/2021 12:55 PM

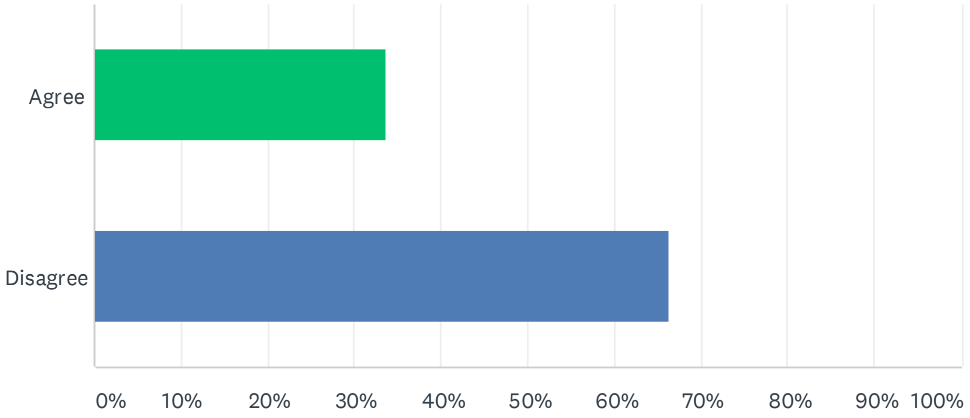
28	That is total bullshit. Poor families lose jobs live on the street. If they take the funds, away. Centrelink would not pay as much staying home with your child. Keep it how it is. Dumbass government	2/11/2021 12:52 PM
29	Studies show that the earlier the diagnosis the better, it has been proven that later in life the child struggles in adult life why would we want to go backwards and cut funding until 9?	2/11/2021 12:46 PM
30	Iby the time they are 9 years old it is way too.late for them. Early intervention before the age of 6 is crucial for them to have the best chance in life.	2/11/2021 12:30 PM
31	Because by then its too hard for them to learn the skills they need. If my son were to wait til then he would not be talking,trying to eat with a spoon, wouldn't not be able to sit still ect.	2/11/2021 12:23 PM
32	Early diagnosis is key to helping autistic kids make progress into a mainstream independent life. It is counter intuitive and illogical to spend lots of money after the horse has bolted from the stable	2/11/2021 12:16 PM
33	A lot of children with autism have developmental and language delays which can not be corrected after certain age . The earlier intervention is started the better .	2/11/2021 12:13 PM
34	Since it has been shown early intervention can greatly help with development being behaviour and independence for example waiting until the child is older will only limit what any child is capable of.	2/11/2021 12:10 PM
35	We have done home therapy with Occupational and Speech Therapists, and it did not work. The Therapists changed their times or were late. Our child failed to respond in the home environment anyway.	2/11/2021 12:09 PM
36	It is a proven fact that Autism is a permanent condition. So, waiting till 9 years of age for permanent disability support would leave families vulnerable to financial, emotional and mental instability.	2/11/2021 11:49 AM
37	Every child's needs are so different. They can't have a broad rule for everyone. In addition - if that was to impact their ability to access early intervention - the consequences would be terrible	2/11/2021 11:47 AM
38	No way. All the research says that intensive early intervention is key for autistic children. 9 years old is far too late. These kids won’t be able to start school .	2/11/2021 11:29 AM
39	Early intervention is key for ASD treatment .. waiting until 9 years will put our kids to disadvantage	2/11/2021 11:24 AM
40	The earlier that children have access to therapy the earlier they begin to learn	2/11/2021 11:21 AM
41	I think this is so wrong as it is way to old to be able help them and change things early intervention is the best thing for asd kids and also to help your child and so they can learn and get the right help from a young age I think 9 year old is way to old to be able to tey and help as they are a lot older and will be harder to help as they age dose not help	2/11/2021 11:17 AM
42	I would just like to ask why 9? Autism is for life. It doesn't start and stop at any specific time. So I don't see why funding has an age limit.	2/11/2021 11:07 AM
43	This concept would set my child back to the point I don’t believe she would ever be able to catch up. Early intervention has been wonderful for our daughter, you can see it in her eyes she is so much happier and enjoys her time at AEIOU.	2/11/2021 11:04 AM
44	It’s proven that early intervention is the best thing a child can receive this could prevent Needing constant therapy for life	2/11/2021 11:03 AM
45	That would be the worst thing to happen, early intervention has been life changing for not only our sons but our whole family. Without early intervention I know our sons would not be able to go mainstream in anyway shape or form in later life. They would end up depending on caregivers for life	2/11/2021 11:03 AM
46	The first five years are the most important when children are developing. Children with autism get stuck in their ways if they are left to continue those behaviors in the early years they will not go to main steam school or be part of the community or have good quality of life . Early child hood studies prove the most effective help for children with autism of any level if they can are verbal or not need at least two years early intervention	2/11/2021 10:53 AM
47	There is absolutely no way my son could have progressed this far without NDIS funding and having an organisation similar to AEIOU. The day care he went to previously were aware of his autism but were not equipped to support him the way the ‘normal’ children received support. It’s scary to think of where we would be without AEIOU. We moved house just so	2/11/2021 10:52 AM

	we could be close to the school and our son could receive more support. He has thrived in the AEIOU community.	
48	The current research is that children benefit from intervention between 3 and 5. If the funding was cut, my child would not receive the therapy he needs, would probably not be able to attend mainstream schooling as he would be much further behind neurotypical children and would need more support during his life.	2/11/2021 10:49 AM
49	Shall we cut it off to people after the age of 65 as they have probably only got 9 yes to live anyway	2/11/2021 10:42 AM
50	I thought early intervention is proven?! Waiting so long will severley disadvantage the child, put unnecessary extra stress on the family, work, etc, and just plainly seems to be going backwards, will cost the governement mofre money in the long run due to mental health issues, loss of productivity, and other issues.	2/11/2021 10:39 AM
51	It has been proven that early intervention helps children with autism. I have seen this first hand and cannot imagine what stage my child would be at if she had not received the early support. It would slow her progress down entirely if she was to wait until 9. Early intervention prepares children for school. Are we supposed to wait until they are in school and unable to function to then seek help?	2/11/2021 10:39 AM
52	Early intervention is so critical and buy the age of 9 most of those behaviours have been engrained. While their minds are young and not committed to a traditional school routine, get the therapy.in and help mould them at the young age. I truely believe early intervention will decrease their need on the NDIS as they become teens and adults.	2/11/2021 10:37 AM
53	They need early intervention. My child cannot speak! One day I hope she will ge able to communicate and early intervention is the only way this may be able to happen!	2/11/2021 10:30 AM
54	We are seeing it much younger and it has a huge effect, that is a massive wait	2/11/2021 10:26 AM
55	All studies indicate that early intervention of therapy for autistic children (before the age of 5) has the BEST prognosis. The proposed changes go against scientific studies, which appears to be cost saving rather than considering the best interest of the child.	2/11/2021 10:25 AM
56	Our son didn't speak 2 years ago, with the intervention support from aeiou he now speaks and requests day to day	2/11/2021 10:23 AM
57	It wouldn't be fair to wait until 9 years of age for adequate supports. Early intervention is so important and our son has improved so much at aeiou	2/11/2021 10:21 AM
58	It would be totally unfair! For instance our child was diagnosed with autism at the age of 2. To have to wait 7 years before we would be able to access permanent disability support would be extremely detrimental considering it is not a condition that is going to go away or be 'cured'. I hand on heart feel that the early intervention our son has received at AEIOU will set him up with a better outcome in life. Who knows, acting early and being able to access these supports now may lead to less supports being needed later in life.	2/11/2021 10:21 AM
59	It is proven that the earlier the intervention, the more chance there is for a positive outcome long term. If the NDIS were to raise the funding age to 9, children with disabilities would be at a great disadvantage to learning and being able to manage multiple important life skills such as communication, appropriate behaviours in a social setting, self care behaviours such as toilet training, emotional regulation and many other important skills required for day to day living	2/11/2021 10:20 AM
60	The whole concept of early intervention is to enhance the chances long term therapeutic efficacy of having the child get help while they are young as research evidence suggest. This in turn reduces chance of children needing care lifelong care which is a good outcome and ability to live independently for the child ,and to live fulfilling life	2/11/2021 10:20 AM
61	Lachlan received an early diagnosis just before he turned two years old. It was a very thorough process to receive his diagnosis (with many hours of the professionals time, and thousands of dollars spent), we fought hard for Lachlan because I knew he needed intense early intervention. Since then, and since attending AEIOU Lachlan has come soo far. I have full confidence that he would not be where he is today without the program offered by AEIOU (and NDIS' support). If Lachlan had to wait until he was 9 years old to receive this level of support, I feel that would greatly impact his life (and our family's lives) negatively. The treatment and therapy that Lachlan has received at AEIOU has been invaluable, even live changing.	2/11/2021 10:19 AM
62	Early signs are a good enough proof that certain areas remain a problem even a kid grows up.	2/11/2021 10:13 AM

