



# Submission on supporting young children and their families early to reach their full potential

Noah's Ark Inc  
February 2021

## About Noah's Ark Inc.

Noah's Ark is currently celebrating its 50<sup>th</sup> anniversary of working with children with disabilities and their families. Noah's Ark's establishment in 1971 coincided with the end of the routine institutionalisation of children with a disability. It was one early attempt to provide support to families in a society unfamiliar with children with disabilities living in the community. Providing havens, advice and support to families supporting their child with disabilities develop at home was new and pioneering work.

In the early 1990s, following the passing of the Disability Discrimination Act (Australian Government, 1992), Noah's Ark became involved in supporting the inclusion of children with disabilities in Child Care. This was also a pioneering role at the time. Mainstream early childhood services had been designed while children with disabilities were isolated from the community. Noah's Ark continued this direct involvement in inclusion in Child Care for the next two decades and continues to directly support inclusion through the Victorian Kindergarten Inclusion Support program.

Noah's Ark worked closely with Early Childhood Intervention Australia (ECIA) and the Victorian Government during the 2000s to reform practice in ECI services. The model changed from group programs for children with disabilities to providing services that worked with children and their families at home, in early childhood settings and other places of importance to the child. This approach was informed by reviews of the international literature (Moore et al, 2010), the translation of research to practice in the USA and Australia (Forster, 2017), and the growing understanding of how children, including children with disabilities, develop (National Research Council, 2000). It is an approach based in making a material change to the lives children and families live. The outcomes of this understanding of how best to support the development of children with disabilities is summarised in the ECIA National Guidelines: Best practice in early childhood intervention (ECIA, 2016). Noah's Ark played a central role in the introduction of the Key Worker model (Alexander & Forster, 2012).

Throughout the past 50 years there have been three drivers in the development of services for children with disabilities. The first has been to develop methods that can support a child to best adapt to the impact of their disability, given in most cases a disability is lifelong. The second has been building the capacity of families to nurture their child and support his or her development. The third has been to build acceptance in the community for the participation of children with a disability and, through that acceptance, open to children with disabilities the opportunities afforded to other children. Although it is now 50 years on from the closing of institutions, that participation is not guaranteed.

Noah's Ark welcomes the opportunity to comment on Supporting young children and their families early to reach their full potential.

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# 1. Introduction

## 1.1 Context for children with a disability

The development of services for children with disabilities were the responsibilities of State and Territory governments until recently. These governments have had very different approaches to supporting children with disabilities, both over time and across jurisdictions. The governing principle for all government policies and programs directed toward children with disabilities must be that they are in the best interests of the child. Children with disabilities are among the most vulnerable members of our community. As the Australian Government's Attorney General's Department states:

*“Under the (Convention on the Rights of the Child) CRC, countries are required to apply the principle of best interests of the child. The principle applies to all actions concerning children and requires active measures to protect their rights and promote their survival, growth, and wellbeing, as well as measures to support and assist parents and others who have day-to-day responsibility for ensuring recognition of children's rights. It requires all legislative, administrative and judicial bodies and institutions to systematically consider how children's rights and interests are or will be affected directly or indirectly by their decisions and actions”. (Australian Government, 2021).*

Prior to the introduction of the NDIS, children and families experienced significant limitations in Early Childhood Intervention Services (ECIS) in Victoria, in which Noah's Ark was based. Under the State system the available funds were substantially less than today. Families had to wait for a place in a service to become available. Each year as one group of children commenced school another group moved into the ECIS to take up their 'places'. The group leaving to go to school entered into an entirely different funding system, managed by the Education Department's schools division.

The NDIS introduced vertical integration into funding for people with disabilities. Rather than funding changing at each transition point in a person's life, for example from early childhood to school and school to post school, and families having to seek new funding under different guidelines, there is now continuity of support. This is a major achievement. However, the introduction of vertical integration has come at a significant cost to the horizontal integration of children with disabilities into early childhood policies, systems, and services. Children with disabilities have become disconnected from early childhood policy, its language, and its desired outcomes. Children with disabilities are now in a policy context dominated by concerns about adults. In Victoria, children with disabilities are no longer connected to the evolving understanding of child development that engages other child and family services including child and maternal health, family services, child protection and community health. They are also more disconnected from early childhood education services and the professional networks which have been strengthened over time (DET, 2009). The connection to the early childhood sector is important to children as it supports both an understanding of child development and the role of families as well as referrals to early childhood intervention, referrals between services and participation in children's services.

In transitioning to the NDIS, young children have become better resourced, but less understood. They are certainly not as well connected. As the ECEI Reset review has identified, seven years after the start of the NDIS there are still no guidelines which clarify either the purpose or outcomes to be expected for children or their families from the services funded by the NDIS (NDIS, 2020a). Significantly more needs to be done to ensure the NDIS is being implemented in the best interest of the child.

## 1.2 Risks to the best interests of the child

**Risk 1:** Young children do not access services early and this compromises the potential benefits of early intervention services.

Contributors to this risk include:

- The lack of community understanding about the NDIS.
- The disconnection of the NDIS from the early childhood referral network.
- The NDIA administrative processes discourage some families seeking support.
- The length of the NDIA administrative processes.
- The length of waitlists for services before a child with a Plan can access an ongoing service.
- Children who are vulnerable are not well supported.

Anecdotes from staff who have been working in early childhood intervention for many years suggest the number of young children aged 0-3 years receiving a service has reduced. This includes reports from within Noah's Ark and the broader service networks. The way in which the NDIA releases data does not make it transparent at what age a child receives a plan. Data by age rather than data by 0 – 6 years would clarify the situation.

The ECEI Reset project consultation report has identified the need to improve communication as a major area of action for the NDIA (NDIS, 2020a).

In 2019 we participated in discussions with a broad range of stakeholders in the early childhood sector which made it clear that the understanding of referrals pathways that had existed prior to the introduction of the NDIS had broken down. Given the pandemic in 2020 it is unlikely that there has been the opportunity to clarify pathways.

