



**Submission to the
Joint Standing
Committee on the
National Disability
Insurance Scheme**

NDIS Planning

September 2019

Noah's Ark Inc

1283 Malvern Road
Malvern, Victoria 3144

Submission to the Joint Standing Committee on the National Disability Scheme Inquiry: NDIS Planning

About Noah's Ark

Noah's Ark is a non-government organisation that has been in operation since 1971. Noah's Ark provides early childhood intervention (ECI) services to children with disabilities and other additional needs and their families and carers. Noah's Ark operates from 20 centres across metropolitan and regional Victoria, as well as one centre in the ACT and another in Albury NSW. Last year these programs reached over 2,200 families. Noah's Ark currently receives funding from the Victorian Government (Department of Education and Training) for the delivery of ECI services and has regional involvement in the Kindergarten Inclusion Support, Pre-School Field Officer and Parent to Parent Programs. In addition, Noah's Ark provides training and resources nationally and internationally. Noah's Ark has been active in the development of services for young children with a disability both in Victoria and nationally and has strong links to the early childhood intervention field internationally.

Noah's Ark has been involved in the National Disability Insurance Scheme (NDIS) from its commencement, through our services for children in the Barwon and ACT trials. Currently we are involved in the roll out throughout Victoria. Since the introduction of the NDIS, Noah's Ark has increasingly supported children in primary school in addition to its previous roles in the early years.

Noah's Ark welcomes the opportunity to comment on NDIS Planning.

John Forster
CEO

Summary

The National Disability Insurance Scheme (NDIS) is a major service for children and young people in Australia. Nearly half the participants in the NDIS are under 19 years of age. There is a major discrepancy in what the NDIS is perceived as and what it does. The NDIS was designed for adults and continues to be presented and managed as if it is a Scheme for adults. This is not in the interests of the participants in the NDIS. There needs to be a radical transformation of the NDIS so that it is informed about and responsive to children and young people. As the National Disability Insurance Agency (NDIA) is the Gateway to the NDIS and the Planning process is the point of access, this transformation needs to occur within the NDIA and to the planning process. It is a matter of urgency.

This submission is in three parts. The first part outlines the problems emerging from the adult centric design of the NDIS. In this section the following areas are addressed:

- The contribution that Early Childhood Intervention (ECI) can make to the NDIS achieving its goals
- The data that 38% of participants in the NDIS are aged under 14 years and 46% are aged under 19 years
- The current failure of the NDIS to respond to the needs of children under two years of age and the mismatch between the current entry process managed by the NDIA and best practice in supporting infants and toddlers
- The need to simplify entry into the NDIA to the establishment of eligibility and funding allocations and increase support to families to understand best practices in services for their children and best practice in service planning.

The second part of this submission directly responds to the questions raised by the Joint Standing Committee on the NDIS.

The third part illustrates the discussion through two case studies.

Recommendations:

1. That the NDIA develop its expertise in working with children and young people through developing expert advisory committees specifically focused on providing advice on children and young people by building the internal capacity of the NDIA by further recognising and supporting its Early Childhood Branch; and developing Branches specifically focussed on children aged seven to 12 years and 15 - 18 years.
2. That the NDIA review its communications and structure to adequately recognise the level of participants aged under 19 years.
3. That the NDIA urgently investigate why so few children under two years of age are accessing services; review its rationale for providing access; move to a risk minimalization approach; and monitor future access closely.
4. That the NDIA clearly delineates that the purpose of the Gateway is to establish eligibility and the allocation of funding and that this should be achieved in the least onerous way, particularly for families first experiencing disability, disability services and government services.
5. That the NDIA recognise the importance of the planning that needs to occur when a family is working with a service to develop actions to support a child's development and make sure that its processes does not cause confusion or stress.
6. That the NDIA support families to understand the NDIS and make informed choices by publishing program or funding guidelines that clearly articulate the purpose of the NDIS and its funding in terms easily understood in the community, and that it publishes accessible information about desirable outcomes and best practice.

Part One: Children and Young People

1.1 Why are Early Childhood Intervention services for young children important?

Early Childhood Intervention (ECI) for children with a disability supports the aim of the NDIS to enhance the independence and social and economic participation of people with a disability. ECI also fits with the insurance approach of the NDIS as it creates the foundation of a sustainable scheme. Investing wisely in the early years of development has been clearly demonstrated to reduce long-term costs¹. Early intervention can be powerfully instrumental in giving children and families a strong foundation for later development and participation.

Best practice in early intervention for children has a dual focus: promoting the development and well-being of each child, as well as building the capacity and supporting the wellbeing of their family².

- a) For children, the aim is to promote the child's development of functional skills that will enable them to participate meaningfully in family and community life. Not providing such support effectively can incur costs in several ways:
- In some instances, early intervention can address an emerging developmental problem so effectively that the problem is resolved, and the child no longer needs more intensive levels of support. Without such support, problems will escalate and become increasingly difficult (and costly) to manage, thereby incurring ongoing financial claims upon the NDIS.
 - In most instances, children's developmental disabilities are not transient and are sufficiently severe to require ongoing support. Early intervention can ameliorate the impact of the developmental disabilities on children's development and ability to participate meaningfully, thereby reducing the demands on the family and other services, and their associated costs.
 - Children with developmental disabilities are at their most vulnerable when they are very young and their relationship with their caregivers is just developing and most at risk of being compromised. The failure of children to develop strong relationships with the key adults in their life has lifelong negative implications.

Overall, the failure to provide effective early intervention for children with disabilities will have long term negative consequences for their development and capacity to participate in the family, education and community. It will result in them needing more costly forms of care and support across the life span.

- b) For families, best practice in early intervention supports family functioning and builds parent capabilities during the difficult period starting from the identification of the child's developmental disability, seeking diagnosis and the realisation of the potential implications of the condition for the first time. The full implications of the child's

¹ Phillips, D. A., & Shonkoff, J. P. (2000). *From neurons to neighborhoods : the science of early childhood development*. Washington, D.C.: Washington, D.C. : National Academy Press.

² Early Childhood Intervention Australia. (2016). National guidelines: Best practice in Early Childhood Intervention. Retrieved from <https://www.ecia.org.au/Resources/National-Guidelines-for-Best-Practice-in-ECI>

developmental disability may only become evident over time. Families experience a range of additional stressors, including: the need to for more information about their child and what to do; interpersonal and family distress; the need for additional resources and threats to their confidence in parenting their child³. The impact of these stressors varies according to the experiences of parents, the size of family networks and the resources available to families.

The stressors experienced by the parents or carers of young children with a disability are on top of the significant demands of raising any young child. They can reduce the ability of families to provide the essential developmental experiences needed by young children to grow and learn successfully³. When effective support is not provided, there are likely to be worse outcomes for the family and the wider society. These can take several forms:

- The demands of parenting a child with developmental disabilities often prevents one of the parents (usually the mother) from working, thereby reducing both the family income and the contribution that the family makes to social productivity as workers and taxpayers⁴.
- Having a child with developmental disabilities increases the level of stress on parents, leading to higher incidence of depression and other stress-related conditions, all of which have additional treatment costs to society⁵.
- Children with developmental disabilities are more likely to be neglected or abused⁶, with adverse effects upon their development and well-being and higher societal costs in the form of child protection and other services⁷.
- In some instances, families find the experience of having a child with a disability so burdensome that they relinquish the child into state care, which has a very high cost.

Overall, the failure to provide appropriate and effective support to families will lead to poorer outcomes for parents and families and additional costs will be borne by the family and the wider society.