63	This is a big problem and misunderstanding because it’s good to start with early age for learning.	2/11/2021 10:11 AM
64	Children would miss out on the interventional therapys for their growth and development which is not fair at all	2/11/2021 10:10 AM
65	The key time for development of ability/skills in autism (and other developmental disorders) is in the 5 and below age group. How can 9 be any kind of apporite age.	2/11/2021 10:08 AM
66	It would be more detrimental. And they would be so much further behind then their peers as to how they already are	2/11/2021 10:04 AM
67	My son’s disabilities are lifelong and I do not believe that early intervention will take away from the challenges he will face for the rest of his life.	2/11/2021 10:03 AM
68	Early development is extremely important to receive therapies before attending a school. It would help them understand social ques a lot more, and they wouldn’t struggle with certain behaviours/speech and general motor skills as they would if they didn’t recieve the aeiou therapies prior to schooling.	2/11/2021 10:03 AM
69	Its is inhumane to make a child wait until 9 to get the support needed to help understand themselves and the world	2/11/2021 10:02 AM
70	I am outraged that support is not to be given until its too late to significantly improve behavior. Studies show the amazing impact of early intervention. Failing to provide this support would be failing the children of our next generation	2/11/2021 10:02 AM
71	Because an age shouldn’t determine those factors at all	2/11/2021 9:57 AM
72	Autism is not a "curable" condition. A person is born autistic and remains so for life. There can be no benefit to a child having to wait until they are 9 to access any form of support when all the evidence indicates that early support and intervention is crucial to improving developmental outcomes	2/11/2021 9:57 AM
73	It has been scientifically proven that providing the required support before the brain is fully devloped (pre age 7) is the best approach to ensure outcomes which lead to a better quality of life. Trying to resolve issues later down the track are not as effective, and generally more costly in the long run (assuming the financial aspect is why the government wants to trim down the program).	2/11/2021 9:56 AM
74	Early intervention is best and so much research has shown this. Waiting until 9 years old could be very detrimental to both child and family.	2/11/2021 9:55 AM

Q12 Do you think that young children with autism should undertake annual assessments to determine their eligibility for the NDIS?

Answered: 101 Skipped: 7



ANSWER CHOICES	RESPONSES	
Agree	33.66%	34
Disagree	66.34%	67
TOTAL		101

#	WE INVITE YOU TO SHARE ANY THOUGHTS YOU HAVE ON THIS CONCEPT IN THE SPACE BELOW.	DATE
1	Harry is continually being assessed at AEIOU and his diagnosis means he needs the help he's receiving. Determining the content of the assistance is already reviewed annually.	2/17/2021 10:40 AM
2	No, they are autistic, it won't FUCKING change. They may develop some skills or they may not but regardless being autistic will not go away magically.	2/15/2021 9:55 AM
3	I like the ongoing reassessment of each child's progress and needs	2/14/2021 4:57 PM
4	Bi annual would be better. Autism is not a condition that can be cured. It is life long.	2/13/2021 7:50 AM
5	Once you have been diagnosed you should not have to be checked in one to see if your lying. Yes if you are requesting more help as some times other problems arise further down the track	2/12/2021 2:49 PM
6	This depends on how long it takes to get a yearly assessment. Most services related to autism is a 12 month wait.	2/12/2021 2:33 PM
7	provided it is funded, why not	2/12/2021 9:32 AM
8	Time wasting Children present very differently in all life scenarios	2/12/2021 9:21 AM
9	A child with autism has already been diagnosed by qualified professionals. To say they need to undergo testing every year is an insult, and ju a t puts more pressure on families who already have enough that they are trying to juggle. Autism is something you are born with, just like cerebral palsy, spina bifida, down syndrome... why is autism the syndrome that "professionals" question whether it suddenly disappears? No. It does not. Please stop questioning this. It's insulting at best and infuriating at worst. Have some compassion for the children and their families and stop making us all go through unnecessary testing. My children were diagnosed at 2yrs 5mos and 2yrs 6mos. Their uniqueness as children with autism has only become more evident as they have grown older and the gap between themselves and their typical were has grown wider.	2/11/2021 11:04 PM
10	Yes please then only parents and nDis knows that funds are given to needy kids and not all..	2/11/2021 10:04 PM
11	No one wished for a child on the spectrum. It just happens so we have to accept it. If the child has the ability to go into mainstream education then the parents will not need NDIS at all. It is obvious why these children need the support of NDIS, otherwise they will not have a chance to participate in the community at all.	2/11/2021 10:02 PM
12	Once diagnosed they never fully improve and always need support even in adult hood	2/11/2021 6:25 PM
13	Things change quickly and re-assessment ensures their current needs are met	2/11/2021 3:48 PM
14	I think that annual assessments should be done to monitor the child's progress and facilitate the individual therapy program, but I do not think that it impact on whether the funding is continued, as I assume the diagnosis of ASD has already been made.	2/11/2021 3:34 PM
15	Why would you? Autism is autism, they will never be cured, they will continue to hopefully improve but as heart breaking as it is they will lead a life full of bumps and they will always need supports - formal or informal.	2/11/2021 3:02 PM
16	I don’t believe my sons Autism will “go away” or resolve. I think he will learn things to help him better manage aspects of his life but I believe he will have struggles through his life unlike neurotypical children and will require support long term. I believe once a formal diagnosis is made it is cruel to make parents prove their child still needs help. Autism is not curable but there are interventions that can be commenced to try and make their lives better. Knowing that my son has a permanent disability diagnosis through NDIS and able to access support through his life gives me hope that although he may have struggles he will always be supported.	2/11/2021 2:42 PM
17	Im only new to this. I know alot of progress can be made (im hoping in 2 years my baby will be so much better)	2/11/2021 2:28 PM
18	I’m on the fence with this one but I think taking annual assessments would somewhat show how the children is progressing with therapy and support.	2/11/2021 1:26 PM
19	To add this layer of stress and uncertainty to families who are already having to do more to meet the additional needs of their children seems unnecessary. There must be better ways to allocate resources	2/11/2021 1:23 PM
20	He has ASD it's lifelong, why would they need to assess to check that he is still autistic?	2/11/2021 1:02 PM