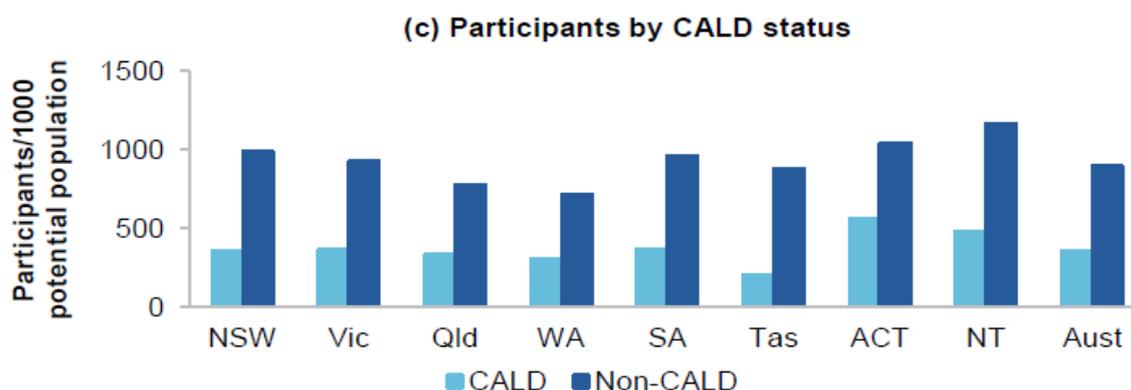
Anecdotally families were reporting delays within the NDIA decision making process, although the pandemic in 2020 makes this difficult to comment on.

The age a child gets a Plan is only one indicator of when a child can access a service. Anecdotally we know in Victoria that many services have closed their waiting lists and we have heard from families that it can take 9-12 months to access a service they want. The NDIS needs to monitor when children start a full service. An inability to access services is likely to be significant contributor to the underspending of Plans. In September 2020, the rate of utilisation of plans in Victoria was 59% (NDIS, 2021a).

The ECEI Reset project consultation report has identified that there are issues for children from low socio economic, remote and vulnerable backgrounds in accessing and gaining support (NDIS, 2020a). Anecdotally we hear that families from culturally and linguistically diverse (CALD) backgrounds find it particularly difficult to negotiate the NDIS and that the use of interpreters continues to be complex.

The following table from the Productivity Commission Report on Government Services indicates the under representation of people from CALD backgrounds in the NDIS across all ages of NDIS participants (Productivity Commission, 2020).

## NDIS participants by special needs group, as at 30 June 2020



***Risk 2: Young children and their families do not gain access to a quality service and this compromises their experience of and the benefits from early childhood intervention.***

Contributors to this risk include:

- The lack of guidance from the NDIS about what best practices and its benefits should be.
- The lack of access to independent advice and information about services and benefits.
- The difficulty for families choosing services when they are not familiar with those services and not well informed about service types and potential benefits.
- A lack of choice when recommended services have a long waitlist and the felt pressure to find 'any' service.
- Poor family wellbeing.

The lack of guidance has been identified in the ECEI Reset project consultation report as problematic and we welcome the recommendation for the development of operational guidelines that are available to families in the community (NDIS, 2020a. p14).

While the ECEI Reset project has identified that the NDIS needs to do more to engage families, it is not proposing new approaches (NDIS, 2020a). One of the issues that has not been identified and discussed is the need for families to have independent advice. This would seem to be a first base requirement for a model of service based on choice. Independent advice can only be provided by organisations that have neither an actual or perceived conflict of interest in the operation of the NDIS, including the NDIA, its contractors or services funded through the NDIS. The NDIS needs a network of independent advisors who are trusted in their community.

The ECEI Implementation Reset Consultation Report has identified the complexities of families having to make decisions about services when they are unfamiliar with services are still coming to terms with the implications of their child's disability (NDIS, 2020a. p54). It has not identified a new strategy to address this, beyond further funding to existing partners. There is a pressure on parents to use any service available, because of significant delays in accessing a 'recommended' service. This situation highlights two fundamental weaknesses in the NDIS. According to the ECEI Report approximately 80% of families/carers of young children aged 0-6 years old are either self-managed or plan-managed and they have a

choice of using either NDIS-registered providers or non-registered providers (NDIS, 2020a. p44). The number of registered providers in Victoria is falling, with 726 active providers to the 0 – 6 years age group in July–September 2020, compared to 1637 providers registered and active since the beginning of the NDIS (NDIS, 2021). The second weakness is the failure to address the workforce shortage in personnel trained to work in early childhood intervention. Addressing these factors is critical to ensuring all children get the benefits of quality early intervention.

One of the important factors for children which is neither recognised nor discussed is family wellbeing. Family wellbeing can impact directly on a child, given the significant role parents have on supporting their child's development. In the Productivity Commission Report on Government Services for disabilities there is a measure for carer health and wellbeing (Productivity Commission, 2020). While this measure is for carers of people aged 0-64 receiving Commonwealth disability services and is therefore only indicative for families with young children, it is significant. Carer health and wellbeing is reported using two measures:

- The proportion of primary carers of people with disability who feel satisfied with their caring role.
- The proportion of primary carers of people with disability who do not experience negative impacts on their wellbeing due to their caring role.

While the Productivity Commission notes it is desirable to have a high or increasing number of carers feeling satisfied with their caring role and who are not experiencing negative impacts on their wellbeing due to their caring role, this is not the case. Nationally in 2018, only 22.1 per cent of primary carers of people with disability were satisfied with their caring role and only 43.7 per cent did not experience negative impacts on their wellbeing due to their caring role (Productivity Commission, 2020. p15).

Given the critical role of families in supporting the development of their child and the potential impact of their wellbeing on their child's development it is a matter of urgency that the NDIS independently monitors and reports on the health and wellbeing of families who have a young child with a disability.

