



Submission to the
Productivity
Commission Inquiry
into the National
Disability Insurance
Scheme (NDIS)
Costs

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Response to the Position Paper information requests, findings and draft recommendations

About Noah's Ark

Noah's Ark has been involved in the NDIS from its commencement through our services for children with disabilities and their families in the Barwon and ACT trials. We are involved in the roll out in North East Metropolitan Melbourne and other areas of Victoria.

Noah's Ark is a non-government organisation providing early intervention to young children (0 – 12 years) with disabilities and other additional needs. Our focus is on a developmental approach that fully involves families and carers. Noah's Ark operates from 19 centres across metropolitan and regional Victoria and one centre in the ACT. Last year these programs reached 1,800 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 involvements in the Kindergarten Inclusion Support, Pre-School Field Officer and Parent to Parent Programs. Noah's Ark was previously funded by the Australian Government (Department of Education) as an Inclusion Support Agency as part of their Inclusion and Professional Support Program.

Noah's Ark also provides training and resources and has strong linkages to the international early childhood intervention profession.

How is the scheme tracking?

1.1 Effective early intervention

The Productivity Commission has observed that scale and pace of the National Disability Insurance Scheme (NDIS) rollout to full scheme is highly ambitious and poses risks to the financial sustainability of the scheme and the scheme in general. It also notes that the NDIS is based on insurance principles, including investment in research and innovation to encourage and build the capacity and capability for evidence-based decisions on early interventions, among other things. Children receiving early intervention supports are one of the largest participant groups in the scheme. It is therefore critical for the NDIA to build an evidence base on early intervention to inform the types of intervention that are most beneficial and should be funded¹.

It is essential that the NDIS clarify its understanding, purpose and approach to implementation of early intervention for children before the rapid implementation of the Scheme forces premature decisions to be made. Noah's Ark supports the slowing down of the roll out of the NDIS while this is clarified.

¹Productivity Commission (2017) **Overview - National Disability Insurance Scheme (NDIS) Costs - Position paper**, Australian Government, Canberra (p.22)

The need to develop an understanding of early intervention for children is required because the current early intervention programs for children have been developed by different jurisdictions in diverse ways and using different approaches. This includes different eligibility for programs, different administrative arrangements, different workforces and various levels of investment. The NDIS is the first attempt to develop a national approach to early intervention for children. It needs to build the foundations for a common approach. The complexity of the differences in children's services was evident in the development of a national approach to early childhood services. This involved national negotiations over a number of years, finally resulting in a common legislative approach to Early Childhood Education and Care.

The need to be clear about the purpose of early intervention for children reflects the diverse contexts across Australia in which services have developed. Over the past 40 years there has been an evolution from a focus on treating the child to a focus on supporting the context in which the child is developing, most notably the family. This has been based on a growing body of scientific evidence². Guralnick (2005)³ proposes that the fundamental principle for early intervention is a developmental orientation, of which the most critical factor is need to centre interventions on the family. This principle 'includes concepts related to parent empowerment, the establishment of parent-professional partnerships, and recognition of the significance of family patterns of interaction to the child's development and wellbeing' (p7).

An early intervention approach based on a developmental orientation puts the focus on:

- the child, not the disability
- the family, not professional services
- high developmental expectations, not treatment or care
- participation and inclusion, not addressing functioning in isolation.

One of the lessons from the period of institutionalisation is the importance of seeing children with a disability holistically, as individuals who have a range of needs and a right to be part of the community, and not defined by their disability.

A developmental approach means that it is important to see services as a support to families raising their child with a disability, not services as an end in themselves.

One of the challenges that still confront children with a disability is the low expectations of professionals who support them, as is evident in the school system⁴. It is important that services support the development of children and are not focused on their care.

A second principle for supporting children with a disability is inclusion. There needs to be an emphasis on building the capacity of the child, and family to participate, both as a right and as a fundamental support to all children's learning and development.

²Institute of Medicine, (2000). **From Neurons to Neighborhoods: The Science of Early Childhood Development**. Washington DC: The National Academies Press.