21	To be fair to all, assessments should atleast be done every six months to see if there has been any progress. Should be increase the support of decrease funding.	2/11/2021 12:55 PM
22	Once autistic always autistic, why do we have to prove this every year it's not something that people grow out of. Having to justify it every year is a bit of a joke.	2/11/2021 12:46 PM
23	I'm not against assessments and perhaps it might be useful to get the best funding for there's current needs but it shouldn't be used to determine eligibility as this creates great uncertainty for the affected family.	2/11/2021 12:30 PM
24	We do so many assessments at the schools and to get the funding I think the funding should stand for 3 to 4 year blocks	2/11/2021 12:16 PM
25	I find some on the spectrum may only need limited support while others require significant support, and support should be judged on a case by case basis.	2/11/2021 12:10 PM
26	It is extremely difficult to assess a child who could be having an extremely good or bad day, as every day is different.	2/11/2021 12:09 PM
27	I think in a situation like AEIOU who do such comprehensive reporting, their reports should be sufficient as they are bound by their professionalism - just as any other person undertaking the assessments.	2/11/2021 11:47 AM
28	I agree because some children do require more help and others require less. So funding should be distributed accordingly.	2/11/2021 11:07 AM
29	It’s not something you grow out of, but something that can be helped in younger years to help those individuals adapt to all ways of life	2/11/2021 11:03 AM
30	A diagnosis of autism should be all you need	2/11/2021 10:53 AM
31	Autism doesn’t get better or go away. It is how someone is born. Our culture doesn’t make enough allowances for people who are ‘different’	2/11/2021 10:52 AM
32	Maybe every three years or so, not yearly as it will result in treatments that are having huge impacts on lives cut back amd then the process falling back	2/11/2021 10:42 AM
33	Would be ok to Agree depending on what the assessment actually is.	2/11/2021 10:39 AM
34	I believe there needs to be ongoing support and that decision need to be made collectively between the child's pead, therapists, school teachers and caregivers. They model could be modified to have tiers of support based on needs. The stress on parents to have that support removed from the end of 1 year to the next would be very challenging.	2/11/2021 10:37 AM
35	Young children with ASD require and benefit from early intervention. I don't believe a yearly assessment is necessary, however I understand that some form of assessment process would be appropriate.	2/11/2021 10:33 AM
36	I don't think it is needed, once you have autism, you have autism, yes you can get greater skills but its not going to go away. For my child in particular if we had to do annual assessments I wouldn't be hesitant to do them as I know my daughter needs all of the help she can get.	2/11/2021 10:30 AM
37	I don’t think we see results that quickly	2/11/2021 10:26 AM
38	A child with autism develops at a very slow rate. The diagnosis in a year will not change.	2/11/2021 10:25 AM
39	Autism doesn't change, the more support that can be provided at an earlier in life will prove to save on supports in the long term	2/11/2021 10:23 AM
40	I think assessments are important to see how your child is progressing and improving. But shouldn't determine their eligibility for NDIS. Once they are diagnosed should prove eligibility for early intervention. And if they are assessed annually and are improving this shouldnt stop them from continuing on	2/11/2021 10:21 AM
41	I dont think there needs to be an annual assessment to determine eligibility. It is a life long condition, unfortunately it is not going away. I understand annual funding may need to be reviewed as supports individuals require will vary as they make progress over time however I dont think families should have to prove their child has a life long disability every twelve months to ensure their child will recieve the adequate supports.	2/11/2021 10:21 AM
42	I don’t believe that an assessment every 12 months is necessary based on personal experience in addition to the fact that assessments are a lengthy process, sometimes taking months to complete, as well as the financial aspect some of the assessments cost. Taking this into consideration, it would cause more stress to families and health care	2/11/2021 10:20 AM

	providers alike, as it would cause a heftier workload on an already over loaded system, for both publicly and privately sourced assessments.	
43	This enable the the families , clinician and NDIS can evaluate progress and tailor the need best For the child . This also helps gain important data in shaping the future services for other children who may require services	2/11/2021 10:20 AM
44	I'm unsure if I agree or disagree with this one, I feel the system should be fair, and early intervention for young children with Autism should be carefully considered with high importance. I do not think these children should be made to wait until they are 9 years old. I think it is fair that they receive annual assessments to ensure the program is the right fit for them, sure. I think it opposes challenges given costs and wait times to see paediatricians etc.	2/11/2021 10:19 AM
45	Why to make life for parents and special needs kids miserable by testing them every year ? Why do they need to prove time and again about their needs. Its totally unfair	2/11/2021 10:13 AM
46	So they get appropriate funding according to their needs	2/11/2021 10:10 AM
47	Annual assessments by whom? Paediatrican/therapy teams? Would be reasonable as there should be some medical oversight of the child. Who else is qualified?	2/11/2021 10:08 AM
48	This is a difficult one to answer. I think children who have been diagnosed at a young age should receive funding till at least school age - and then have an assessment to see how they have progressed... to see if they need more or less funding. There is alot of change/learning/meeting goals in 1 yr... however at such a young age... perhaps they could establish tier system. If you get $5000-10 000 funding a year... have assessment every 18 months (just as an example). It's a complex issue, and assessments do need to be done to establish eligibility but at the same time... what is the perfect timing?	2/11/2021 10:07 AM
49	This is ridiculous. I have enough worries without feeling that I would have to subject him to regular assessments to “prove” his disabilities and needs.	2/11/2021 10:03 AM
50	The AEIOU are professionally trained specialists who work with these children day in day out they build trust Why are they not capable of assessment instead the government wants a complete stranger to asses (this will lead to unreliable data collection)	2/11/2021 10:02 AM
51	Autism is a neurological condition you are born with. Its hard and a constant strugle. Its not something the heels over time. Imposing that restriction would create extra cost and hardship for the child	2/11/2021 10:02 AM
52	It’s a system and certain goals will change yearly	2/11/2021 9:57 AM
53	As with my comment above, an autistic person is autistic for life. Participants should not be forced to annually "prove" their disability.	2/11/2021 9:57 AM
54	I believe they should be monitored for progress, but I think a full assessment every year is quite overwhelming and invasive.	2/11/2021 9:56 AM
55	If they have autism they are eligible, making these kids go through more unnecessary assessments is a waste of time and not fair on the child.	2/11/2021 9:55 AM

Appendix III: AEIOU NDIS ECEI Reset survey, Qualitative, February 2021.

Q9 Please complete this sentence, or comment on how this scenario might affect you and your household:Keeping my current personal, family and financial resources in mind, if I had to coordinate all of my child's therapies myself at home or via clinics, and learn how to deliver more of their therapy myself, the impact would be:

Answered: 101 Skipped: 7

#	RESPONSES	DATE
1	It would mean we would be unable to continue to work the hours we currently do, which would place us in difficult financial situations. Ultimately, Harry would either suffer with less therapies, and make less progress, and/or we would need financial assistance to make ends meet.	2/17/2021 10:37 AM
2	Heavy	2/15/2021 6:57 PM
3	A mental breakdown for myself. My other children will suffer from this as I will have no time for them because I'm too busy with the autistic responsibilities. Financially unstable. No time to actually get a paid job either. What the fuck is wrong with you NDIS, you have no idea of the impact this will be on everyday families	2/15/2021 9:50 AM
4	Increased anxiety and stress on an already stressful situation. We have no family support here, and both need to work. This means we would have to reduce hours to keep up with the demands of intensive therapy which would also reduce our household income.	2/14/2021 7:06 PM
5	It didn't work before and it was making my wife more stressed than I've ever seen her. She has been able to find permanent work and is now more willing to socialise with new work colleagues and new aeiou families.	2/14/2021 4:53 PM
6	Unemployment I would not be able to financially support my family. In addition because Sonny's mum also has Autism it would put significant strain on her ability to do the same and would lead to increased mental melt downs for both her and Sonny placing them both at risk.	2/13/2021 7:31 AM
7	Tiring and lonely	2/12/2021 6:43 PM
8	That I would not be able to study and work. I might not be able to support him as must as he needs having the therapist helping him every day. The therapy and school takes a lot of time and finding the time to work and take him to a private therapy and school might be difficult for both my son and myself.	2/12/2021 4:35 PM
9	My other son would be impacted there would be no structure set routine for Brody	2/12/2021 2:47 PM
10	I am a full time worker and so is my husband. I would have to quit work to support and teach my child. Meaning that we would not be able to afford many things such as bills, cars, house, food, petrol etc. my mental health would be at risk and it would put a strain on my husband and myself. I love my child but not having have some one to talk to, or even know that I am doing things correctly would make me constantly worry. If it was that easy I would of been doing it from the start.	2/12/2021 2:41 PM
11	As a dairy farmer who currently works seven days a week 365 days a year I somehow find the time to drive my son 108 Klms 7 days a week to seek amazing therapy. To teach Daniel from home would be extra hard as I don’t have the qualifications nor would he sit still for a zoom show. Living near Toowoomba it’s very hard to find a therapist that you can see weekly or even monthly. The lack of services in our area is very poor. AEIOU have truly been a blessing for our child and family.	2/12/2021 2:30 PM
12	Profound and place more pressures and stress upon my family, that could see it fractured and burdened beyond repair.	2/12/2021 10:26 AM
13	Quite considerable. We do not have the professional experience to co-ordinate therapies at home especially with two children with severe autism and we do not receive funding we cannot afford therapies for two children. They need consistent therapy. As one of us works, coordinating therapy would fall one one parent which is too difficult	2/12/2021 9:44 AM
14	I will not be able to maintain my employment and lose my carer which i have worked so hard for. Financially, it will be devastating. I will not be able to provide for my children with disabilities a secured future (as i do not expect them to get fulltime employment as a worse case scenario) and as well as i will not be able to save for my own expense and nest egg for retirement. If you look as the option of getting a carer payment, firstly, it is not enough and secondly, the allowed work hours per fortnight you are allowed to do (24 hrs including travel time) and how much you should only be earning (270 dollars!!) Which is getting a job that pays you less than thr minimum wage which i do mot inderstand. Not all parents of kids with diability are unemployed, stay home parents or parents on the minimum wage. Some have great and amazing careers they’ve worked hard and built for years just to throw it all away.	2/12/2021 9:30 AM
15	Exhausting and overwhelming Stressful Defeated	2/12/2021 9:20 AM
16	It will impact my family and our mental health and our child with autism	2/12/2021 7:30 AM

17	not good	2/11/2021 11:41 PM
18	Significant. AEIOU allows an intensive program of therapies catered to children with autism for 5.5hrs per day, 5 days per week. I have another child just 2 years older who also has severe autism, also non-verbal, and she receives 4 hours of therapies per week in total. These must all be coordinated which adds additional stress and expense.	2/11/2021 10:45 PM
19	quite severe and limit my ability to work and perform all duties associated with family life, including take care of the needs of our other two children.	2/11/2021 10:37 PM
20	The biggest challenge is kids don’t listen to parents and like Chinese whisper game.. the information that we learn will be lost by the time we train kids. Also, for autism and early intervention teraphies under one shelter like AEIOU give the teachers the wholistic view.. in the past we used to take my kids to different teraphy centres for OT, BT and speech, as all these used to operate in sylos and focus on their goals, it used to be difficult for them to observe my child fully.. AEIOU is only source for kids with autism to become normal else sorry ….	2/11/2021 10:00 PM
21	A huge burden on our family causing extra pressure would result in a dis functional environment.	2/11/2021 9:53 PM
22	I would be overtired and not have much time for my other neurotypical child. This will result in great amount of guilt and affect my mental wellness, which will further impede on my ability to cater for my child with autism.	2/11/2021 9:49 PM
23	No peace of mind and cannot do my other household responsibilities. Deceased attention and care for the other kid. It’s hard to deliver the therapy at home as these kids take mum for granted and this causes increased stress on all of us.	2/11/2021 9:44 PM
24	A small window of time to fit therapies at home into as there are other children’s needs in our family to consider	2/11/2021 7:41 PM
25	Very difficult aeiou is the best solution for my child	2/11/2021 7:01 PM
26	Absolutely terrible as trying to organise everything my child needs through individual providers is terrible where with aeiou it is all rolled into one	2/11/2021 6:22 PM
27	significant in negative way as i do have to every thing myself.	2/11/2021 5:37 PM
28	I wouldn’t be able to work	2/11/2021 5:21 PM
29	I am full time worker not being able to provide my child with all the required support for us to conduct therapies at home and hence all the stress will come on my wife and this will lead to family disputes and stress	2/11/2021 5:00 PM
30	Stressful, overwhelming and impossible!	2/11/2021 4:42 PM
31	Unfortunate for myself and my Child. I would have to quit my job.	2/11/2021 3:47 PM
32	suboptimal for my son's development, as I do no think I would be able to deliver such coordinated program as that given at AEIOU. Trying to coordinate all the therapies, and get my son to them, would be significantly more stressful and possibly overwhelming.	2/11/2021 3:28 PM
33	The impact would be I would suffer extreme mental, emotional and physical exhaustion that would eventually lead to resentment and possibly breakdown of relationships, depression and anxiety. Eventually I would have just sacrificed my health and wellbeing and will still probably not have gotten anywhere with my child's progress. I know this because I had to co-ordinate clinics appointments with Speech & OT before coming to AEIOU, unknowingly it was straining me mentally. Emotionally and mentally I was having so much trouble switching from being a therapist to being just a Mum, I had nothing to give at the end of the day to my partner because I've just spent all day giving everything to my child, I was always doubtful, full of guilt and always questioning if I was doing the right therapy, if my child was progressing, I had so much parenting insecurity. The older my child was getting the more excluded I felt from society - my friends who all have children close to age, their kids were meeting milestones easily that we were struggling to meet even with multiple therapies, it was and still is so hard not to compare. You grieve what you lost, opportunities and a life with ease, to raise children and be confident that they will be fine when your gone. Everyone acknowledges the everyday pressure of being a parent, juggling different roles, being a mum, having a career/work, being a friend/sister/daughter/spouse, maintaining a household, looking after yourself it's hard add being a therapist without actual proper training is just another mental load a parent can not be expected to take on without dropping the other balls you are constantly juggling in the air. Before my daughter started attending AEIOU my mental load was so huge I was miserable, I felt disconnected, I felt like I was failing at being a parent. I think if I hadn't found support through the AEIOU staff and started	2/11/2021 2:53 PM