***Risk 3: Young children do not participate in children's services and this compromises their social development and learning.***

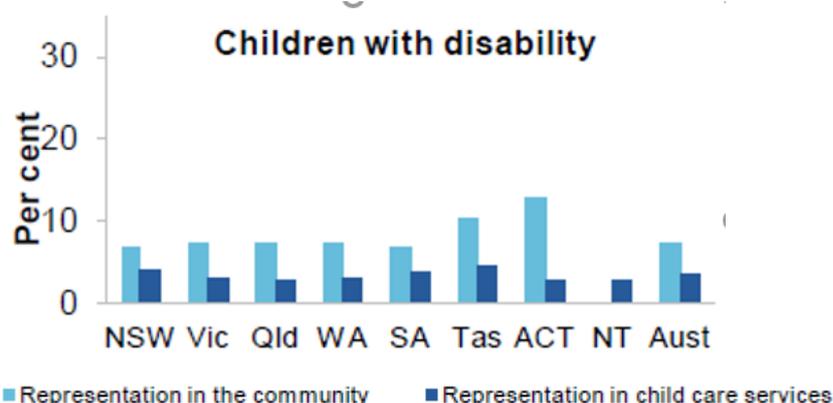
Our understanding is that support to build acceptance in the community for the participation of children with a disability and, through that acceptance, open to children with disabilities the opportunities afforded to other children is not being systematically supported.

Contributors to this risk include:

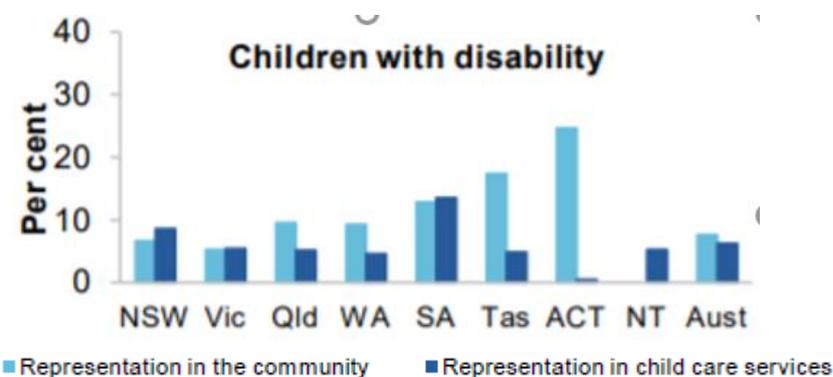
- A lack of access to children's services including Child Care and Preschool.
- A lack of support to educators to understand the needs of children with disabilities and support their participation.
- A lack of support at entry into school.
- A lack of clarity about which level of government should support children's participation.

The Productivity Commissions' Report on Government Services indicates that children with disabilities are significantly underrepresented in Child Care and there are significant differences nationally in Preschool participation, although the State data on Preschools is not fully comparable (Productivity Commission, 2020).

Proportion of children aged 0–12 years attending CCS approved child-care services who are from special needs groups, compared with their representation in the community (Productivity Commission, 2020, p3).



Proportion of children enrolled in a preschool program in the YBFS who are from special needs groups, 2018, compared with children aged 4–5 years in the community (per cent) Productivity Commission, 2020. p3).



Anecdotally we have heard many stories of educators being less supported since the change to the NDIS because services working with the child with a disability may not communicate with the children’s services or may have little or no understanding of the early childhood environment or they are not able to translate their understanding of the child’s development into ideas that can be incorporated into an early childhood program. This situation needs to be monitored as a matter of urgency.

Anecdotally we are also hearing about children starting school without the necessary information being provided to the school, in part because families assume if they have an NDIS Plan they do not need to provide additional information, leading to children not meeting deadlines for school’s funding and support being delayed until later in the year.

The bigger question for children with disabilities and their families is whether either the NDIA or the State governments will take responsibility for addressing these types of issues. If they do not, then the developmental opportunities for children with disabilities are being seriously compromised.

The section on early childhood development in the Principles To Determine The Responsibilities Of The NDIS And Other Service Systems (COAG, 2015), which was an agreement on roles between the NDIS and State Governments, says that the role of the NDIS ‘includes Information, Linkages and Capacity Building focusing on children with disability (or development delay) where this improves awareness, builds community capacity, creates networks or ‘circles of support’ for children and parents’ and ‘the coordination of NDIS supports with the systems providing early childhood support and other relevant service systems. We have not seen any evidence that these have been put in place.

Perhaps what is more concerning is in the section on disabilities in the Productivity Commissions’ Report on Government Services which reports on outcomes for NDIS participants. There are no reportable outcomes for children from 0-14 years. The report has measures for choice and control, social participation of people with disability and the use of mainstream services by people with disability. These are important measures. However, in each instance the data reported on is only for people with disabilities aged 15–64 years (Productivity Commission, 2020).

It is difficult to comprehend how this is considered adequate given 169,748 active participants in July – September 2020, or 41% of NDIS participants, were aged under 15 years (NDIS, 2021). Given “*What doesn’t get measured doesn’t get managed*”, it is a significant risk to young children.

It is also unclear who in NDIS Management structure has specific responsibility to ensure that the interests of the 41% of participants in the NDIS are aged between 0-14 years as no position specifically includes children and young people in its title (NDIA, 2021). The coordination of NDIS supports with the systems providing early childhood support will need a significant level of authority to be able to negotiate meaningful outcomes with State and Territory systems. State and Territory systems will also need to improve their performance to create progress.

## **Summary**

In conclusion we would observe that, from our experience, the benefits of vertical integration of children with disabilities into an NDIS attempting to meet the needs of all people with disabilities aged 0-64 years has come at a significant cost to the vertical integration with the early childhood services and policy context. The loss of a specific focus on the challenges for young children’s development, their families, and access to mainstream early childhood services are currently offsetting benefits from the additional resources available in the NDIS. This leaves young children with disabilities currently facing a number of developmental risks.

## 2. Responses to the recommendations

Our responses to the recommendations in the ECEI Rest consultation report are grouped under three headings. These are:

- Improving communication and engagement.
- Supporting fair and equitable decision making.
- Improving the operations of the ECEI approach.

### 2.1 Improving communication and engagement.

The ECEI Reset Report identifies a series of areas that relate to improving communication and engagement. A principle of early intervention is that the pathway to the service is straight forward so that families can be quickly referred, and children access services as soon as possible.

#### 2.1.1 Communication

Three of the recommendations for improved communication are designed to create greater clarity of purpose for ECEI funded services. These recommendations are:

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

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

**Recommendation 3:** Develop and publish new Early Childhood-specific Operating Guidelines – so our decision-making processes and best practice evidence are transparent and implemented consistently by partners and NDIS planners.

While we support the intent to improve communication about the ECEI approach, in our view this will only be successful if it is done in the context of improving communication within the community and services networks. Services for young children and their families need to be embedded in their communities.