³Guralnick M (2005) *An Overview of the Developmental A Systems Model for Early Intervention* in Guralnick M (ed) **The Developmental Systems Approach To Early Intervention**, International Issues in Early Intervention Series, Paul H. Brookes Publishing

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While this purpose is not in conflict with the objectives of the NDIS, careful consideration needs to be given to the age appropriate implementation of the NDIS. For example, the NDIS has been constructed around the locus of action being the client with a disability. A shift to a developmental approach means working with the family as participants in the service, not working with families as the representatives and carer of children with a disability. Similarly, plans that are constructed on allocations of therapy hours do not build the capacity of families to support their child's development and are therefore not consistent with best practice.

The need to be clear about the approach to implementation arises because of the lack of tertiary courses specifically designed for early intervention for children. State and Territory historical approaches means there is not a cohesive workforce capable of implementing a consistent early intervention approach. The NDIA has commissioned work on best practices in early intervention for young children from Early Childhood Intervention Australia. This was based on national consultations and draws on available evidence. The best practices can be found in Box 1⁵. The recognition of best practices is an important start, but it is not enough. There needs to be investment in building the workforce capacity to use these approaches and quality assurance to ensure they are implemented effectively.

1.2 Early Childhood Early Intervention (ECEI)

The Productivity Commission identifies that the NDIA has put in place initiatives such as the ECEI to address emerging cost pressures caused by the entry of greater numbers of children than anticipated and that it is too early to assess the effectiveness of these initiatives.

The ECEI approach is now being characterised primarily as a mechanism for restricting children's entry into the NDIS. The NDIA is identifying that there are too many children entering the scheme. Discussion of the ECEI needs to take into consideration three issues: its effectiveness as a soft entry for parents encountering disability for the first time; the reasons more than expected numbers of children are entering the scheme and the challenge of introducing consistent eligibility criteria across Australia.

The ECEI approach needs to be considered primarily in terms of its effectiveness as a soft entry for parents encountering disability. The ECEI approach was developed, in part, in recognition that 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.

⁵ ECIA, (2016). **National Guidelines: Best Practice in Early Childhood Intervention**
<https://www.ecia.org.au/documents/item/186>

BOX 1 KEY BEST PRACTICES IN EARLY CHILDHOOD INTERVENTION

Quality Area 1: Family

1. 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.

2. 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

3. 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.

4. 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

5. 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.

6. Capacity-Building Practice: encompasses building the capacity of the child, family, professionals and community through coaching and collaborative team work. 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

7. 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.

8. 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.

Source: Early Childhood Intervention Australia

Family's capacity to provide care can also be challenged. When a child is very ill, requires extended hospitalisation or home care or other intensive treatments, family resources can be severely challenged. Some parents find that having a child with a disability challenges their confidence in parenting their child. Stresses can arise from the uncertainty of the child's condition. Receiving a diagnosis of disability is not always straight forward. The term developmental delay is used to describe the uncertainty about a child's condition. It can be evident that a child is not developing well without it being clear why. Many families are hopeful that issues will resolve themselves and in some instances, this does occur.

In this context of disruption and uncertainty, it is important families are supported to seek assistance for their young child. Highly impersonal or bureaucratic gateways to services are neither helpful nor encouraging. A responsive ECEI approach is necessary to make the NDIS accessible to families seeking support. It is also essential for effective early intervention. Early intervention for young children is based on the principles of early childhood development. Humans learn more rapidly in the early years than at any other stage in life. During this time, the basic architecture for future development is established. If a child is not developing well, the sooner the situation can be addressed then the greater benefit for future development. The economic imperative for early intervention is based on the importance of intervening early. The costs of intervening later are greater, because early developmental opportunities have been lost, poor adaptations have occurred and it requires greater intervention to bring about change.

The reasons that more than the expected number of children are entering the scheme has not been examined. In the first instance, different age groups of children are having quite different experiences. The experience for children aged 0 to 4 years are entering the scheme at just over 2%⁶. The NDIA's long term projection is that less than 2% of this age group will enter the scheme. This is a very low percentage, lower than the current expectation of Victorian services for this age group. It is therefore anticipating a narrowing of eligibility for service. Any narrowing of eligibility needs to be considered in the context of whether it undermines the effectiveness of the early intervention approach.

The 5 – 9 year old age group does show significantly higher numbers of participants than might be expected⁷. This raises questions about the interaction between children entering school and parents making requests for, and being granted, support from the NDIS. The NDIS needs to develop a broader approach to understanding the pressures on families and children and the potential impacts these have on the NDIS. What is occurring in the life of these children that is leading to these requests for additional assistance at this late age? Why are the early intervention strategies not working?