	seeing progress with my child through their therapy I would probably be a single mum by now who would be relying on unhealthy coping mechanisms.	
34	devastating and almost impossible to manage	2/11/2021 2:39 PM
35	Before we were at AEIOU and while we were getting my son diagnosed we were attempting to manage his therapies on our own. The stress it caused on my family , my marriage and our family life was overwhelming, there is no way we could have insured that intensity for a long period. We are so grateful to have the assistance of AEIOU, all of my sons supports are in one spot, I do not have to schedule when and how things are done which is a huge task taken off my shoulders. Having a child with Autism is very difficult and that is with the level of help we receive from AEIOU. Without this type of support I would not be able to manage, emotionally, mentally or physically.... I love my child but it takes so much more to parent a child with autism then it does a neurotypical child and I am forever grateful to AEIOU for their support.	2/11/2021 2:26 PM
36	My daughter would continually be behind her pears as we can not afford to miss work so she can have her appointments, 1 or 2 hours a week does not work I have tried it for 15 months . Even my daughters main stream daycare said she needs more.	2/11/2021 2:25 PM
37	Reduced therapy time for my child so less progress for her. As previously stated she has not been able to settle into a regular daycare so her socialisation would be negatively affected. My mental health would be affected as to be the primary resource coordinator as a non-autism specialist is highly stressful. My ability to work would be affected.	2/11/2021 1:18 PM
38	Without funding, financial resources impact on my family would be greatly affected. There will be less money for everything, such as food, transport, bills, therapy sessions. Having to deliver the therapy myself for over a year before starting AEIOU, was extremely stressful, there less time for work, family, rest and even then it wasn’t as successful because we aren’t professionals doing this for years, so I’m compromising on my children’s learning. The funding didn’t just affect financial resources, but everything in general, and down the chain as well.	2/11/2021 1:18 PM
39	Significant if not catastrophic. The stress of raising a child or in many cases multiple children with ASD should not be overlooked or underestimated. It is hard enough getting through each day as it is whilst running a household, holding down a job and attempting to have some downtime myself to recharge the batteries so I can do it all again tomorrow. Transferring this responsibility onto families would have severe consequences sequences and I fear would see a huge rise in mental health/ family violence/ broken households... the list goes on.	2/11/2021 1:04 PM
40	I wouldn't be able to do it. It would break me down. Mentally I would not survived because some days are good but most days are bad.	2/11/2021 1:00 PM
41	Too much. Having kids on the spectrum is really challenging, getting support from NDIS and other providers keep our sanity and giving us parents a time to recharge and be the best parents for our kids after their sessions in the Centres. If we will handle everything ourselves, I personally believe we can no longer deliver as we don’t have the know how, expertise and knowledge. We will always go back to square one with no progress.	2/11/2021 12:50 PM
42	Very hard to make my child learn from. Bloody bullshit. Rather keep my child at aeiou	2/11/2021 12:48 PM
43	The impact would be negative for my family	2/11/2021 12:46 PM
44	Drastic, I would not be able to work firstly and I would loose the home we live in just to pay for it.	2/11/2021 12:42 PM
45	Very significant. I would probably have to stop.working full time and this would further impact us financially. Plus we are not experts in autsm so it is very hard to know how best to get the help he needs. Often the good therapists are fully booked so it becomes impossible to co-ordinate between therapists which is very important. It would quickly become overwhelming.	2/11/2021 12:25 PM
46	That i would be mentally exhausted an not be able to focus on my other child. Plus my eldest child would not stop interupting his very important therapies so that he can be prepared for school an life	2/11/2021 12:21 PM
47	devastating because I would not have time, knowledge or resources to navigate the complex funding environment necessary to get our daughter the great help she currently gets from AEIOU and other organisations	2/11/2021 12:13 PM
48	I would be financially ruined and I would not be able to work due the time shortage of I needed to provide therapy for my child myself	2/11/2021 12:11 PM

49	I had tried previously before aeiou, with my son getting on hr a week speech therapy to do alternative sessions at home.And found with other commitments I was only able to do an hr a day which I felt guilty because it just wasn't enough.	2/11/2021 12:05 PM
50	Added financial, time management, and mental stress to the family. Before aeiou, we had home therapy, which we bore the cost of, with Occupational and Speech Therapists, which for us, had no observable, beneficial effect, and created huge financial and mental stress. The home environment did not work, as our child did not want to cooperate in the home environment. He does much better in the classroom environment. We continue home therapy where possible without much success.	2/11/2021 12:04 PM
51	I am not sure but i believe the stress level would increase significantly.	2/11/2021 11:58 AM
52	Horrible. After 6 months of doing it at home (before we learned about and were accepted into AEIOU) it was so difficult. I have twin toddlers who I had to find care for during his sessions and my autistic son's older sister now needs literacy support as she has failed English 2 years in a row at primary school - I can't help but feel that has so much to do with us not being able to support her better as we were so focussed on our autistic son.	2/11/2021 11:45 AM
53	Financially: We won't be able to work full time. Physically and emotionally: We will feel exhausted all the time. Relationship: Our relationship as a couple would come under strain. Our relationship as parents with our kids will be more like a liability.	2/11/2021 11:45 AM
54	I would have no time for my other child (6 months old). No time to run my household and work.	2/11/2021 11:44 AM
55	Devastating. Before we started at AEIOU my mental health had deteriorated. I was seeing a psychologist and was thinking of walking out on my family. With my husband working full time it all came down to me to arrange therapy for Oscar as well as look after my two other children. AEIOU has literally saved my family life.	2/11/2021 11:25 AM
56	Detrimental to me emotionally, as I have no support at home and financially as I will be unable to work to support my household	2/11/2021 11:24 AM
57	It will take a toll on our family life and it will make a big financial impact	2/11/2021 11:22 AM
58	Severe. With a household with 4 children, all with different disabilities, my child would not get as much treatment as he receives through AEIOU.	2/11/2021 11:20 AM
59	I would have to leave my job to cater for my childs needs and out financial situation would decline which would put unwanted stress on myself and my family	2/11/2021 11:20 AM
60	Very stressful and I have 2 asd who need a lot of special needs high demand help	2/11/2021 11:15 AM
61	We already did at home therapies before we found AEIOU. We found this very overwhelming, time consuming and costly.	2/11/2021 11:03 AM
62	Non beneficial to my children, having all the extra support and care provided by aeiou makes home time actual family time and not just constantly therapy time	2/11/2021 11:02 AM
63	Devastating for my child as I cannot manage all the therapy, work and give 100% of my time to her when I have two other younger children.	2/11/2021 11:01 AM
64	It has already been mentally physically and financially straining in every member of our household. I myself have been diagnosed with depression and am medicated due to the struggles that goes with children with autism.	2/11/2021 10:59 AM
65	Absolutely devastating to our metal health and financial situation. Our children will be severely disadvantaged	2/11/2021 10:58 AM
66	Huge. We have kids, work and school committments. Add on therapies for a severly autistic child and it just wont work.	2/11/2021 10:54 AM
67	Devastating we already struggle on one income we are living off things like after pay to get our kids back to school and pay bills	2/11/2021 10:49 AM
68	It would be detrimental to my child. I also have autism, a carer and community support. My son benefits from the services, therapy and community available through AEIOU that was never available to me as a child. If I could have been diagnosed earlier, my life could have be so different. AEIOU provides necessary and essential services for the well-being of my family.	2/11/2021 10:46 AM
69	gargantous! We have 3 small children who require a lot of our time and attention. Not only would we feel like not enough was being done for Angus, but before attending AEIOU we could not get Angus into any therapy as everywhere had enormous waiting lists. The	2/11/2021 10:46 AM