1.2 Children and young people are nearly half the participants in the NDIS

The latest quarterly report identifies that 13% of participants in the NDIS are under seven years of age. 25% of participants in the NDIS are aged between eight to 12 years. Combined, 38% of participants are under 15 years of age. If the participants under 19 years of age are included, then nearly half NDIS participants, or 46%, are children and young adults. Given the actual profile of participants, the focus, design and expertise of the NDIA does not reflect the population it is serving.

³ Guralnick, M. (2005). An overview of the developmental systems model for early intervention In *The developmental systems approach to Early Intervention*: H. Brookes Publishing Co.

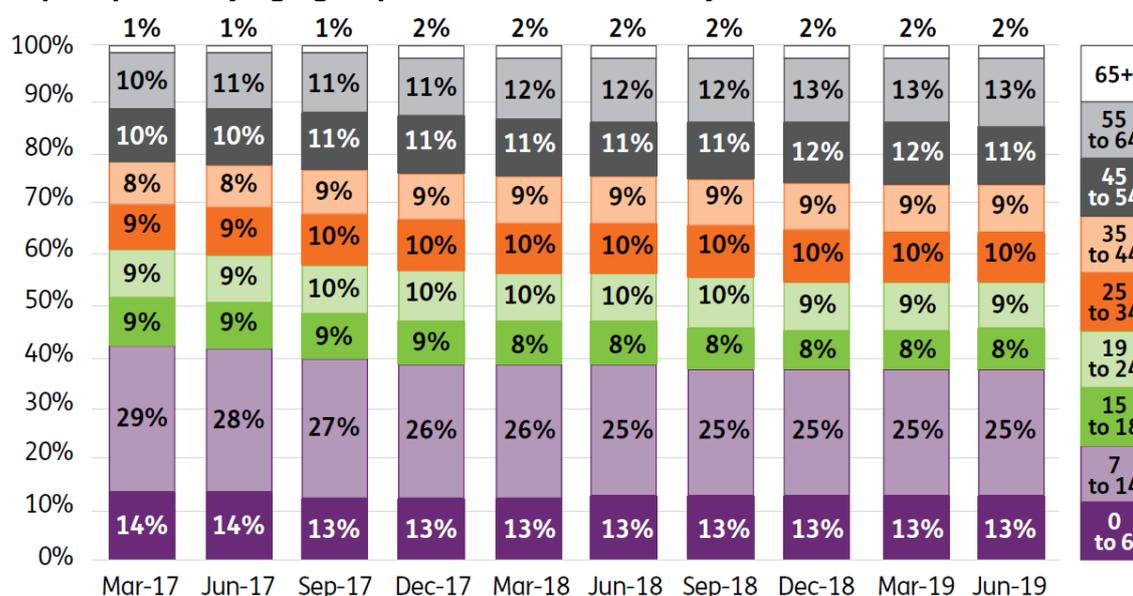
⁴ Australian Bureau of Statistics. (2012). Australian Social Trends. Retrieved from <https://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4102.0Main+Features30Jun+2012>

⁵ Totsika, V., Hastings, R., Emerson, E., Lancaster, G., & Berridge, D. (2011). A Population-Based Investigation of Behavioural and Emotional Problems and Maternal Mental Health: Associations with Autism Spectrum Disorder and Intellectual Disability. *Journal of Child Psychology and Psychiatry*, 52(1), 91-99. doi:10.1111/j.1469-7610.2010.02295.x

⁶ Sullivan, P., & Knutson, J. (2000). Maltreatment and disabilities: A population-based epidemiological study. *Child Abuse & Neglect*, 24(10), 1257-1273.

⁷ Moore, S., Scott, J. G., Ferrari, A. J., Mills, R., Dunne, M. P., Erskine, H. E., . . . Norman, R. E. (2015). Burden attributable to child maltreatment in Australia. *Child Abuse & Neglect*, 48, 208-220. doi:10.1016/j.chiabu.2015.05.006

Participant profile by age group over time cumulatively



Source: COAG Disability Reform Council Quarterly Report, June 2019

To develop a proportionate focus on children and young people the NDIA urgently needs to initiate new advisory structures so that people with expertise in the areas of children, young people and their families can assist the NDIA to develop the appropriate systems to support what is nearly half the participants of the NDIS. The current advisory structures, as illustrated by the work of the Independent Advisory Council (IAC), are essentially focused on issues related to adults. While the IAC acknowledges children in its work, it does not have either the focus or the specialist advisors required to examine the needs and promote the interests of children and young people. Specific and suitable recognition is required.

The Australian Government has limited experience in services for children with a disability. The Australian Government only has a research base for children with autism. When the Australian Government introduced Helping Children with Autism and Better Start programs, these programs were supplementary to State and Territory programs. The existing State and Territory programs had a strong focus on families. The development of the NDIS appears to have been almost exclusively informed through a health perspective. It has not drawn on expertise in the education sector, which has played a primary role in research on early childhood intervention. In the USA, for example, the national lead agency for early childhood intervention is the Office of Special Education Programs.

Recommendations:

That the NDIA develop its expertise in working with children and young people through the appointment of specific expert advisory committees focused on providing advice on children and young people and by building the internal capacity of the NDIA, by further recognising and supporting its Early Childhood Branch and establishing Branches specifically focused on children aged seven to 12 years and 15 - 18 years.

That the NDIA review its communications and structure to adequately recognise the level of participants aged under 19 years.

1.3 The failure to support infants through the NDIS

There appears to be a dramatic decrease in the number of young children receiving early intervention as a result of the introduction of the NDIS. We cannot be categorical about this as the NDIA does not release information on participants by specific age. The issue of the youngest children not receiving services was initially raised with us by the parent organisation the Association for Children with a Disability (ACD). We confirmed it through our own data. In August 2019 Noah's Ark was working with 31 children aged under two years out of a population of 1704 children under seven years, or 2%. This is a significant decrease since services were funded by the state government.

We have subsequently confirmed that there are very small numbers of the youngest children with NDIS plans in discussion with other disability services organisations and the Victorian Department of Health and Human Services (DHHS). This situation is also being reported by colleagues in other states, who have suggested that the access to NDIS of children under three years of age needs to be monitored urgently.

We know two families whose babies were diagnosed with significantly disabling syndromes in utero. Despite prompt contact with the NDIS, the babies were aged five and seven months old before they received their first plan and were able to access supports. Such lengthy delays create an unacceptable risk to the child's development and the family's wellbeing.

While there are potential transitional issues, it is also reported to us that the NDIS has adopted a different approach to funding young children with a disability than was the practice in the past. Specifically, children are only getting plans when they have a demonstrable functional deficit arising from their disability. There appears to be a disconnect between access to the Scheme through the identified disabilities in List D and the actual receipt of supports. In addition, where List D is being applied it is being used in our experience to refute eligibility for babies that have complex genetic disorders not specified on List D. They are being refused eligibility as the "disorder" is not on List D.

The changed approach represents a significant departure from ECI as risk minimalization. It highlights a lack of understanding in the NDIS planning approach of early development, the role of families and the need to support families to provide the best environment to foster their child's learning and development. It also indicates a lack of understanding about how disability impacts on children's development.

a) Why is risk minimalization important?

The risks to development associated with many disabilities are well understood, for example the impact of different genetic disabilities. While it is not possible to predict the exact impact of a disability on a particular child, it is possible to predict the range of likely impacts. This means it is possible to prepare a child's family to both the developmental risks faced by their child and how they can best respond to the support their child's developmental needs.

Through providing the most supportive environment for the child and providing the child with the best developmental opportunities the intention is to minimize the impact of the disability on the child's development.

b) Why is intervention in early childhood particularly important?