It is important that the NDIS develops a life cycle approach that recognises that children go through different periods of development and these lead to different demands on them. The requirements of the environments they are in also keep changing. The general administrative divisions for children's development are between the period prior to school, primary school, secondary school and transition to work or the community. All other service systems recognise these changes. While a strength of the NDIS is its capacity to support people regardless of the stage of life they are experiencing, its implementation needs to reflect these changing stages.

⁶ Productivity Commission (2017) **National Disability Insurance Scheme (NDIS) Costs Position Paper**. Australian Government, Canberra (p. 102)

⁷ Ibid

Placing emphasis on the ECEI approach as the mechanism to resolve these issues may be unrealistic. The ECEI has been established to deal with the 0- 6 year old age group, not the 0 – 9 year old age group. The NDIA does not make available age specific data, so it is not possible to determine at what age the proportion of children increases.

There is a challenge of introducing consistent eligibility criteria across Australia. Entry into the NDIS should be determined by how its eligibility is defined and applied. The greater than anticipated number of 5 – 9 year old children entering NDIS may also reflect a lack of clarity about what the eligibility criteria is and how it is to be applied. Given the different historical services in the different States and territories then arriving at a consensus may take some time. The development of greater specialisation through the establishment of the ECEI will assist planning processes that are age appropriate. It will still need a national process for a common approach to be developed and applied.

Scheme eligibility

2.1 Activity domains

The Productivity Commission is proposing to recommend that when determining that an individual is eligible for individualised support through the NDIS under the disability requirements, the NDIA should collect data on which of the activity domains outlined in section 24 of the *National Disability Insurance Scheme Act 2013* (Cwlth) are relevant for each individual when they enter the scheme.

These activity areas are:

- Communication
- Social interaction
- Learning
- Mobility
- Self-care
- Self-management,

To make such data meaningful the NDIS needs to develop an approach that recognises how each activity area changes over the life cycle. Such an approach might consider children's developing skills, the growing independence of the child, the need for the child to participate in increasing complex settings and social environments, and the ability of relevant adults to understand the child's capacity and how to support the child's development and increasing independence.

2.2 List D

The Productivity Commission has asked for information about whether List D — (Permanent Impairment/Early Intervention, Under 7 years — No Further Assessment Required) should be retained. As it notes, 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 it identifies are that families don't have to demonstrate that their child will benefit from early intervention. This approach provides certainty of support and it reduces the administrative burden on the NDIA.

The disadvantage is that it may lead to some children receiving supports who are unlikely to benefit from such supports. It is interesting that the Scheme anticipates children will be exiting early intervention, given the narrow population it is targeting.

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. This level of

maturity would appear to be some way off. It will require a highly specialised workforce 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. It is not unrealistic to expect that children with the conditions in List D to need early intervention. It is not realistic to have planning processes that respond to the diagnosis rather than being tailored to the situation of each child. Disabilities impact children differently. 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.

2.3 Reasonable and necessary

The Productivity Commission has asked for information on whether the *National Disability Insurance Scheme Act 2013* (Cwth) is sufficiently clear about how or whether the 'reasonable and necessary' criterion should be applied. Is there sufficient clarity around how the section 34(1) criteria relate to the consideration of what is reasonable and necessary?

The NDIS Act describes reasonable and necessary supports as including:

- support that will assist the participant to pursue the goals, objectives and aspirations included in the participant's statement of goals and aspirations;
- support that will assist the participant to undertake activities, so as to facilitate the participant's social and economic participation;
- support that represents value for money in that the costs of the support are reasonable, relative to both the benefits achieved and the cost of alternative support;
- support that will be, or is likely to be, effective and beneficial for the participant, having regard to current good practice;
- support that takes into consideration of what it is reasonable to expect families, carers, informal networks and the community to provide;
- support that is most appropriately funded or provided through the National Disability Insurance Scheme, and is not more appropriately funded or provided through other general systems of service delivery or support services offered by a person, agency or body, or systems of service delivery or support services offered;
- support that is part of a universal service obligation; and,
- support that is in accordance with reasonable adjustments required under a law dealing with discrimination on the basis of disability.