	therapy we managed to get him into was once per week for 45 hours and they charged me $200 travel each session plus $100.00 for being the last session of the day when our appointments were at 11:30am. They were an absolute waste of our funding. Rather than cut the funding, the NDIS needs to stop allowing companies to charge so much for travel and cut the last appointment of the day fee!!	
70	This is not suitable as the times available arnt always suitable and available.	2/11/2021 10:42 AM
71	unachievable	2/11/2021 10:37 AM
72	It would be a struggle,our lives are so busy already, my wife would have to quit work to cater for this	2/11/2021 10:37 AM
73	Extreme mental and physical stress, reduction in work / employment, and stress on relationships, and less improvment in my child's condition.	2/11/2021 10:34 AM
74	A massive financial, emotional, mental and physical impact. I would not be able to support the rest of my family and be there for my daughter and husband. I would not be able to work. It would mean we would have to sell our house and downsize to truely afford the care our son requires. My mental health would greatly suffer as I would be the main caregiver delivering therapies. It's would be unfair on our family dynamic.	2/11/2021 10:32 AM
75	Absolutely detrimental to our current family environment. Not only financially but from a emotional and mental health point of view as well. It is invaluable to have access to professionals who are able to provide the types of therapies required. I would not feel I could provide a sufficient level of therapy to my child at home and such this would cause immense stress and strain on myself and the family unit as a whole.	2/11/2021 10:31 AM
76	I would not be able to cope mentally. I was struggling until I discovered aeiou. I do not have the time or resources to coordinate my childs therapy. The best people to do this are the therapists at aeiou. I am not qualified to provide therapy for my child. In an already busy schedule with 2 other children under 5 it is nearly impossible to do so . I am able to get some form of respite while my child is getting early intervention at aeiou.	2/11/2021 10:30 AM
77	Very troubling, it would distract me from My work as a full time doctor, it would take my and wife and I away from also looking after our other child, the effects are huge personally, professionally and for the wider social interaction of us into the community	2/11/2021 10:25 AM
78	When we have attended individual therapies my child has not been focused. The appointment has been for approx 45mins and we usually achieve 5-10mins of participation. My child is non verbal and her concentration skills are limited so to send her to a centre like aeiou is mandatory for her to try and get a head start in life. It is slow steps for someone like my child but for her to have attention is so important. We also would not be able to afford to do speech, OT and other therapies without funding as these appointments cost so much. Early intervention for kids like my daughter is what they need. They need all the help they can get! As a parent we try our hardest to support our kids but we don't have the specialised skills behind us to make a massive difference but we can only try.	2/11/2021 10:25 AM
79	This would be impossible. I have tried doing this in the past prior to AEIOU. My son was not benefiting from home therapy as he was too reliant on me and I only saw improvement once he started attending AEIOU.	2/11/2021 10:21 AM
80	Financially we would struggle as we wouldn't be able to work full time	2/11/2021 10:20 AM
81	Severe in impacting my family. Not only financially as we both need to work to survive. But mentally and physically. We do not have the means of funds or the professional understanding of how to provide intensive therapy for our child. It is important for him to have this intensive program aeiou with ongoing therapy and family support. This will give him the best start on life as a peer and has been and incredible support system for us as a family	2/11/2021 10:14 AM
82	Working full time and paying bills along with managing a kid with Autism is going to make us crazy. Its simple way to put it.	2/11/2021 10:11 AM
83	Colossal. I have other kids and a partner who I also provide care for due to a workplace injury. Having to do all of my child’s therapies at home and via private clinics, beyond what I am already doing, would cause a lot of extra strain on not only myself, but the rest of my family as well. I would be more time strained, less financial due to extra travel and I believe my mental health would suffer as a result.	2/11/2021 10:11 AM
84	Devastating. The mental pressure of doing this on my own before we found AEIOU was debilitating for my own mental well being. Raising children is a hard job in itself however raising a child with special needs is extremely difficult. Our family doesnt have any external support to help with our children so before we found AEIOU I literally did not have a minute	2/11/2021 10:11 AM

	to myself for most of the week. It wears you down mentally, you feel helpless that you aren't doing enough. You try your best but raising a child with autism is exhausting, physically, mentally and emotionally. You also have to be there for your other children and your spouse which leaves no time to work on your own well being. Having a job would not be an option for me.	
85	Severe financial hardship which could very well lead to us losing our home and affecting our marriage potentially destroying our family	2/11/2021 10:10 AM
86	Severe negative impact on the development of the other kids as my child requires intensive input an attention. Severe financial hardship as it would mean leaving work to be a full time carer . No social interaction for my child as she was not accepted into main stream education and means no social interaction and possibly my child may end up institutionalised . Possible relationship difficulties due to these psychosocial strains	2/11/2021 10:09 AM
87	We did that and we can get anything, autistic need environment with professional team to teach and direction them. Children can't learn at home even with therapy.	2/11/2021 10:08 AM
88	Devastating. With full time work and other children, there is no way we could come close to providing the same early intervention that is provided by AEIOU. We would not be in a financial position to fund therapy at home either. AEIOU has been a live changing for our child and family.	2/11/2021 10:06 AM
89	Huge mental stress, having to be on long waiting lists for the therapist, not knowing if my chid would get the best therapy	2/11/2021 10:05 AM
90	We ran a home program for 6-9 months in the lead up to his diagnosis and then the time to get into AEIOU. Andy made some progress, but was glacial. It is also almost impossible for us to acutally get anything close to 20 hours of therapy time - I work very full time and his father already had to basicaly stop work to do this. It is very difficult for a parent who is extremely busy with limitied home time (me) or for a parent who has no therapy training to learn the skills and apply them consistently (and then to teach them to the parent who WASNT able to attend the therapy learnng opportunities themself) and with any kind of reliablity. We tried it. It was subpar and impacted on our mental health as well as being insufficient for his needs. I could not realistlically envision a future where Andy was able to attend a mainstream school with any success if we had to run it outselves and do most of the therapy ourselves. And i do see that hop enow	2/11/2021 10:05 AM
91	Extreme as I have so much to juggle already with 3 other asd children	2/11/2021 10:03 AM
92	I would face bankruptcy if I was responsible for providing all of my son's needs as well as the emotional burnout I would face. I struggle with his behaviours as it is.	2/11/2021 10:02 AM
93	completely detrimental to the physical, mental, emotional, financial health to myself, my husband, my son and especially my son with ASD. It would break us.	2/11/2021 10:02 AM
94	Substantial in the way of my mental health. I am not a qualified therapist and still need to learn everything in relation to autism myself and what my daughter would need. My relationship with my older child will most likely change due to the amount of focus I would need to put forward for my ASD daughter. Financially would be okay however, my mental health and family relationship is more value to me and my daughter than finance. I would not only have to ensure all home duties are done, errands that need to be done and also include full days of learning for my daughter which is too much on one parent.	2/11/2021 10:00 AM
95	I have major mental health issues and the AEIOU has helped immensely with the strain I am under with 3 special needs children under 5	2/11/2021 9:59 AM
96	Very stressful and impossible.	2/11/2021 9:58 AM
97	Both myself and my husband would need to quit our jobs and go on social benefits to help manage his development. This will have severe impact on our financials, mental and physical health	2/11/2021 9:57 AM
98	Mentally physically draining	2/11/2021 9:56 AM
99	I would have to quit my job and would not be able to afford rent anymore as my child needs such intense therapy I cannot work and coordinate/do all the therapy myself.	2/11/2021 9:54 AM
100	Extra time and money spent, a lot more stress in our household, more pressure on our relationships.	2/11/2021 9:54 AM
101	Absolutely immense. I would have to leave the work force which would severely impact my financial situation now and in the future (I.e. superannuation). It would also be detrimental to	2/11/2021 9:54 AM

	my mental health, my marriage and my ability to parent my non-autistic child. I would have serious reservations about our ability to cope with this.	

Q10 What were the limitations and challenges that you and/or your family experienced when trying to facilitate therapy remotely (i.e. with online tutorials / support)?