Early intervention is particularly important in early childhood because it is the period in which humans experience their most rapid growth. During this period the foundations for the future adult develops. There is enormous development in the brain which is influenced by the experiences a child has. It is also a significant time because young children's brains have neuroplasticity. This includes functional plasticity, when the brain is able to move

functions from a damaged area of the brain to other undamaged areas. It also includes structural plasticity, which involves the brain changing physical structure as the result of learning. Typically, the number of neurons in the human brain increase until adolescence. Early intervention from birth to adolescence which strengthen functional brain activity are critical to achieving functional independence, a central tenant of the NDIS.

c) Why is a child's environment so important?

The risk to a child's development comes from both the impact of their disability and the capacity of the environment in which they live to respond. Historically, there was a debate about the relative influence of 'nature' or 'nurture', or genetics and environment. The science has established that development is the result of a complex interaction between these two factors. A child's capabilities impact on how they interact with others in their environment and this in turn is influenced by how key adults interact with the child. An environment that is not supportive of the child, for example as the result of deprivation or 'toxic stress,' damages the development of any child across multiple dimensions.

d) Why do children with a disability face particular risk?

The impact of a disability on a child's capabilities can limit the child's interaction with the key adults in their life. Many disabilities limit the capacity of children to interact with adults in the same way as their typically developing peers. This reduces the triggers that children usually provide to promote interaction with adults. For example, if a disability limits a child's ability to verbally initiate or respond to an adult then the adult may not feel motivated to interact as they otherwise would. The adult may develop responses which are not helpful, for example talking all the time because the child is not responding. The adult may stop interacting. Depending on the situation what may be required is that the adult pause for a much longer period to let the child respond. Supporting the adult to change their response to meet the child's needs is essential to giving the child the best learning opportunities. Adults need support to understand how to promote the child's learning.

a) Children learn all the time, not in 'special learning sessions'

Children learn new skills, whether language, physical, social or cognitive skills through a process of constant interaction and practice throughout the day. Learning occurs when the child is interested. Learning occurs during everyday situations like bath time and mealtimes. A child's learning is not linear and so those adults who spend significant time with the child have to provide and take advantage of the opportunities as they arise. To effectively support the development of a child with a disability the key adults spending time with the child need to understand their complex learning needs. They may need professional support to do this. An approach in which all the learning is supposed to happen during the therapy session by a professional will not be effective. For example, if the only way a child learnt language was through a fortnightly visit from a language teacher then they would not learn to talk. Language needs constant interaction in which to develop. The same is true of other aspects of children's development.

b) What is the role of therapists and teachers?

Therapists and teachers have a very important role in understanding complex learning needs and different strategies that may be effective for children with specific disabilities. Their role is to make sure those adults who spend time with the child understand these strategies so that the key adults can provide the development opportunities when the opportunity arises. The key adults may choose to work on those strategies that they consider will provide the greatest benefit from the perspective of the family.

At present in Australia, access to functional learning is problematic through the NDIS as qualification categories exclude Special Education Teachers - specialists in supporting access to learning independent functional skills that support community participation; a somewhat perplexing decision.

c) What is the empirical evidence for developmental risk minimalization?

The scientific evidence on the development of children is based on the whole population of children and children who have experienced environmental deprivation. The range of impacts caused by disability means that the interaction between disability type and environment is difficult to study. However, it is essential to base early intervention for children with a disability on what is known about children's development in general. Children with a disability are children first. To suggest otherwise is to suggest they are not children.

d) A planning approach designed for children

The current planning approach does not demonstrate an understanding of the factors that impact on a child. It considers the child in isolation from their environment. It does not recognise how children develop. It does not show any indication that early intervention for young children should be a matter of urgency. It needs to be redesigned with appropriate professional advice immediately.

Recommendation:

That the NDIA urgently investigate why so few children under two years are accessing services, review its rationale for providing access, move to a risk minimalization approach and monitor future access closely.

1.4 Designing access to the NDIS that supports children and families

In the NDIS the role of Planning has become a major focus. Yet its utility is actually to provide a Gateway to enable children and adults with a disability to receive direct supports through access to the Scheme's funding. In the future the largest number of new participants in the NDIS will be children. Is it fit for purpose?

a) How does the NDIS establish eligibility and funding?

Entry to services has certainly become more onerous since the introduction of the NDIS. In the Victorian ECI systems this gateway was called 'Central Intake' and it was administered by the Department of Education and Training (DET). Central Intake was staffed by specialists in early childhood and disability. The role of these teams was to establish eligibility, provide informational support about the nature of ECI services and to provide linkages and supports while children and families were waiting to access Early Childhood Intervention Services. The priority was for children to access services as quickly as possible, although waitlists often frustrated this intention. The resources to Central Intake were kept to a minimum to maximise the direct services to children and their families.

Under the NDIS, the Gateway has become much more complicated. Determining eligibility and funding allocation now involves a Planning Process that includes setting 'goals' and developing a 'plan'. In the Victorian system the setting goals and developing of plans was not done by Central Intake. It was something that families did directly with the services that was supporting them as a necessary step in deciding how to support their child's development.

b) What is the purpose of the NDIS Plan?

The purpose of the NDIS Plan is to determine eligibility and the level of funding allocated. The goals required by the NDIS are not based on the families' priorities and the Plan is not a detailed proposal for how to support the child's development. Instead the family sets goals which are consistent with the purpose of funding under the NDIS. It is not clear why this

mechanism is used. In other situations, the purpose of funding is set out in program or funding guidelines. Such guidelines clearly articulated what the funding is for. For families that are new to disability, disability services and government funding programs, the use of funding guidelines would be far more transparent. They would help families to understand the situation, whereas the current Planning process makes things more complicated.

The Plan is also a needs assessment to determine the level of funding a child is going to receive. As a need assessment, it is focused on deficits. It requires reports on what the child can't do and the problems this causes for the child and the family. This can be very negative experience. It is not helpful to call this a planning process. A plan based on deficits is not best practice. While processes used by Early Childhood Early Intervention (ECEI) Partners attempt to support families, the underlying decision making remains the same.

c) How do families know what services and supports they can get?

An underlying assumption in models that rely on markets leading to better solutions is that consumers make rational decisions. Making good decisions relies on being informed. Unlike many adults in the NDIS, who have a history of experiences, exposure to services and past opportunities to explore interests, families first experiencing a child with a disability do not. In the absence of clear funding guidelines that describe the purpose of the funding program then it is difficult for families to understand what the situation is. How are they then to make good decisions, particularly when the stakes are as high as decisions about supporting their child's development?

d) How do families know about Best Practice?

While the NDIA commissioned the development of the National Guidelines for Best Practice, the agency has not made this readily available to families. It would be impossible to find on the NDIA website if you didn't already know what to look for. Why does the NDIA have a problem with providing families with information?

The ECEI Partners have become a source of information once families approach them. The role of the ECEI Partners are more complicated than the role of Central Intake. In the Victorian system there were broad guidelines about the intention of the funding. Once eligibility was established Central Intake staff could talk with families directly about services. In the NDIS the ECEI Partners are able to talk to families but there is no overarching framework. The Planning process also complicates the relationship. Partners are trying to combine providing information, providing support and determining eligibility at the same time. Families have to choose how open to be at the risk of it impacting on the support they receive in a situation in which there are no written rules.

The NDIS approach means the information provided to families is variable, they may not be informed as to best practice services, providers may not follow best practice and best practice may not be selected by families, knowingly or not⁸. NDIS planning itself is not being undertaken in a manner which would be considered best practice as families are not being supported in their decision-making by an evidence informed framework⁸, and the resultant plans are not always reflecting either best practice or the best interests of the child and family.

e) What is the experience for families in going through the NDIS Planning process?