While this description is not child or family friendly, it is not clear that the Act is the best place to elaborate on the changing needs of persons with a disability across the life cycle. As mentioned previously, the NDIS needs to adopt a life cycle approach if it is to be responsive to the evolving needs of individuals. The complexities of such an undertaking would be better suited to regulations than the Act. Regulations is also the place to articulate the understanding, rationale and implementation of early intervention approaches.

2.4 Delegation of Plans

The Productivity Commission has asked for information on whether the NDIA should have the ability to delegate plan approval functions to Local Area Coordinators and what the costs, benefits and risks of doing so are.

For families with young children there are advantages to having the first plan with families completed through an ECEI. It simplifies the process for families and allows plans to be done by people with appropriate specialisation. A delegation to the the ECEI of authority to approve plans is potentially in conflict its community enabling role, as is discussed below.

One of the significant roles of the ECEI is to create community linkages for children with a disability. A significant risk in the development of the NDIS is that it is putting children with a disability in a new silo away from other children. Children and family services are primarily the responsibility of State and Territory governments. The creation of the NDIS removes services for children with a disability from the policy and administrative connections that they have previously had. For example, in Victoria maternal and child health nurses and four-year-old kindergartens have previously been administered within the same policy and administrative context as services for children with a disability. Maternal and child health nurses have played a significant role in early identification and kindergarten offers crucial experiences in early childhood education and care.

The NDIS is not operating within the same policy context as Victorian family and children's services. It does not share the same developmental approach. Therefore, the linkages between the workforce funded through the NDIS and the state funded workforces will not be as strong as in the past. The ECEI has a key role to play in bridging this gap. This is critical to opening opportunities for children with disabilities and their families to benefit from other children and family services. If the ECEI is not able to fully develop its community enabling role then families will become more dependent on the NDIS.

If the ECEI is primarily seen as determining eligibility and therefore screening out children who subsequently become the responsibility of the state and territory services, it may make it more difficult to work closely with these services to create opportunities in the community.

2.5 Changes to the planning process

Noah's Ark supports the Productivity Commission's proposed recommendation that the National Disability Insurance Agency should:

- implement a process for allowing minor amendments or adjustments to plans without triggering a full plan review
- review its protocols relating to how phone planning is used
 - provide clear, comprehensive and up-to-date information about how the planning process operates, what to expect during the planning process, and participants' rights and options by having the Local Area Coordinators on the ground six months before the scheme is rolled out in an area, so it's staff can engage in pre-planning with participants.

Children's developmental needs change quickly and planning and services need to respond accordingly. Phone planning is not desirable with families who do not understand how the NDIS works. Clear guidelines will assist making the process of accessing the NDIS and getting a plan transparent and reduce the stress for families.

There is a conflict in LACs / ECEIs being both the source of independent advice for families and determining eligibility for the Scheme. There needs to be independent advice available to families.

Noah's Ark also supports the Productivity Commission's proposed recommendation that the NDIA should consider specialised planning teams. The focus of the recommendation is on disability types. We would suggest that consideration also needs to be given to the distinct stages in the life cycle that children go through.

Boundaries and interfaces with the NDIS

3.1 Interface between the NDIS and Early Education and Care.

The Productivity Commission has indicated it believes that it is a false economy to have too few resources for Information Linkages and Capacity Building, particularly during the transition period. This is a critical period to be putting in place structures to ensure people with disability are adequately connected with appropriate services.

There is an opportunity for the Australian Government to set an example in the interface between the NDIS and Early Childhood Education and Care (ECEC). There is currently no policy or research document that addresses how the NDIS might become involved in helping the ECEC sector become better prepared to support children with a disability. The Australian Government has responsibility for both the Inclusion Support Program in Child Care and the NDIS. Historically there has been a division of roles between the role of the Inclusion Support Program and State based ECIS. The Inclusion Support program has focused on general access to the Child Care program. The ECIS have focused on supporting individual children's development by providing advice and to Child Care staff on how the child can best benefit from the developmental opportunities offered by Child Care program. The Australian Government can demonstrate leadership in resolving the boundary issues in this area by seeking to maximise the developmental opportunities available to children with a disability.

3.2 Transparency

Noah's Ark supports greater transparency by the Australian, State and Territory Governments about their approach to providing continuity of support and the services they intend to provide to people beyond supports provided through the NDIS.