Renaming the ECEI Approach (**Rec. 1**) may contribute to a better understanding of the NDIS, but communications need to be understood by a range of families, in different communities and be situated in the broader service system. Clear communications about the intent of the ECEI Approach and the Agency’s commitment to best practice is also necessary (**Rec. 2**). It is important to consider how this information is to be made relevant to different communities and the importance of ‘ambassadors’ which might include parent advocacy peak bodies (e.g., CYDA, ACD) and cultural organisations. Platforms such as the Raising Children Network should also be considered because they provide multi-media communications for all parents. Publication of early childhood specific Operating Guidelines (**Rec.3**) is also welcome as part of an overarching communication plan. In addition to Operating Guidelines, we would also like to see a range policy papers on the EC Approach which are not evident to date.

#### 2.1.2 Engagement

There are also recommendations with a focus on providing greater assistance for children and families from backgrounds in which they are disadvantaged socially, economically and/or geographically. This includes the provision of supports to better identify, understand,

and respond to, young children and their families experiencing social disadvantage, providing culturally appropriate services and resources, and strengthening access to services for families living in remote areas. These recommendations include:

**Recommendation 7:** Improve sector-wide understanding of how to identify families and young children experiencing disadvantage or vulnerability and tailor culturally appropriate services and resources so they can benefit from early interventions support.

**Recommendation 8:** Implement tailored methods of delivering supports for young children and their families living in remote and very remote areas to strengthen access to services.

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

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

Parents of children newly diagnosed with a disability or developmental delay are challenged by both their personal situation and the bureaucracy and nature of services they encounter when they seek assistance. Families are challenged by their lack of knowledge of disability, its consequences, what can be done to ameliorate its effect and the long-term consequences. Disability can raise family and personal issues for parents and the extended family. It raises questions of failure or blame and in some communities and some cultures disability still carries a stigma. Some families are better resourced to adapt to their situation and seek out services.

In a study of families transitioning to the NDIS in NSW, (Broaden et al., 2020), the nature of the resources that families draw on is described at an individual, community and service level. Families who had successful experiences transitioning could identify contributing factors such as educational and social capital that helped them navigate the NDIA. Factors that had an influence included education, employment, training, social support networks and the family's general socio-economic status. The families with the highest resources were best placed to engage social supports, prepare, and articulate their needs.

At a community level, some families were better connected and were able to contact their friends, extended family, or peer support networks to gather information and develop a foundational understanding of the NDIA and gain confidence about what was required. Other families made connections online, although some were negative, or had relationships with services they could draw on.

At a service level, those who had already entered the NDIS had a more positive view of their transition. Families who had poor interactions with services or the NDIA were at a higher risk of delays, gaps in services and frustration.

In another survey of families, (Ranasinghe et al., 2017), the majority of parents reported that they had no difficulty registering for the NDIS, but those who did have difficulties reported on the complexity of the application form, the lack of information on the website, problems related to computer skills, lack of information about the support available, parents' education and information provided by diagnosing or treating health professionals.

Strategies to support families experiencing disadvantage need actions targeted towards individuals, communities and services. In a systematic review of the literature on hard-to-reach families, Boag- Munroe and Evangelou (2010) noted that engaging families is complex. The consistent message across the literature is that there is no one simple solution and policymakers need to combine consistent and sustainable effort with creativity and a holistic approach.

To engage individual families, services need to be skilful at:

- Communication
- Flexibility
- Adaptability
- Contextualised and community-based work
- Careful design of appropriate settings
- Relationship building (Boag- Munroe & Evangelou, 2010. p27).

At a services level, the priority is the development of strong interagency practices. In a summary of practices to engage families in child and family services, McDonald (2010) identifies four key strategies. The first involves outreach or “*go to where the families are*”. Some families will not attend a service if it is unfamiliar, appears intimidating or is in an inconvenient location. The second approach is to *promote and deliver services in a non-stigmatising and non-threatening way*. Some families need to engage initially in a more informal context. Indigenous and culturally and linguistically diverse (CALD) families may be intimidated by services due to their past experiences and/or cultural difference. The third is to *employ strategies that empower families’* ability to solve problems for themselves, rather than promoting a relationship of dependency. The fourth strategy notes the importance of *developing relationships* at three levels: relationships with families, relationships with communities and relationships with other services.

The Centre for Child Health (2010) notes that factors that make families vulnerable, including lack of trust, limited confidence and personal resources, also act as barriers to them accessing services. It emphasises the importance of building trust through shared decision making. While individual services need to build their capacity to engage disadvantaged families, services networks need to develop stronger links and build outreach capacity to reach families that are disconnected. The consensus of the reviews is the need for multiple strategies, for families, communities, services and service networks.

a) Cultural Awareness and sensitivity

We welcome the recommendation that highlights the need for sector wide understanding of how to tailor culturally appropriate services and resources (**Rec. 7**).

We note that there are no specific recommendations to support access and engagement with Aboriginal and Torres Strait Islander children, families, and communities, despite the worrying data that the average annualised committed supports, utilisation and level of self-management for this community of ECEI participants is lower, or significantly lower, than non-Indigenous participants (NDIS, 2020a, p. 45). We are aware of the Aboriginal and Torres Strait Islander Engagement Strategy (NDIA, 2021) with its focus on engaging in the ‘proper way’ and are interested to learn how the EC Reset recommendations interact with the goals and priority areas outlined in other NDIS Strategy proposals (e.g., Cultural and Linguistic Diversity Strategy (NDIS, 2018) and Rural and Remote Strategy) (NDIS, 2016).

b) Community Support Coordinators

While we acknowledge the role of the EC Partners in identifying and helping families experiencing social, economic, or geographic disadvantage and linking families to local services and networks (**Rec. 10 & 11**), we do not think this strategy is an adequate response to the challenges of engagement as identified above. EC Partners may not be perceived as ‘local’ or connected to early childhood networks. EC partners also have multiple roles and it is proposed that they have a role in Assessment, making their capacity to engage with disadvantaged families more difficult and making some families wary. We recommend the use of ‘community support coordinators’ to provide independent advice and support,

including promoting peer support networks that connect families and help them navigate the service system. These could be located with parent organisations such as Children and Young People with Disability Australia (CYDA), Association for Children with a Disability (ACD), and in other culturally appropriate community organisations, as well as linking into early childhood networks.