The current system of planning for children in the NDIS involves families meeting with a designated NDIS planner, who may be employed directly by the NDIA or by a partner agency, perhaps in person or perhaps over the phone. The planner who may or may not

⁸ Moore, T., Forster, J., & Bull, K. (2019). Supporting parental choice: The impact of a funding model. *Young Exceptional Children Monograph Series*(18).

have expertise in ECI, creates a plan with funding attached which generally lasts for a period of twelve months.

Entering their NDIS planning meeting, a family may or may not have:

- support from a familiar professional with a detailed knowledge of the family and their circumstances,
- a range of supporting documentation,
- good written and spoken English
- interpersonal and advocacy skills.

It is likely that the family has experienced an emotional upheaval in relation to their concerns about their child's development⁹. While some families have multiple children with developmental concerns, it is also more likely than not, that the family has limited or no experience with ECI services. They are therefore likely to have limited knowledge about what might be available or helpful for their child and their family from these services. Consequently, while family circumstances will vary widely, it is most likely that the family come to the situation of being in an NDIS planning meeting in a vulnerable or disadvantaged position.

f) *What is planning in best practice early childhood intervention?*

Best practice planning in ECI involves services developing a deep and detailed understanding of the family and their child. It is the basis of a potentially long term and complex relationship designed to support the family to support their child's development.

If the family selects a primary service provider or Key Worker service, which is recognised as best practice in the NDIA commissioned National Best Practice Guidelines², the Key Worker from a high quality service provider is likely to begin their service with a family by completing an ecomap and then conducting a Routines-Based Interview (RBI)¹⁰. An ecomap involves a conversation with a family about their formal and informal supports and developing a picture of this¹¹. This helps the Key Worker get to know the family and develop an understanding of the strengths and gaps in their existing supports. The RBI is a semi-structured interview about the child's functioning and participation in the routine activities of an average day¹¹. This interview takes approximately two hours and results in the family developing and prioritising goals that have arisen from this discussion. High-quality goals are contextually appropriate; support families in their real-life situations; are prioritised by the family; address the skills the child needs in their everyday life; are easily understood by the family; and are measurable and achievable¹¹. Given the richness of the data provided by the ecomap and RBI and the relationship-building nature of engaging in this process with a family, it is very important that this undertaken by a person who will have an ongoing relationship with the family, that is, the primary service provider or Key Worker¹⁰.

g) *Why the NDIS should stop its Planning*

The NDIS use of the term Planning is confusing and potentially misleading. The NDIS cannot provide the complex and ongoing type of planning process that children and young people need. Children and young people require a dynamic model of planning that responds to the fact that they are developing and changing.

⁹ Fortier, L. M., & Wanlass, R. L. (1984). Family Crisis following the Diagnosis of a Handicapped Child. *Family Relations*, 33(1), 13-24. doi:10.2307/584585

¹⁰ Alexander, S., & Forster, J. (2012). *The Key Worker: Resources for Early Childhood Intervention professionals*. Malvern, VIC: ECII.

¹¹ Boavida, T., Aguiar, C., & McWilliam, R. A. (2014). A Training Program to Improve IFSP/IEP Goals and Objectives Through the Routines-Based Interview. *Topics in Early Childhood Special Education*, 33(4), 200-211. doi:10.1177/0271121413494416

Children and young people are in a state of flux. Priorities change quickly, whether it is because of the rapid development of infants and toddlers or the changes caused through puberty. It is not helpful for children and young people to be caught up in planning processes that are rigid or difficult to change. The NDIS needs an alternative approach.

Recommendations:

That the NDIA clearly delineates that the purpose of the Gateway is to establish eligibility and the allocation of funding and that this should be achieved in the least onerous way, particularly for families first experiencing disability, disability services and government services.

That the NDIA recognise the importance of the planning that needs to occur when a family is working with a service to develop actions to support a child's development and make sure that its processes does not cause confusion.

That the NDIA support families to understand the NDIS and make informed choices by publishing program or funding guidelines that clearly articulate the purpose of the NDIS and its funding in terms easily understood in the community and that it publishes prominently information about desirable outcomes and best practice.

Part 2: Questions raised by the Joint Standing Committee on the NDIS

2.1 The experience, expertise and qualifications of planners

The experience, expertise and qualifications of planners appears to vary widely. While many of our staff and the families we support have had positive experiences with planners, there have also been many negative experiences which have related to the knowledge and skill set of planners such as limited:

- understanding of child development and disability
- understanding of best practice and the Primary Service Provider or Key Worker role
- organisational skills
- sensitivity to families' situations
- understanding of time needed to undertake some intervention tasks such as assessments for specialised equipment

Examples provided by our staff include:

- Planners not reading professional reports provided
- Planners losing confidential documents and time limited quotes
- Planners making inappropriate recommendations to families regarding possible diagnosis of their child or inappropriate interventions
- Planners not understanding the recommendations or content of the lengthy reports requested
- Families discovering that the chat they had on the phone was their planning meeting when they unexpectedly receive a plan
- Parents being pressured to take on self-management and sometimes not being offered plan management as an option. This includes a mother with a disability who did not have a computer or reliable internet access who was in tears when she discovered what she was expected to do to self-mange her child's package. In

another family one child was given a self-managed plan and the other child a managed plan which was very confusing for the family.

- Families undertaking extremely lengthy processes from referral through to eligibility through to planning. This is often many months for families, sometimes almost a year, wasting crucial developmental opportunities at a time when the brain is developing rapidly.
- One planner without a background in ECI declined an application for a standing frame for a child against the documented advice of the Key Worker. When this refusal was queried, the planner said that she had not included the standing frame as the child may be likely to require a walker in another couple of years and NDIA could not justify the expense of both. The Key Worker explained that the child needed support to stand in order to enhance the later possibility of walking.

In some areas, highly skilled planners have been employed and our staff have been very pleased with the quality of the plans they have produced. However, the waiting time for these plans has averaged nine to ten months. Families develop a relationship with planners and then have to start all over again with a service provider. Nine to ten months of a child's neural development is far too long to sacrifice for this planning approach.

2.2 The ability of planners to understand and address complex needs

There has again, been very mixed experiences regarding the ability of planners to understand and address complex needs.

To illustrate, one family supported by our organisation has a child with complex high physical support needs. This family started out with a very experienced planner from a partner agency who understood the child and family's needs very well. Then, without communication with the family, planning was transferred back from the partner agency to NDIA. All supporting documents and quotes were lost when the transfer occurred and had to be resent. The new planner at NDIA did not read the reports provided in preparation for the planning meeting and appeared to have a very poor understanding of the child's needs. This family requires major car modifications. They are planning on buying an expensive van but do not want to make the purchase until modifications are approved. NDIA won't approve the modifications until the car is purchased. The family does not want to buy the car and risk the modifications not being approved (this has happened before), have to wait for the modifications to be completed, have a car too old, or have mileage too high to be modified. Under NDIA rules the car must be less than three years old and have mileage of less than 45,000kms. Families have waited too long for approvals and then the car has been too old and not approved based on this. Under previous SWEP funding the car only had to be less than ten years old. The child in this example has a powered wheelchair. He sustains frequent bone fractures due to his condition and can't take his chair out anywhere as it cannot be transported.