Answered: 99 Skipped: 9

#	RESPONSES	DATE
1	They mainly revolved around time. We had to take time off work, and this caused stress in our family life as we attempted to make everything work. As a result, Harry's therapy was disjointed/uncoordinated compared with attending AEIOU.	2/17/2021 10:37 AM
2	Child can not sit still therefor does not learn	2/15/2021 6:57 PM
3	I have identical triplet boys that are all ASD LEVEL 3 NON VERBAL. The expense for 1:1 supports at home would send me broke.	2/15/2021 9:50 AM
4	My child would not participate in remote therapy or online support as he is very hands on and would need to receive this in person	2/14/2021 7:06 PM
5	Our son did not engage for more than a minute or so and then it was just the therapist telling us the same things for the remainder of the session. This was both in face to face and telehealth appointments. Most local therapists that had experience in autism had long wait lists too; and when available did not allow for ongoing flexibility making holding a job near impossible	2/14/2021 4:53 PM
6	There are a lot of information and resources available on line. However every child is different and has different needs. Trying to keep Sonny confined so that a therapist could observe his behaviour for any length of time on line is highly challenging and would result in a melt down. The benefits kids with autism have of coming to a facility where all the resources are in one place and where the professional support can observe the kids together and work collaboratively to support the children with Autism is invaluable and from an economic perspective highly efficient. If we want autistic kids to develop the skills to be productive members of society programs and facilities like Aeiou are invaluable parts of this process. In the short time Sonny has intended the centre we have seen amazing progress. To see this service option taken away would be a significant setback to Sonnys development and would result be a risk to his growth and long term safety.	2/13/2021 7:31 AM
7	Having someone to ask questions to when needed	2/12/2021 6:43 PM
8	It was hard to juggle everything altogether. Finding time to take him to the therapy, school and work was to must for both of us.	2/12/2021 4:35 PM
9	Lack of therapists within our location sessions where to short and had no impact on Brody	2/12/2021 2:47 PM
10	My child would not focus, pay attention or try to do the activity’s. Meaning that even through COVID he had to attend and go to he’s appointments as he’s therapists understood this	2/12/2021 2:41 PM
11	Daniel wouldn’t sit still long enough. As a goat dairy farmer who currently milk for 14 hours any spare time I have outside of the dairy is spent with Daniel .	2/12/2021 2:30 PM
12	My child would not engage or attend in a remote environment. There would simply be little to no benefit in attempting to access supports remotely.	2/12/2021 10:26 AM
13	As the boys are only young they had not yet started therapy before attending AEIOU. The boys require help that we are not equipped in providing and we are still coming to terms with their diagnosis	2/12/2021 9:44 AM
14	it is difficult and challenging!	2/12/2021 9:30 AM
15	Online is too difficult and you don’t process enough	2/12/2021 9:29 AM
16	Child focus and attention Other children in the house Routine disruption	2/12/2021 9:20 AM
17	We can’t do it our child doesn’t react to it in appropriate way and the other kids at home doesn’t let us do anything	2/12/2021 7:30 AM
18	very hard	2/11/2021 11:41 PM
19	My child had difficulty paying attention. There are distractions in the home environment. It is always easier to be guided by someone else than by mum / dad / caregiver. My child had a lack of awareness of the technology being used so using a computer to engage with others was not engaging to him. Sitting still and paying attention are skills he is developing and online is not an appropriate forum for him to learn this. He is also a hands on child, so needs physical touch and direction. He seeks attention as a means of reward from his caregivers and this could not be conveyed through a screen.	2/11/2021 10:45 PM
20	Not applicable	2/11/2021 10:37 PM
21	Kids don’t listen to parents when it comes to therapy. Also, how can we learn and teach at the same time.. Many of us don’t even understand what needs to be done when child is	2/11/2021 10:00 PM

	crancy as when mind is agitated the strategy will never strike.. I totally disagree for remote therapies	
22	We haven’t attempted this due to our busy work commitments	2/11/2021 9:53 PM
23	My child does not focus on the screen but responds well to therapists in person. He is also more driven and keen when working in a group therapy.	2/11/2021 9:49 PM
24	I strongly believe therapy cannot be virtual or online when you are trying to provide a early intervention. The kids are not matured to understand. If they had that maturity why would they need the therapy?	2/11/2021 9:44 PM
25	Time limitations and a structured environment to learn in	2/11/2021 7:41 PM
26	Its too difficult for me i have other small children it will be very difficult	2/11/2021 7:01 PM
27	Just trying to get appointments for everything was a nightmare as they always clashed and also had to travel distances to get to them	2/11/2021 6:22 PM
28	There are always less effectivness via online therapy. Very hard to make kid sit down and focus on the therapy via online.	2/11/2021 5:37 PM
29	As mentioned since one of us is a full time employee the responsibility of catering for home therapy will fall on my spouse and this will eventually lead to frustration and family disputes	2/11/2021 5:00 PM
30	Limited times available, work and family commitments	2/11/2021 4:42 PM
31	Availability, language barriers, child had no interest in interacting remotely.	2/11/2021 3:47 PM
32	Poor access to allied health services in general, as there was little face to face access where I lived in regional Qld, and the private services that were present had significantly long wait times. Due to this, I decided to move my family back to SE Qld to access better services, namely placement at AEIOU. Trying to deliver 4 hrs a day of therapy remotely would involve my physical presence for 4 hrs and this would further exclude me being able to work as I do not have any family or social supports to assist with childcare.	2/11/2021 3:28 PM
33	My daughter didn't take me seriously, never followed instructions like she did with her therapist, it was difficult switching from therapy time to regular being at home as a family time. Some days you just don't end up doing therapy at all because either you feel unwell, too tired (from shift working), the therapy isn't getting anywhere and it's just so easy to give it up for the day and next thing you know you are not providing proper therapy.	2/11/2021 2:53 PM
34	Effectiveness is low Kids with autism are great at ignoring therapy instructions being given by parents but do feel obliged to listen to the therapists	2/11/2021 2:39 PM
35	Trying to juggle our careers, business and other children and also get to all of the therapies needed. Trying to get available times for the therapies he needed that fit around our other commitments. Trying to find therapists when ours left their position... this happened numerous times. Being put on wait lists for over 6months. The therapist prior to AEIOU only saw my son for 30min windows twice a week and therefore it was hard for him to grasp what they were trying to teach. They also didn’t seem to make progress with him. I personally felt very overwhelmed by the whole situation as my husband worked more so I had to try and navigate it all which I found very stressful and difficult.	2/11/2021 2:26 PM
36	Our child does not want to interact or engage .	2/11/2021 2:25 PM
37	The skills we are trying to teach our daughter are not on-screen skills. She has difficulty sitting still and staying focused would be impossible for her.	2/11/2021 1:18 PM
38	Learning had to be done in small sessions (less than 5 minutes) due to less interest in what or how we’re trying to teach him. Sometimes we don’t know how to react or adapt to the challenges. Trying to measure progress was a hit and miss as well. It’s like trying to diagnose your sickness online and not going to the doctors, its very hard and broad.	2/11/2021 1:18 PM
39	Trying to absorb information through online tutorials and support was a waste of time and money. Nothing can replicate the value and impact of face to face. I ended up having to cease my boys OT, psych and speech therapy over covid.	2/11/2021 1:04 PM
40	Time and technology resources, internet access is a major barrier	2/11/2021 1:00 PM
41	Limited finances and support.	2/11/2021 12:50 PM
42	Very challenging. Didnt have Aeiou would very hard.	2/11/2021 12:48 PM
43	My child thrives in the environment with other children like him and the staff at AEIOU have been a tremendous impact on his development	2/11/2021 12:46 PM