## 2.2 Supporting fair and equitable decision making

The second group of recommendations addressed in this submission focus on fair and equitable decision making. Recommendations 9, 13, 15 & 18 are to implement Independent Assessments (IA), clarify developmental delay criteria use EI criteria under Section 25 of the Act, use the EI criteria under 25 of the Act to make decisions about access, and provide guidance about reasonable and necessary supports for children with ASD. These recommendations are:

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

**Recommendation 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.<sup>1</sup>

**Recommendation 15:** Use the early intervention criteria, under Section 25 of the NDIS Act (2013) to make decisions around access to the NDIS for all young children.

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

### 2.2.1 Decision making

Noah's Ark is keen to respond to the upcoming report and recommendations regarding clarification of the Developmental Delay criteria under Section 25 of the Act. (**Rec. 13**). We are particularly interested in the criterion that will be used to determine eligibility thresholds with an understanding that these are typically determined through standard deviations, percent delay or cut off score. Given the IA Framework indicates that "The NDIA acknowledges that decision making cannot be automated..." (NDIS, 2020b p24), it is important for transparent communications about how decision for eligibility will be made by delegates and to ensure a focus on prevention.

Noah's Ark approves of the recommendation to use the early intervention criteria under Section 25 of the NDIS Act to make access decisions (**Rec. 15**). However, clarification is required in relation to decision making for infants under 12 months of age following the removal of List D and an understanding that the proposed approach to IA does not include children under the age of 1 year. Consideration must also be given to whether 12 months of age is a sensible cut-off point given the dynamic and unpredictable developmental needs of young children with a disability/developmental delay over the first three years of life.

In relation to the removal of List D, there are advantages and disadvantages in having an approach where admission to the NDIS is in part defined by a child's diagnosis. The advantages are that families don't have to demonstrate that their child will benefit from early intervention. It is not unrealistic to expect that children with the conditions in List D would benefit from these supports. This approach provides certainty of support and it reduces the

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<sup>1</sup> Specifically, establish clear definitions and thresholds for the criteria 'substantial delay in functional capacity' and 'extended duration'.

administrative burden on the NDIA. The disadvantage is that diagnosis is not a measure of functional capacity or predictor of participation. Eligibility by diagnosis may lead to some children receiving supports who are unlikely to benefit. In principle, it is possible to argue that the focus of eligibility should remain on children's capacity to function and participate and the focus on diagnosis should reduce. It will require a highly specialised workforce and a carefully considered approach that aligns with the best available evidence to undertake such assessments.

The issues raised by using diagnosis as a mechanism for entering the Scheme are reduced if the plans developed for the child are reflective of their individual needs and functional capacity. Good planning processes should intentionally allocate resources. If the expectations and outcomes related to the early intervention approach are clear, then these become a mechanism for making informed decisions about a child's progress and the supports they need.

Noah's Ark is keen to respond to the upcoming guidance about reasonable and necessary supports for children with ASD (**Rec. 18**). These guidelines should provide a mechanism for supporting fair and equitable decision making. We encourage the Agency to provide guidelines for the range of developmental disabilities, rather than a sole focus on ASD.

#### 2.2.2 Independent Assessment for children with disabilities and their families

Noah's Ark supports the need for a more consistent and equitable approach to NDIS access and planning decisions and a focus on individual's functional capacity and the influence of environment, health and other individual factors outlined in the IA Framework (NDIS, 2020b). However, there are specific issues that must be considered in relation to children with a developmental delay and/or disability and their families. Furthermore, an IA approach is contrary to what we know enables access to, and engagement with, services for families experiencing disadvantage.

*“Early childhood assessment is a flexible, collaborative decision making process in which teams of parents and professionals repeatedly revise their judgments and reach consensus about the changing developmental educational, medical, and mental health service needs for young children and their families”.*  
(Neisworth & Bagnato, 2005, p. 2)

IA is not a new idea and there is much to be learnt from others about the risks and benefits of such an approach. For example, independent doctors and clinical psychologists are contracted for the Disability Support Pension assessment, and the Australian Government utilises a national panel of assessors for Supported Employment assessments. In Victoria, the Department of Education and Training contracts an independent provider to conduct assessments for the Program for Students with a Disability. In the USA, many states use a vendor based system for conducting independent assessments for EI services. Other US states ensure multi-disciplinary authentic, criterion and norm-referenced eligibility assessments, through the local EI service providers who meet practice standards and utilise an established suite of measures.

## *An Overview of Independent Assessment for children with disabilities and their families*

In addition to learning from the experience of state/territory, commonwealth and international approaches to IA, Noah's Ark also recommends that the NDIS revisit the approach to IA through the lens of participants – children and their families. The proposed approach for 7-65 year old participants presented in the corresponding consultation papers (NDIS, 2020b) has 6 steps within the access and eligibility process and a further 7 steps within the planning process. That is 13 steps before the family can begin to engage with service providers and implement the plan. This arduous process does not address the current challenges described in the planning consultation paper, including that the NDIS is confusing and frustrating and is too complex and difficult to navigate (NDIS, 2020b. p5).

The proposed approach to IAs for young children described in the ECEI Implementation Reset Project Consultation Report is said to “uphold(s) the early intervention best practice” (NDIS 2020a). This requires consideration of the (often evolving) environmental context of children and their families. Whilst some best practice elements have been addressed in the criteria in the IA Framework (NDIS 2020b), (including the need for suitable governance, future research, and coverage of developmental domains, reliability, validity, and functional content with the chosen measures), there are additional criteria that should be considered for young children and their families. Macy & Bagnato (2010) offer a framework of standards for judging assessment in EI that include eight elements: Acceptability, Authenticity, Collaboration, Evidence, Multi-factors, Sensitivity, Universality and Utility. Two of the issues in these standards that we believe have not been given due consideration in the IA Framework include:

### a) Collaboration

Collaboration with parents is obviously critically important and has been discussed throughout this submission. Collaboration with a multi-disciplinary team of professionals is also essential. Parents of young children with a developmental delay or disability have typically been worrying about their child's development for a long time before they interact with the NDIS. They have sometimes been involved in screening assessments through their local Maternal and Child Health Nurse, medical assessments through the GP, developmental assessment with a Paediatrician, and specialist assessments with the audiologist or speech pathologist. The approach proposed in the IA Framework is not clear about the extent to which information provided by these other professionals is either welcome or utilised. The synthesis of perspectives from parents and a range of professionals provides more robust information on which to make decisions about eligibility and planning. It is interesting to note that the revision to Part C (Children 0-2 years) of the Individuals with Disabilities Education Act (IDEA) for how eligibility for services is determined and provided in the USA, highlights the need for caregiver involvement, in conjunction with the requirement for team involvement, with at least two early interventionists from separate disciplines participating in the evaluation and planning process (CDCP, 2011).