In another example of a child with high complex physical needs the family requested a large amount of funding which included time for assessment and application writing for several pieces of equipment as well as home modifications. The child was granted a three-month plan with a quarter of the funds requested and told that if they could not spend all the funds in the three-month period, they would not receive the remaining three quarters of the funding requested. The time frame between the funds being made available and the end of the three-month plan is not enough for appropriate assessment to take place as this requires the input of a range of professionals.

In another family, a child had multiple disabilities including vision loss, ASD and a complex speech and language disorder. The planner did not read the reports provided prior to the planning meeting and only focused questions on the child's vision loss. Part way through

the meeting the planner realised that there were more concerns but asked the family only to answer in relation to the vision loss and not their other concerns. The child consequently received a small plan and the family is hesitant to risk upsetting the authorities by asking for more. The family will run out of funding less than halfway through the plan.

2.3 The ongoing training and professional development of planners

It seems that in some areas, planners have been selected based on skills, knowledge and experience in early childhood while in other areas there may have been a deliberate focus on other skills or experience, or perhaps due to more difficulty recruiting staff with suitable backgrounds. Some planners are giving families incorrect advice about a range of issues indicating a lack of knowledge regarding disability, child development, equipment, the Key Worker role, NDIS rules and the early years services system. Some interactions with families suggest limited skills, knowledge and sensitivity. Examples provided by our staff include:

- Tendency for planners to recommend set hours for certain therapies rather than a Primary Service provider or Key Worker approach
- Planners advising families not to select services that have cancellation policies
- Local Area Coordinators (LACs) advising a family cannot use their NDIS funds for psychology intervention and must get a Mental Health Care Plan
- Planners requiring an ASD level in a five-year-old, where diagnosis is not essential
- Planners suggesting a family get a diagnosis of ASD when child does not meet criteria

At a foundational level, planners require a solid understanding of the principles of best practice (e.g. family-centred practices, inclusion, natural environments) and child development. They also require exemplary communication and interpersonal skills. This knowledge is crucial for any professional in a role supporting families with a child with a disability or developmental delay. Planners need to understand the role of ECI in building the skills, knowledge and confidence of parents in identifying and addressing their child and family needs and in supporting the development of positive and responsive parent-child relationships. Without this understanding planners will continue to give advice to families which results in the choice of services that do not take a holistic, outcomes-focussed approach and do not build the strength and capacity of the family. A failure to address this will ultimately result in poorer child and family outcomes, higher dependency on services and higher costs to the NDIS in the longer term.

Recruiting staff with qualifications in early childhood education or therapy and experience working with families with young children with disabilities or developmental delay is highly recommended. Consideration of role design and management needs to be reviewed to understand what it is that attracts and retains skilled professionals in planner roles. Continuing to build their skills and knowledge over time with professional development in areas such as family-centredness; strengths-based practice; inclusion and participation; and learning in natural environments would also be beneficial.

2.4 The overall number of planners relative to the demand for plans

Considerable delays have been experienced by families supported by Noah's Ark in all aspects of NDIS processes including planning. These delays coupled with the lack of preparation by some planners for meetings indicate that planners are overloaded, that there are insufficient planning staff to meet the demand for plans in a timely and professional fashion. This is particularly apparent in rural and regional areas but has been noted

throughout the trials and the subsequent roll-out of the scheme throughout Victoria, ACT and rural NSW.

It is unlikely given the current planning structure (annual reviews), that the number of planners will be able to respond to the workflow demand for the foreseeable future. It is suggested that once eligibility has been established that agencies working with the families are funded to complete comprehensive reviews and the approval for all but the most complex plans is completed via a desktop review system.

Delays in the provision of ECI services can be costly on many levels. There is some evidence that children with disabilities or developmental delays can experience a decline in their cognitive functioning in the absence of early intervention services¹². Brain development is most intensive in the first three years with neuronal growth and development continuing into adolescence. Missing out the opportunity to foster that development may be costly both for the individual child's development and also for the taxpayer as intervening later is both more costly and less effective¹³.

2.5 Participant involvement in planning processes and the efficacy of introducing draft plans

To be effective, children's plans need to be meaningful and relevant to families¹⁴. There have been some concerns from staff at Noah's Ark regarding some families having a limited understanding and participation in the NDIS planning process. Several families have had planning meetings over the phone and have not known that this was the planning meeting until they have received a plan. One family where the mother requires an interpreter and the father has conversational English had a planning meeting. The family was not offered an interpreter and it was only by chance that the father was at home as he did not know that the meeting had been arranged. The father thought this was a pre-planning meeting and was expecting a second session to which the Key Worker could be invited but received a completed plan in the mail. Without the support of an interpreter, the father didn't understand the purpose of the meeting and the family were not provided with the opportunity to have their Key Worker present as they had hoped.

Another concern of workers is that goals are often written by planners in a way that uses the language of the NDIS and are not meaningful to families. In particular for vulnerable families with low literacy, non-English speaking background etc, they may struggle to understand these goals that are produced in NDIS language and categories, rather the way they would express them.

Most families are currently not receiving a draft version of their plan and instead just receiving a final copy. This severely limits family input into the plan as they will not be clear whether they have managed to communicate their needs and circumstances sufficiently to a planner until they see what the planner has written down. If this is a final plan and it is apparent that it will not be suitable, the possibility of going down the path of an appeals process escalates. Some families with well-developed advocacy skills will negotiate to see a draft of their plan but this is rare in families new to ECI and is mostly seen in families with older children. Consequently, most of our Key Workers have had some experience of the appeals process, which is a time consuming, stressful and presumably, a costly process.

¹² Guralnick, M. (1998). Effectiveness of Early Intervention for vulnerable children: A developmental perspective. *American Journal on Mental Retardation*, 102(4), 319-345.

¹³ Perry, B. (2004). Maltreatment and the developing child: How early childhood experience shapes child and culture. Retrieved from <http://www.lfcc.on.ca/mccain/perry.pdf>

Perry, B. (2013). Bonding and attachment in maltreated children. Retrieved from https://childtrauma.org/wp-content/uploads/2013/11/Bonding_13.pdf

¹⁴ Jung, L. A. (2010). Identifying families' supports and other resources. In R. McWilliam (Ed.), *Working with families with young children with special needs*. New York: The Guildford Press.

As discussed, the purpose of ECI and school aged services is to promote the wellbeing, functional development and community participation of children with a disability². Promoting the empowerment and participation of children within their services and strategically ensuring their *voice* is heard is an important step towards this aim. In addition to promoting their safety, listening to the voices of children also brings further benefits in terms of their learning and development. When children feel empowered and with “a strong sense of agency” they develop a sense of ownership over their learning and development which can increase their engagement and participation¹⁵. They may work harder and with greater focus and persistence; setting themselves more challenging goals¹⁶. Accordingly, the Victorian Early Years Learning and Development Framework (VEYLDF) (2009) includes outcomes that children will have a strong sense of identity, contribute to their world, and communicate effectively¹⁷. Supporting children to develop their skills and confidence in communicating their views is a step on the path to children playing a genuine role in decision-making, ultimately fully exercising their rights as democratic citizens¹⁶. Ensuring that the voices of children are heard in the planning process would be a good step along this path.

2.6 The incidence, severity and impact of plan gaps

There have been various issues with plan gaps. In some geographical areas, services have had to be suspended for periods of up to six weeks while there has been a gap between plans. In other areas, the gap has been avoided by existing plans being rolled over for periods of three months. However, in many cases there has been no communication regarding this roll-over of the old plan and so services have been suspended anyway because neither families nor Key Workers were aware that this had occurred. These gaps in service delivery obviously have a significant impact on families who are left without support and services during this time. There is a risk of losing gains made with the child’s development as well as a risk of increasing the stress experienced by families. Increased parental stress is detrimental to parent-child relationships and increases the risk of attachment problems, child maltreatment and neglect¹⁸.