44	I have not experienced online but I don't see how it will be beneficial at all.	2/11/2021 12:42 PM
45	Our son is too young for online therapy sessions to have any chance of working and whilst tutorials can provide useful information we are not trained professionals and cannot be a substitute for them.	2/11/2021 12:25 PM
46	Jasper can not focus so was very difficult to supply the therapy	2/11/2021 12:21 PM
47	It just does not work due to the behaviour problems our daughter has and she needs the help of experienced qualified teachers to make any kind of progress. We do not have the ability to do it	2/11/2021 12:13 PM
48	I found that those online therapy sessions as not effective as face to face sessions	2/11/2021 12:11 PM
49	The most being there was such a high demand on therapist I was on the waiting list for 9 months and with high demand I was limited to the amount of therapy I could access.	2/11/2021 12:05 PM
50	As a family that works shift work, the time management is almost impossible. The changing schedule of our work and tutorials means that it is near impossible to meet those challenges.	2/11/2021 12:04 PM
51	My son wouldn't respond to online therapy	2/11/2021 11:58 AM
52	Finding care for my three other children. Their needs just fell by the wayside because I couldn't manage it all. My husband was also put on a management plan at work as his work started to slide too. My daughter started failing at school and was having behavioural issues. I had to beg others to mind the twins during sessions as we couldn't afford therapy at home and babysitting for them (which is not covered by NDIS).	2/11/2021 11:45 AM
53	We are not trained for providing therapy neither we are professionals. Moreover, my son with autism wouldn’t listen to me but his therapists. The discipline, social skills and getting ready for school can’t be taught through online tutorials.	2/11/2021 11:45 AM
54	My child can’t be involved. My child just wants to take the iPad and would have a tantrum over it. Therapist can’t see if we are doing the therapy correctly or see how child responds.	2/11/2021 11:44 AM
55	No time to do this as I had two other children in my care. Oscar also would not listen to me so we would make no progress.	2/11/2021 11:25 AM
56	Difficulty engaging the child	2/11/2021 11:24 AM
57	Not much support and my son would not respond to online therapy and me not being specialised in providing therapy, I struggled a lot	2/11/2021 11:22 AM
58	Couldn't always log in being rural. And my child doesn't concentrate enough in the home environment	2/11/2021 11:20 AM
59	It didn't work at all	2/11/2021 11:20 AM
60	It was very hard as my children need one on one attention	2/11/2021 11:15 AM
61	Trying to keep my child engaged.	2/11/2021 11:03 AM
62	Not enough time in therapy with an actual professional and lots of wait list times, no make up sessions available eg: if therapist or child is sick there is never spare appointments to make up the missed session.	2/11/2021 11:02 AM
63	My child would not listen to remote therapy, uninterested in learning this way.	2/11/2021 11:01 AM
64	There is a huge waitlist for any therapy in our area currently. Before AEIOU I could not get any therapy for my youngest son for a whole year	2/11/2021 10:59 AM
65	Working, children unable to participate due to time between places and commute	2/11/2021 10:58 AM
66	Keeping the child interested and focused. It can't be done, espeiclaly when we have to work to sustain our household.	2/11/2021 10:54 AM
67	No in home support we had it taken away with our new review plan . We had signed with a company to help us while we were waiting for them to find the right person to work with us our review came through they helped with our support for AEIOU but took away the on home support. We are struggling with trying to do things on our own and one income and no support . Trying to do therapy remotely is not as affective . Our kids struggled while at home during the lock down they are doing so much better since going back to face to face therapy and one on one support for self harming behaviors	2/11/2021 10:49 AM
68	I have learning disabilities, my partner is ESL and we do not have the resources for remote	2/11/2021 10:46 AM

	learning (computers, devises, etc).	
69	the waiting lists, we could not get our son to sit for a video call. they wasted our funding on travel and last appointment of the day fees. The therapists were young girls working on their own, fresh out of uni with very little experience in children with autism.	2/11/2021 10:46 AM
70	Not being able to concentrate in that session to focus on things that need focussing.	2/11/2021 10:42 AM
71	understanding of theory into practice	2/11/2021 10:37 AM
72	It’s a disaster, we have 2 other young children and is impossible to set aside time to do this with all 3 children around,we are not trained in dealing with autism, it is not my career and the progress we have seen in 3 weeks from the Aeiou center is amazing.	2/11/2021 10:37 AM
73	Child is not engaged, have tried it during early stages of pandemic, simply does not work! Parents are not professionally trained therapists. Children need interaction with others, which trying to do from home would be doing the opposite.	2/11/2021 10:34 AM
74	My son's behaviour decreases and he becomes very withdrawn and upset. His home is his home and not a place for intensive learning and therapy. He functions better and advances significantly in a structured environment. During Covid we did telehealth speech and OT and reports from both his specialist said his functions delinced in this period due to lack of engagement.	2/11/2021 10:32 AM
75	It was not possible.	2/11/2021 10:30 AM
76	Not enough understanding or engagement	2/11/2021 10:25 AM
77	Not being able to sit. Didnt understand what was going on Was not successful at all	2/11/2021 10:25 AM
78	My son has trouble transitioning, which meant I couldn’t take him to different centres to receive therapy. Mobile therapy was too expensive.	2/11/2021 10:21 AM
79	Keeping the attention of our son is a struggle in this type of environment	2/11/2021 10:20 AM
80	Not personalised to our son as an individual. Every child with autism learns and thrives in different ways	2/11/2021 10:14 AM
81	My kid would never pay attention or sit at once place unless physically interacted or supervised. Online experience had been terrible.	2/11/2021 10:11 AM
82	My child wouldn’t engage in online support even with one to one support from me	2/11/2021 10:11 AM
83	Lack of cooperation from our child. He does not cope well in unfamiliar environments or with unfamiliar people so shuttling him around to multiple places was exhausting and stressful for him as well as myself. He did not take any therapy in whatsoever because the process of getting him to and from appointments was so distressing. Online services were not helpful as there were too many distractions at home.	2/11/2021 10:11 AM
84	My child cannot concentrate for long periods via screen. My child would not sit down and she found this distressing and running away with the screen device . This coupled with trying to keep other siblings away from her meant I had to cut down hours from work so both me and can stay at home to try and facilitate therapy session. No continuity as therapy would end up stopped just to manage distress	2/11/2021 10:09 AM
85	It’s hard to make my child settled and teach him remotely. learning face to face with a good environment and lots of different things.	2/11/2021 10:08 AM
86	Time constraints to give provide the same length of time in therapy. We cannot afford to drop hours at work. Of course we will always do our absolute best to learn and fit therapy in to our routine, but it is not even close to comparable as having Lachlan attend the center	2/11/2021 10:06 AM
87	It not appropriate for my child as he needs face to face sessions	2/11/2021 10:05 AM
88	The theory is all well and good. But the practical application in your own home, with your own child, when you are an introvert with no teaching or therapy experience is extremely challenging / limited. Cooridinating things so both parents can attend/view (so the blind dont have to lead the blind) is also virtually impossible (or has to be done in the evening when everyone is exhausted)	2/11/2021 10:05 AM
89	Couldnt get him to engage	2/11/2021 10:03 AM
90	My son doesn’t care for visual or online support and there would be no engagement by him whatsoever.	2/11/2021 10:02 AM
91	Time limitations due to work hours. Lack of understanding on how to deliver support. My	2/11/2021 10:02 AM

	son not in an environment where he would always be able to participate. Having long wait periods to access trained professionals. The cost of sessions for therapy. - very high.	
92	I would be okay in the way of online therapy however some days our internet will get switched off due to upgrades (more frequently lately)	2/11/2021 10:00 AM
93	3 children all with needs i am only 1 person	2/11/2021 9:59 AM
94	Very difficult and stressful, no progress happened during these online sessions….	2/11/2021 9:58 AM
95	Time restraints, home environment too restrictive and familiar for the teraphy to have any effect.	2/11/2021 9:57 AM
96	Uninown	2/11/2021 9:56 AM
97	My child would/could not listen or participate because our home environment was far too distracting for him.	2/11/2021 9:54 AM
98	It is not as engaging for our child and sometimes he just does not concentrate (and the session is wasted).	2/11/2021 9:54 AM
99	Connal has very very limited ability to settle to a task and he would simply not settle to any kind of virtual task.	2/11/2021 9:54 AM