### b) Multi-factors

The IA Framework indicates that “Some people present with a degree of complexity that requires more in-depth deliberation than assessment findings can provide on their own. The complexity, nuances and intertwining factors may need to be examined more closely or may prompt more questions that need to be answered” (NDIS, 2020b. p.24). We suggest that children, by the very nature of their dependence on parents/caregivers, and the evolving and unpredictable nature of their developmental trajectory at this early stage of life, present with complexity that requires a more robust approach to assessment, including the synthesis of ecological data. This ecological approach, which includes collection of data

across *multiple* methods, sources, settings, and occasions, is described in Macy & Bagnato standards (2010) as 'multi-factors'. Such an ecological approach to assessment should also include assessment of family support needs. This focus on family support needs is reflected in the US legislation for children 0-2 years in the IDEA, which indicates that the initial assessment refers not only to that of the child, but also of the family's needs which must be completed prior to the first Individual Family Service Plan meeting (CDCP, 2011; Hallam et al, 2014).

*Issues with the NDIS approach to assessments for children 1-6 years*

It is beyond the scope of this submission to comment in detail about the suite of assessments intended for use for children 1-6 years of age. We have read the IA Selection of Assessment Tools paper (NDIS 2020d) and the Addendum for children 1-6 years (NDIS, 2020e), and note there are some aspects to the proposed approach and measures that are not supported by research on child assessment for eligibility in ECI. These are presented below.

Best practice in child assessment	Issues
<p>Families have a central role in their child’s life and an intimate knowledge about their child’s functioning, participation, and interactions that supports assessment (DEC, 2015; Guralnick, 2016; Neisworth &amp; Bagnato, 2005)</p>	<p>The proposed IA Framework focuses a standard suite of assessments but does not appear to include an approach to soliciting further information from families regarding the child’s interests, abilities, and needs across multiple methods, sources, settings, and occasions. Nor does it appear feasible to gather this information, along with establishment of rapport with children and families, observation, report writing and completion of the four required assessments in the designated 3-hour time frame.</p>
<p>Infants with an identified disability have immediate access to appropriate services and supports, irrespective of whether they display a functional impairment at this early stage of life (Bagnato, Smith-Jones, Matesa, &amp; McKeating-Esterle, 2006; Bagnato, Matesa, Fevola, &amp; Smith-Jones, Dunst, Trivette, Appl, &amp; Bagnato, 2004; Mott, &amp; Dunst, 2006).</p>	<p>Whilst eligibility based solely on diagnosis does not provide sufficient information regarding the need or level of supports required, it should provide easy, prompt access to appropriate services and support for those children whose characteristics warrant it. With the removal of List D, there is risk that infants with an identified disability will not have a streamlined approach to the Scheme. NOTE: The recent pathway implemented for young children with a hearing loss appears to be successful in terms of prompt access to the Scheme.</p>
<p>A preventative approach to ECI ensures easy, prompt access to suitable services and supports early in life, including for those children identified with emerging developmental needs. (Bagnato, Smith-Jones, Matesa, &amp; McKeating-Esterle, 2006; Bagnato, Matesa, Fevola, &amp; Smith-Jones, Dunst, Trivette, Appl, &amp; Bagnato, 2004; Mott, &amp; Dunst, 2006).</p>	<p>ECI services in Victoria are reporting a significant reduction in the percentage of young children 0-3 years entering the Scheme since the NDIS commenced. This is contrary to the underlying rationale for ECI. Given the developmental significance of the earliest stages of life, prompt access to support should be provided as early as possible.</p>
<p>Eligibility assessment should include family support needs (CDCP, 2011; Hallam et al, 2014).</p>	<p>The proposed approach doesn’t appear to include assessment of the family preferences and support needs in regard to their interactions with their children and their own well-being that will have an impact on child functioning.</p>
<p>Assessment must include opportunity for sensitive feedback from a trusted professional to ensure a shared understanding of the assessment findings and to develop a plan for next steps (Neisworth &amp; Bagnato, 2005).</p>	<p>There is no mention in the consultation papers of how feedback will be provided to families, apart from a report. The estimated time provided in the IA report for the suite of assessments to be conducted for children 1-6 years is 115-135 minutes. This leaves 45-65 minutes for any observation, gathering of further information on personal and environmental factors, individual goals (NDIS, 2020b, p24), and report writing. It appears unlikely there is time for careful feedback and appropriate emotional support at this critical time for families within the 3-hour time-frame.</p>