With one family we worked with, the child’s plan was rolled over for three months but neither the family nor Key Worker were informed. They found out a week before the plan ended. The child was then deemed ineligible for services post seven years old and so missed out on the last three months of access to services which may have assisted with his transition out of federally funded services.

The gaps in service provision are also problematic for providers as they reduce the amount and consistency of income, and more importantly, can fracture the delicate relationship-building process with families. The quality of the relationship between workers and families is a significant factor in family and child outcomes¹⁹.

¹⁵ Victorian State Government. (2018). *Amplify: Empowering students through voice, agency and leadership (Draft for consultation)*. Victoria: State of Victoria.

¹⁶ Lansdown, G. (2001). *Promoting children's participation in democratic decision-making*. UNICEF.

¹⁷ Victorian State Government. (2009). *Victorian Early Years Learning and Development Framework (VEYLDF)*. Melbourne Retrieved from https://www.vcaa.vic.edu.au/Documents/earlyyears/veyldf_for_children_from_birth_to_8_1.pdf.

¹⁸ Howe, D. (2006). Disabled children, maltreatment and attachment. *British Journal of Social Work*, 36, 743-760.

¹⁹ Popp, T. K., & Wilcox, M. (2012). Capturing the complexity of parent-provider relationships in early intervention: The association with maternal responsivity and children's social-emotional development. *Infants & Young Children*, 25(3), 213-231.

2.7 The reassessment process, including the incidence and impact of funding changes

The reassessment process for children seeking to transition from ECEI to continue NDIS after they turn seven years old is not operating smoothly. There is often a period where the Key Worker and family have no one to contact as the family sits unallocated for a lengthy period of time. Information provided by planners varies regarding what information is required and what type/ level of disability will be accepted. Decision-making regarding who is eligible to continue in NDIA has been inconsistent. Some children without a diagnosis have been accepted while other children with a diagnosis and significant functional impact have not been accepted. There is a sense that there is a heavy reliance on the word of professionals and that families without this support find the process much more challenging. While there is some focus on functionality and what supports might be helpful, the process is geared towards an emphasis on negative aspects of the child and family situation in order to gain funding – that is, talking about how bad everything is rather than focusing on goals, strengths and needs.

We have had other families still in the ECEI phase who have received a standard letter from the NDIA saying that their child will be re-assessed, and they will be informed of the outcome. One family had a planning meeting and did not hear anything for months. They contacted NDIA and discovered that their planner had left and did not submit a plan for them before leaving. Another planning meeting was set up six months after the first and the family told their story again to another planner. They then received a plan and a short time later received a letter in the mail saying that their child's eligibility was being reviewed and they may lose their supports. These kinds of experiences would be stressful for any family, let alone families who are in the process of adjusting to having a child with developmental problems.

2.8 The review process and means to streamline it

The review process is expensive, complicated, time consuming and can be stressful for families.

- Usually there is an expectation that all professionals working with the child and family will write reports for a planner who may or may not read them before the meeting.
- Due to systems issues and high staff turnover, the review is often completed by someone unknown to the family and they are required to re-tell their story.
- Currently there is an expectation that families have their plan reviewed every twelve months. Some plans are written with great detail and it is necessary for an annual review as children and family's needs can change considerably in a twelve-month period. However, if the plan was more general and flexible and mainly provided a funding ceiling, then the process could be streamlined. Key Workers could provide an annual update for accountability purposes and families could elect whether they wanted their funding cap and plan rolled over for another twelve months without a meeting or choose to have a meeting if they were seeking changes to their plan. The Key Worker, who has the ongoing relationship with the family, could repeat the RBI or another appropriate functional goal setting process annually, to update the working goals.

2.9 The incidence of appeals to the Administrative Appeals Tribunal (AAT) and possible measures to reduce the number

There are too many incidences of appeals to the AAT. Most could be avoided by:

- better communication
- improving the skills and knowledge of the planners
- increasing the understanding and participation of the families in the planning process
- increasing the quality of the planning process
- providing and discussing draft plans.

When plans do go to appeal the experience has been that the process is lengthy, and staff are often requested to provide the same information/documents already provided.

2.10 The circumstances in which plans could be automatically rolled over

As discussed under point eight, if plans were general and flexible, largely providing a funding cap for Key Worker services families could elect to avoid having a meeting with a stranger to gain funding approval for another twelve months. Heading closer to the end of their eligibility for ECI it may be advisable to meet with the NDIS (with the support of the Key Worker if they choose) to discuss whether their child will be continue to be eligible for funding and to discuss what their services might look like as they progress through the school years. If a child and family's need for funding is relatively stable during the ECI years it would be more economical and less stressful for families if they had the option to choose to roll-over their funding without meeting.

It is recommended the planning process align with the developmental phases of children and young people and enables family's choice and control in how they establish their goals. For example:

- Determination of eligibility
- Provision of funding for children under seven that met the requisite eligibility criteria
- Review pathways for children under seven with complex needs or significant changes in circumstances
- Transitional planning review at school entry to map appropriate school aged supports
- Review of supports for school aged children based on change of circumstances or specific complex needs
- Transitional review as children move from childhood to adolescence.

2.11 The circumstances in which longer plans could be introduced

See point 8 and 10.

2.12 The adequacy of the planning process for rural and regional participants

While the NDIA aspires to be "responsive to and appropriate for people with disability, their families and carers living in rural and remote areas"²⁰, there is currently a severe shortage of planners in rural and regional areas resulting in inequitable experiences for country families. They are more likely to be offered (or just given) a phone meeting or made to have

²⁰ P.3 National Disability Insurance Agency. (2016). *National Disability Insurance Agency Rural and Remote Strategy 2016-2019*. Retrieved from file:///C:/Users/Stace/Downloads/PB%20Rural%20Remote%20Strategy%20PDF.pdf

the meeting in a public place (such as a crowded McDonalds). Waiting times are long and it is very difficult to get into contact with planners. As Noah's Ark, operates services in many rural and regional areas we are very aware of the difficulties of recruiting adequately qualified and experienced professionals in some areas. Market Deepening strategies such could be implemented to enhance the likelihood of securing suitable employees for both planning and Key Worker roles. For example:

- Incentives for experienced workers to move to rural and remote areas (e.g. relocation expenses, skilled migration programs, financial incentives)
- Incentives for experienced workers to remain in rural and remote areas (e.g. financial incentives)
- Incentives for universities to boost places for required undergraduate training courses (e.g. speech pathology, occupational therapy, early childhood special education) and actively promote careers in ECI
- Incentives for some professions such as physiotherapists and psychologists to focus on careers in ECI
- NDIA increasing understanding and valuing of the skills and expertise of specialist early educator and encouraging them to remain or return to the sector
- Scholarships for graduates to accept extended posts in rural and regional areas
- Enabling student placements without creating financial disadvantage to providers
- Subsidies to enable adequate training of the workforce

2.13 Any other related matters

Our staff have raised several other related concerns including:

- Waiting lists for paediatricians are very long, particularly in rural and regional areas. This can significantly impact the waiting time for NDIS of families when there is a heavy reliance on diagnosis rather than functional need.
- There are issues with families having line items put in their plans that they have not requested (e.g. Support Coordination), and other situations when such line items are denied when they are specifically requested.
- The time spent on portal and payment issues by staff and families is considerable. It is very stressful for families who are often not provided with adequate support regarding this. It is challenging for organisations as staff are not remunerated for any of these administrative activities.
- There have been considerable challenges regarding adaptability to family circumstances. Something as simple as a phone number change has proven to be highly problematic along with more complex changes such as altered living or custody arrangements for children.
- Many children over the age of seven years with quite significant needs have received very small funding packages that would be difficult to do anything effective with.
- Our primary concern is the very low numbers of children under the age of two years entering ECEI. Delaying access to support is of great detriment to individual children and their families and jeopardises the sustainability of the scheme.