<p>Families require reliable information, support, and continuity of care from professional/s they trust and have an ongoing relationship with</p>	<p>Parents will not have an ongoing relationship with EC Partner Assessors – nor should they. The relationships should be built with the services they choose to engage with.</p>
<p>Quality assessment is conducted by suitably skilled and qualified practitioners with supervisory support to enable them to maintain ethical standards and recommended practices (Neisworth &amp; Bagnato, 2005).</p>	<p>With the ongoing difficulties with recruitment and retention in the ECI sector, it is likely the trend for EC Partners recruiting new graduates will continue. Conducting child assessment requires suitably qualified, trained and experienced practitioners, governance structures and practice standards.</p>
<p>There is a growing body of research that supports the use of authentic assessments to understand the child’s developmental needs and determine eligibility (Bagnato, Goins, Pretti-Frontczak, &amp; Neisworth, 2014; Bagnato, Smith-Jones, Matesa, &amp; McKeating-Esterle, 2006; de Sam Lazaro, 2017; DEC 2015; Macy &amp; Bagnato, 2010; Neisworth &amp; Bagnato, 2005).</p>	<p>There is weak evidence supporting use of standardized, norm-referenced tests to identify eligible young children with delays and flaws with using these tests for determining eligibility (Bagnato et al., 2007). The IA framework indicates that “The ideal solution would be a single, easy to use, generic, standardised and norm referenced assessment tool... (NDIS, 2020b, p.23). We suggest that an ideal solution would be development of authentic assessments that incorporate a range of information sources across settings, rather than standardised and norm referenced tests.</p>
<p>Practitioners should use clinical reasoning to support determination of the child’s eligibility and plan for next steps (Bagnato, Smith-Jones, Matesa, &amp; McKeating-Esterle, 2006; de Sam Lazaro, 2017; DEC 2015; Neisworth &amp; Bagnato, 2005; Squires, 2015).</p>	<p>Robust clinical reasoning relies on expertise and experience of the assessors and clear practice guidelines. This is particularly important for children with developmental concerns (e.g., behavioural, socio-emotional) that are particularly sensitive to certain settings, people or environments. Assessment and practitioners’ competencies are critical to effective assessment for eligibility, planning and monitoring of child functioning and family needs. The following are some recommended tools that address this issue:</p> <ul style="list-style-type: none"> <li>- DEC Program Appraisal Scale for Assessment (Neisworth &amp; Bagnato, 2005).</li> <li>- ECTA Practice evaluation tools for assessment <a href="https://ectacenter.org/decrp/topic-assessment.asp">https://ectacenter.org/decrp/topic-assessment.asp</a></li> <li>- ECPTA example of professional standard curriculum modules <a href="https://ecpcta.org/curriculum-module/standard-4-assessment-processes/">https://ecpcta.org/curriculum-module/standard-4-assessment-processes/</a></li> </ul>
<p>Eligibility assessment should include information obtained about the child’s skills in daily activities, routines, and environments such as home, pre-school, and community - multiple methods, sources, settings, and occasions (Bagnato et al., 2014; DEC, 2015; Hebbeler &amp; Spiker, 2016).</p>	<p>Conventional norm-referenced tests are designed to estimate a child’s level of functioning under a controlled and pre-set series of conditions. Any suite of proposed assessments must be used to complement other information gathered from multiple people in multiple environments across multiple occasions (e.g., authentic assessments).</p>

<p>Child assessment requires respect for language and cultural differences (de Sam Lazaro, 2017; DEC, 2015).</p>	<p>Norm-referenced assessments are rarely sensitive to differences in children that are a result of disability, cultural, or linguistic differences. Cross-cultural validity has not been established for the PEM-CY, PEDI-CAT Speedy or PEDI-CAT ASD.</p>
<p>Assessment should include information from knowledgeable, informed, and familiar people in the child’s life, (e.g., teachers, therapists) to report on the child’s functional competencies displayed in meeting the challenges of real-life routines (Bagnato et al., 2014).</p>	<p>The extent to which reports from therapists and teachers that know the child well is not clear in the IA Framework. A synthesis of perspectives from parents and a range of professionals provides more robust information on which to make decisions about eligibility and planning.</p>
<p>Decision making for eligibility should be based on consensus of information from multiple settings and individuals (Neisworth &amp; Bagnato, 2005).</p>	<p>The proposed approach suggests that a single Planner/Assessor will be making a recommendation to the delegate, rather than a consensus from a multi-disciplinary team.</p>
<p>Assessments have a range of functions that should complement each other (e.g., eligibility, early identification, planning, monitoring progress and measuring outcomes) (Neisworth &amp; Bagnato, 2005).</p>	<p>The IA process sets itself apart from other assessments, with no link to the comprehensive multi-disciplinary assessments required for monitoring progress and measuring outcomes or assessments required for diagnostic purposes (e.g., ASD). In this context, assessments that allow for the monitoring of child functioning data is critical in the decision-making required for families to continue (or not) with the NDIS system.</p>
<p>Eligibility assessments are more effective and useful when also used to inform the delivery of early intervention services (Macy et al., 2005; Macy &amp; Bagnato, 2010 ).</p>	<p>Although it is understood that the primary purpose for the selected measures is an assessment of functional capacity for NDIS access and planning decisions, further consideration should be given to other assessment needs such as monitoring progress, and child and family outcomes. Assessment that only reflects the obligations of each system or program fails to consider the impact of multiple assessments on the child and family.</p>
<p>Assessments should integrate with measures used in mainstream and specialist services wherever possible (Neisworth &amp; Bagnato, 2005).</p>	<p>There is no indication that assessments for purposes other than NDIS access and planning decisions will utilise previous assessments conducted by other professionals in order to avoid duplication and additional stress for children and their families. For example, the Vineland Adaptive Scales (Sparrow, Cicchetti &amp; Balla, 1984) may be used for Victoria’s Department of Education and Training requirements for Program for Students with a Disability funding or may be used as part of the diagnostic assessment for ASD.</p>

We recommend the NDIS develop an approach to improving early identification, referral and eligibility practices that is better integrated into the current state-based early childhood service system, respects the role of families in their child's life, is in line with best practice guidelines and also ensures a more consistent and equitable approach to NDIS access and planning decisions. Established international frameworks might prove helpful (Dunst, Trivette, Appl, & Bagnato, 2004; Guralnick, 2019).

An integrated and developmental approach also requires further research to examine:

- The role of conventional and authentic assessments in determining eligibility.
- The degree to which conventional tests accomplish or do not accomplish eligibility and planning decisions.
- The development of more appropriate authentic measures that will enable the right children to receive the right support at the right time.
- The development of an assessment system that allows for tracking and monitoring of child progress and family needs.

### 2.3 Improving the operations of the ECEI approach.

There are three recommendations proposing an increase in the scope of the current activities of the ECEI operations. The most significant change is increasing the age group to under 9 years of age. It is also proposed to expand activities in short term supports. Finally, there is an intent to focus on research and outcomes. The recommendations are:

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

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

**Recommendation 20:** Undertake further ongoing research and study on the outcomes of young children after receiving early intervention support, to inform future policy and operational changes.

#### 2.3.1 Areas of expansion

Noah's Ark is very pleased to see the recommendation to extend the EC Approach to include children under 9 years of age (**Rec. 14**). This is consistent with the national early childhood policy context (e.g., Early Years Learning Framework) and aligns with the World Health Organisation's definition of young children. This is one way of responding to the needs of children with a developmental delay or disability and acknowledges the need for a holistic family-centred approach throughout the child's early years. It also helps address the stress for families who currently navigate the dual transition from the ECEI Approach to the adult-centric focus of the Scheme for 7-65 year old's through the Local Area Coordinators (LACs), whilst also managing the transition from preschool to primary school. Efforts will need to be made to operationalise this change, particularly in relation to the interaction with education and community programs that provide services to these school-aged children.

In contrast, the proposed approach to increase capacity of EC Partners to provide Short Term Early Intervention (STEI) (**Rec. 12**) is a particular concern to Noah's Ark. This does not appear to address the interface with mainstream and community services, such as Community Health and other child and family community programs, currently available to children who would benefit from short-term supports. Rather, it is adding a service within the disability service system – the NDIS.

Noah's Ark supports the need for further investment in services for children who would benefit from short-term supports, but recommend the investment is with mainstream and community services, not EC Partners. This would avoid the risk of children being unnecessarily engaged with a disability service, rather than participating in programs in their local community.

Noah's Ark also recommends that national practice guidelines for STEI be developed that support consistent evidence based practices, including "group, individual or parent programs, capacity building therapy, and other activities used to build a child or family's capacity in environments familiar to them" (NDIS, 2020a. p7). STEI best practice guidelines would complement the current national guidelines (ECIA, 2016).

We welcome the recommendation to undertake research on child outcomes (**Rec. 20**) and encourage the Scheme to broaden its research agenda to include investigation of family outcomes, children's inclusion and participation in pre-school, school and community life, the role of conventional and authentic assessments in determining eligibility, the degree to which conventional tests accomplish or do not accomplish eligibility and planning decisions, and the development of more appropriate measures.

### 2.3.2 Supporting best practice.

Noah's Ark is pleased the NDIA is seeking to support the implementation of best practice in the NDIS. The relevant recommendations are:

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

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

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

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

Noah's Ark welcomes the recommendation to enhance compliance to the Practice Standards on EC Supports and increase awareness of best practice providers (**Rec 6**). Data indicates that 80% of families of young children partly self-manage, fully self-manage or plan manage their funding and a choice to access non-registered providers (NDIS, 2020a, Exhibit 14, p48). Whilst non-registered providers are required to comply with the NDIS Code of Conduct, there are no further requirements in relation to the NDIS Practice Standards on Early Childhood Supports (NDIS, 2020f). Our concern about the lack of mechanisms for ensuring compliance to quality practices is heightened due to the lack of accessible information provided for families on best practice to support them in making informed decisions. Noah's Ark recommends mandatory registration with the NDIS Commission for all early childhood providers and a requirement that self-managed and plan-managed participants use only registered providers. This will need to be supported by funded initiatives to develop a suitably trained workforce.

Support with implementing a child's plan in order to help families connect to the right services and supports is also beneficial (**Rec. 16**). These recommendations must be considered in light of a broader strategy that reinvigorates an integrated service system. The sector has suffered significant disruption to the integration of services across health,

education, and community programs, and also across local, state, and federal government services. An integrated service system across all jurisdictions, levels of government and services must be a primary focus of the EC Reset. The focus on promoting peer support networks in order to connect families and help them navigate the service system would be better placed with parent advocacy bodies such as Children and Young People with Disability Australia (CYDA), Association for Children with a Disability (ACD), and other similar peak organisation, rather than EC Partners.

We are very pleased to see the recommendation that works to actively encourage capacity building in natural settings (**Rec. 17**) in line with principles of best practice in ECI but require further information about how this will be operationalised. We recommend that the NDIS review the whole approach to funding EC supports to align with best practice.

We are concerned by the recommendation that EC Partners be empowered to provide families with clear advice about the best providers for their child and family (**Rec. 19**). As we have indicated elsewhere, EC Partners have multiple roles and, in their situation, actual, potential and perceived conflicts of interest will arise. Such an approach requires clear guidelines to mitigate conflict of interest. This further role increases the power of the Partners to influence their local market. Once again, our preference is the resources of 'community support coordinators', including parent bodies (e.g., CYDA), which are better-placed to provide accessible and non-biased information to families about the benefits of using registered providers and resources on how to make informed choices about high quality services.

### 2.3.3 Transitions

The final area we wish to comment on is recommendations about transitions. There are three recommendations which aim to improve the current progress review process, ensure providers are using the provider outcomes report and offer families a transition-out plan:

**Recommendation 21:** Improve the existing annual progress review process for young children, to support families to celebrate the achievement of reaching their goals and outcomes and transition out of NDIS supports to the next stage of their lives.

**Recommendation 22:** Ensure providers are using the recently introduced 'provider outcomes report', as a mandatory measure to evaluate the effectiveness of their supports and services.

**Recommendation 23:** Offer families of young children a 'transition out' plan for up to 3 months' duration, to support them to transition to the next stage of their lives, if they are no longer eligible for the NDIS.

It is interesting that the Scheme anticipates children will be exiting early intervention, given the narrow population it is targeting. The ongoing belief that children will improve through early support and 'transition out' of the NDIS is also of interest. We are keen that the NDIA publish its data and the assumptions supporting this expectation.

Despite this lack of clarity, it's important that the EC Reset address transitions. Improving the annual progress review process to celebrate achievement and focus on strengths as well as offering a transition-out plan where children no longer need the support of the Scheme are both welcome strategies (**Rec. 21 & 23**). Key Workers at Noah's Ark have been concerned about the current practice which sees parents informed that their child is deemed ineligible for the Scheme, typically at 7 years of age, without appropriate discussion and support to engage with other services that are available to them. This has been a particular concern over the past 12-months when families were managing lock-down restrictions due to COVID-19 and they were losing relationships with service providers.

Noah's Ark favours the use of a Provider Outcomes Report to increase transparency and ensure accountability for outcomes and quality service provision (**Rec. 22**). However, Key Workers indicate that the current reporting template is repetitive and difficult to use. In particular, Key Workers have expressed concern about being professionally compromised when the family is engaging more than one provider and they don't agree with what has been written by clinicians from another service.

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