Summary of responses to the questions posed by the Joint Standing Committee

- Experience, skills and qualifications of planners vary greatly. Clarification of their role is required before determining what is ideal. Knowledge of child development and best practice is essential.
- The current system of planning is not working and is wasting crucial time in a child's development and limited resources in the scheme.
- Streamlining is urgently required. We suggest NDIS determine eligibility and then assist families to link in urgently with a Key Worker. Funding for initial plans could be generic and flexible while the Key Worker, who has an ongoing relationship with family undertakes a detailed best practice approach to planning. Reviews could also be undertaken by the Key Worker, with the family retaining the option to return to NDIS planners if there is a significant change required or they reach a developmental transition point, such as moving out of ECEI, becoming an adolescent or transitioning to adulthood.
- The 'early' has been lost from early childhood intervention. This needs to be rectified urgently for the sake of children, families, communities and the sustainability of the NDIS.

Part 3: Case Studies

The following two case studies, one for an infant and one for a school aged child, are based on the planning process experienced by families accessing Noah's Ark Services. All names and identifying details have been changed.

CASE STUDY 1

Amina and Nick welcomed their third child with joy and excitement, but also nervousness and worries about their new baby who had been diagnosed with Down Syndrome during a routine prenatal test. Kayla was born at 37 weeks and required medical care and hospitalisation for the two weeks of her life. Her health stabilised and she settled into the routines of the family life with kindergarten drop off for Lucas and playgroup for Alexa. Life was busy with Nick on shift work and no family support but lots of friends they had met through the children's activities in the large rural town.

During a routine check at the Maternal and Child Health Centre at four months of age, the nurse asked Amina about whether she had contacted the NDIS. Amina and Nick had been provided with information about the scheme by their paediatrician when Kayla was born but had put the brochure aside. But now seemed the right time for them to make contact and get some help for Kayla and themselves.

Amina rang the ECEI Partner and an appointment was made for her to meet with a Planner in two months. Amina and Nick went to the meeting together to talk about Kayla's feeding difficulties and their concern about her developmental milestones. They both felt overwhelmed when they entered the office building – like they had just entered a new world – a world of disability. They talked with the Planner about their family life, the supports they had and their daily activities. Then they answered questions about Kayla's development. They felt more and more anxious about the questions, worrying about whether Kayla would

have difficulty talking and being independent in the future. The Planner indicated that he normally works on adult plans so was enjoying hearing about Kayla's needs. He typed all the details into his computer and indicated they would hear back from the NDIS in a few weeks.

Two months later, a letter arrived indicating that Kayla was not eligible for the NDIS. Amina called the ECEI Partner immediately and was informed that the eligibility assessments were indicating that Kayla did not have a functional impairment and "had the same needs as other babies". They discussed the issues with their paediatrician who indicated that infants with Down Syndrome were automatically eligible (indicated on LIST D) and they should lodge an appeal. The decision was overturned when Kayla was ten months old. She was not babbling or rolling. She was still having difficulties with drinking and introducing solids was causing ongoing worries for her parents. Nick and Amina were distressed by the experience.

Kayla was 14 months old when she received her first NDIS Plan which outlined her need to see a physiotherapist and speech pathologist. They knew of a clinic near Lucas's kindergarten, so Nick took Kayla to the fortnightly physiotherapy appointments and Amina drove to the speech pathologist's clinic every other week. The drive was a 45-minute round trip and the weekly schedule became difficult for the family to manage, but they persisted. Friends helped care for Kayla's older siblings when she attended the therapy sessions and both Kayla and Nick were starting to see some progress with Kayla's motor development. Kayla was rolling over and sitting up with some support.

At 18 months, Amina took Kayla back to the Maternal and Child Health Nurse for her regular check. She never missed these appointments and had grown to trust the nurse. They talked about Kayla's therapy schedule and the burden the appointments were having on family life. The nurse shared information about an Early Childhood Intervention (ECI) service in the township that offered a different model of support that was home based and provided a Key Worker as a primary source of contact for the family. Kayla's NDIS plan was due for review, so Amina talked with the Planner about the Key Worker model and learned that it was endorsed by the NDIS as a model of best practice. The Planner was different from the initial one she had met – this time Kayla gained more information about the range of services for young children and the subsequent Plan had a flexible core budget rather than specific line items of therapy support.

Kayla called the ECI service and after discussion with the Team Leader they decided that a specialist teacher would be a good fit for the family as the Key Worker. Kayla was interested in trying this approach with a teacher who knew about child learning and development and could help with Kayla's transition to childcare in a few months. She felt reassured that she would also have access to the broader team of a speech pathologist, physiotherapist and occupational therapists as required.

The Key Worker started regular home visits to identify and address the family needs and to learn about Kayla's engagement, social relationships and independence in all her daily routines. She learnt about the strategies the family were currently using that were working well, the family support networks, and what they wanted and hoped for in the future. Together they developed a comprehensive plan that described the goals Amina and Nick had for Kayla and for the rest of their family. The Key Worker provided professional expertise in relation to Kayla's learning and development, information and advice so Nick and Amina could make informed decisions and support with coordinating services. She also developed a trusting partnership with them, providing them with emotional support as they continued to adjust to Kayla's very individual needs.

CASE STUDY 2

The Bowen family have two children. Oliver, turning seven shortly, has an ASD diagnosis and is an NDIS participant. His sister Lilly is four. Their mother Cath contacted Noah's Ark in a distressed state. She had received a letter from the Local Area Coordination Service (LAC) informing her that Oliver had a review meeting and that as he was turning seven, she would need to provide additional evidence to prove that his disability was now ongoing and permanent.

Cath was already anxious regarding Oliver's transition to school and experienced significant additional stress at the possibility of the NDIS funding finishing and the need to access all the professional reports again to prevent this occurring. In addition to the high cost of seeking specific diagnostic reports, Cath was worried about the impact of assessments on Oliver. She remembered too well the meltdowns they had to manage for the week after he went through the assessment process last time. Oliver understands when he is being assessed and needs to complete tasks until he can no longer do them; Oliver becomes frustrated during the assessments and screams and hits himself. Cath insists Oliver is given regular breaks and the assessments take a long time to complete. Cath comforts Oliver but when he is calm and not within earshot, she quietly weeps, exhausted from trying to support her child, family and herself. Cath rallies and does what is required, demonstrating Oliver's needs by gathering reports from her paediatrician and provider that describe all the things her amazing son is unable to do. Cath is supported by her Key Worker and the Association for Children with a Disability (ACD) to prepare for her planning meeting and goes into the meeting with a clear understanding of Oliver's goals. Cath does not take Oliver to the meeting as she is aware that she will be required to discuss all the things her son can't do and how this impacts their family with a stranger.

Cath meets with the planner who seems pleasant enough, but it is soon apparent the planner has no knowledge of either child development or disability. Through the course of the conversation the planner discloses that this is their first job in the sector and that their last career was a hairdresser but that they had completed a lot of training to be able to do their LAC role.

Cath talks about Oliver's ASD and the impacts of his anxiety and that this is a major impact on his daily life and the supports he needs to manage this both at home and with his Occupational Therapy and Psychology Team. The LAC is clear that it is Medicare's job to fund anything to do with Oliver's anxiety and that she would not receive Psychology support for this.

Cath broaches the need for a therapy dog and how this could support Oliver at school and to build his independence like attending play dates with friends. The LAC is clear that this would require a specific assessment however that it is unlikely to be supported and as such they were not willing to include it in the plan. Cath protests but after arguing with the planner for some ten minutes to no avail moves on.

Cath provides a description of Oliver's day from waking to bed. The LAC identifies the need for in-home supports. Cath agrees but reiterates that she also needs specific supports through therapists for his ASD and anxiety for the in-home supports and support workers to help him access after school activities to be successful. The LAC finally agrees to 15 hours of therapy supports for the year.

Cath leaves the meeting angry deflated and in a state of disbelief.

Fast forward six months: Oliver has not attended school for a month as he is unable to leave the house without Cath and will not attend school as he cannot have her with him. Oliver's ASD and comorbid anxiety affect him and his family at every level of daily life. Cath

has used all Oliver's therapy supports and while she is aware Oliver's not attending school is a change of circumstances she cannot reengage with the NIDS and experience the trauma of her first meeting with the LAC.

Cath is exhausted and in disbelief that a system that offered supports for Oliver from two to six years is gone. The progress he had achieved has all but vanished. Cath's work is supportive, but she has resigned as Oliver's needs are progressively deteriorating and requires her full time care. Cath and her partner are privately funding what they can however what supports they can provide are limited due to their financial position. Cath describes her and Oliver's wishes as having disappeared.

Conclusion

Noah's Ark recognises that the NDIS is a major social reform that will take time to implement in a form that best responds to all its participants. We acknowledge that it is both an important and challenging initiative. We also acknowledge that it faces major establishment issues.

In this submission, we have presented planning through three different approaches. In the first section we consider structural issues, in the second section, we consider the questions raised by the Joint Standing Committee and finally, through case studies, we attempt to bring our concerns to life.

The experiences of the families we work with have been mixed. Some families have had good experiences. Families can purchase important services and supports through the funding provided by the NDIS. Some families are successfully supporting their child's development through high quality services.

However, the experiences have been mixed. There are also many negative experiences reported by families and staff. Problems include knowledge, skills and actions of planners; lengthy delays; poor communication; inefficiencies; family stress from the process/experience; significant rural/regional disadvantage; and disadvantage for other marginalised families (e.g. CALD, parental disability). While we have responded in detail to the questions posed by the Joint Standing Committee, there are more systemic problems in how the NDIS is being conceptualised and implemented for children and their families.

The National Disability Insurance Scheme (NDIS) is a major service for children and young people in Australia. Nearly half the participants in the NDIS are under 19 years of age. We do not believe that this has been recognised in either the design or the management of the NDIS. There is a major discrepancy in what the NDIS is perceived as and what it does. The NDIS needs to build its capacity to respond to the needs of children and young people in fundamental ways. This includes developing the knowledge and skill base in the NDIA. It also requires redesigning the Gateway for children and how eligibility and the allocation of funding is determined. The current model of Planning is not fit for purpose for the young children who will be the major new participants in the NDIS.

The current failure of the NDIS to respond to the needs of children under two years of age demonstrates the consequences of the NDIA not understanding the importance of early intervention for children. This situation needs to be urgently investigated and addressed. Poor practice in early childhood intervention can be harmful to children's development.

Early Childhood Intervention provided with a best practice approach and as early as possible can in some cases prevent a child's developmental delay from becoming a permanent disability. In other cases, ECI can reduce the impact of a disability or delay on both a child and their family, enhancing the child's development, wellbeing and participation and improving the family's knowledge, confidence and quality of life. Effective ECI has an important role in the ongoing sustainability of the NDIS by reducing future dependence on services. Services for school-age children can then build upon these early gains to give young people the best chance of becoming adults who can be fully participating and contributing members of their communities.

Noah's Ark has made the following recommendations:

- That the NDIA develop its expertise in working with children and young people through developing expert advisory committees specifically focused on providing advice on children and young people by building the internal capacity of the NDIA by further recognising and supporting its Early Childhood Branch; and developing Branches specifically focussed on children aged seven to 12 years and 15 - 18 years.
- That the NDIA review its communications and structure to adequately recognise the level of participants aged under 19 years.
- That the NDIA urgently investigate why so few children under two years of age are accessing services; review its rationale for providing access; move to a risk minimization approach; and monitor future access closely.
- That the NDIA clearly delineates that the purpose of the Gateway is to establish eligibility and the allocation of funding and that this should be achieved in the least onerous way, particularly for families first experiencing disability, disability services and government services.
- That the NDIA recognise the importance of the planning that needs to occur when a family is working with a service to develop actions to support a child's development and make sure that its processes do not cause confusion or stress.
- That the NDIA support families to understand the NDIS and make informed choices by publishing program or funding guidelines that clearly articulate the purpose of the NDIS and its funding in terms easily understood in the community, and that it publishes accessible information about desirable outcomes and best practice.

The implementation of these recommendations will provide solid foundations for the ongoing development of the NDIS.

BOX 1 KEY BEST PRACTICES IN EARLY CHILDHOOD INTERVENTION

Quality Area 1: Family

Family-Centred and Strengths-Based Practice: is a set of values, skills, behaviours and knowledge that recognises the central role of families in children's lives. Family-centred practice is a way of thinking and acting that ensures that professionals and families work in partnership and that family life, and family priorities and choices, drive what happens in planning and intervention. Family-centred practice builds on family strengths and assists families to develop their own networks of resources – both informal and formal.

Culturally Responsive Practice: creates welcoming and culturally inclusive environments where all families are encouraged to participate in and contribute to children's learning and development. Practitioners are knowledgeable and respectful of diversity and provide services and supports in flexible ways that are responsive to each family's cultural, ethnic, racial, language and socioeconomic characteristics.

Quality Area 2: Inclusion

Inclusive and Participatory Practice: recognises that every child regardless of their needs has the right to participate fully in their family and community life and to have the same choices, opportunities and experiences as other children. All children need to feel accepted and to have a real sense of belonging. Children with disability and/or developmental delay may require additional support to enable them to participate meaningfully in their families, community and early childhood settings.

Engaging the Child in Natural Environments: promotes children's inclusion through participation in daily routines, at home, in the community, and in early childhood settings. These natural learning environments contain many opportunities for all children to engage, participate, learn and practise skills, thus strengthening their sense of belonging.

Quality Area 3: Teamwork

Collaborative Teamwork Practice: is where the family and professionals work together as a collaborative and integrated team around the child, communicating and sharing information, knowledge and skills, with one team member nominated as a key worker and main person working with the family.

Capacity-Building Practice: encompasses building the capacity of the child, family, professionals and community through coaching and collaborative teamwork. The goal is to build the knowledge, skills and abilities of the individuals who will spend the most time with the child in order to have as great an impact as possible on the child's learning and development.

Quality Area 4: Universal Principles

Evidence Base, Standards, Accountability and Practice: ECI services comprise practitioners with appropriate expertise and qualifications who use intervention strategies that are grounded in research and sound clinical reasoning. Standards based on these ECI key best practices will ensure ECI practitioners and services are accountable to continuous improvement and high-quality services.

Outcome Based Approach focuses on outcomes that parents want for their child and family, and on identifying the skills needed to achieve these outcomes. ECI practitioners share their professional expertise and knowledge to enable families to make informed decisions. Outcomes focus on participation in meaningful activities in the home and community with outcomes measured and evaluated by ECI services from a child, family and community perspective.

(Early Childhood Intervention Australia)