Noah's Ark also supports great consultation, including participant and service experience, about the interface between the NDIS and other services.

Provider readiness

4.1 Price setting

Noah's Ark supports the Productivity Commission's proposed recommendation that the Australian Government should introduce an independent price monitor to review the transitional and efficient maximum prices for scheme supports.

This would separate out the conflict of interest the NDIA has in setting costs and its responsibility for overall expenditure.

4.2 Thin markets

The Productivity Commission has identified that in a market-based model for disability supports, thin markets will persist for some groups, including some participants:

- living in outer regional, remote and very remote areas
- with complex, specialised or high intensity needs, or very challenging behaviours
- from culturally and linguistically diverse backgrounds
- who are Aboriginal and Torres Strait Islander Australians
- who have an acute and immediate need (crisis care and accommodation).

The Productivity Commission has not acknowledged the challenge of engaging some families, particularly those who are already disengaged from services or who find services difficult to approach. Many of these families come from low socioeconomic backgrounds

and have limited educational backgrounds. Children from such a family will benefit most from early intervention, both in a general sense and specifically in relation to their disability. These families do not fit into a market model very easily. They are more difficult to engage and motivate and there is the likelihood of high numbers of cancellations. In a commercial sense, they are not good customers. On the other hand, if these families are not engaged, then the costs associated with the child's disability may escalate through the school system and other forms of family intervention. The NDIS does not appear to either have conceptualised or addressed this issue.

The Productivity Commission has requested information about the circumstances in which it would be helpful to use measures such as:

- cross-government collaboration
- leveraging established community organisations
- using hub and spoke (scaffolding) models
- relying on other mainstream providers

In assessing how to respond to thin markets, it is paramount that the model of early intervention and the intended outcomes are clearly identified first. There are clear benefits in non-market approaches to supporting a developmental approach for children and their families.

Cross government collaboration

There are many benefits for cross government collaboration on children and families. For example, there are benefits in coordinated approaches to the referral of families engaged with state and territory services to the NDIS. There are benefits in coordination between education and care services and schools and the NDIS. State and territory governments provide infrastructure in remote areas and engage with a wide range of communities.

Leveraging established community organisations

Established organisations similarly have established networks, relationships with families and areas of expertise.

Using hub and spoke models.

Hub and spoke models are particularly useful in providing specific types of supports, particularly outside the metropolitan areas and regional centres. The Federal Government is appointing a National Rural Health Commissioner and linking with such roles may provide additional insights into meeting rural needs.

Building capacity of mainstream providers

Building the capacity of mainstream providers, including Early Childhood Education and Care is essential to enabling children with a disability to have similar developmental opportunities to their peers. This is particularly important in more remote communities.

Workforce readiness

The Productivity Commission has identified that it is unlikely that the disability care workforce will be sufficient to deliver the supports expected to be allocated by the National Disability Insurance Agency by 2020. It has asked for information on the best way for governments and the National Disability Insurance Agency to work together to develop a

holistic workforce strategy to meet the workforce needs of the National Disability Insurance Scheme

It is recommended that the NDIS clarify its relationship with its workforce. The development of the workforce for early intervention for young children does not appear to be a priority in the development of the NDIS. The absence of a model for early intervention in early childhood means it is unclear what the professional opportunities will be for people choosing to work in this area. Early intervention for young children employs therapists and educators who have choices outside the NDIS, in hospitals and schools. There is a shortage of therapists in Australia. The NDIA has not made it clear whether the NDIS needs a highly skilled early intervention workforce, or a cheap one, or if it is positioning the NDIS as a long-term employer.

Noah's Ark supports the recommendation that the NDIA publish more detailed market position statements on an annual basis and that these should include information on the number of participants, committed supports, existing providers and previous actual expenditure by local government area.

Participant readiness

The Productivity Commission has asked for information on whether support coordination being appropriately targeted to meet the aims for which it was designed. Our experience in the Victorian roll out in Norther East Melbourne was that all families of young children were provided with funding for support coordination. Our understanding is that this was to compensate for the rapid rate in which planners were completing first plans and the information and resource needs of families. Rather than supporting the individual needs of participants, this created further confusion. For some families, it resulted in them accessing several service providers; one for service coordination and another for early childhood supports.

A stand-alone component of Service Coordination does not fit with ECIA Best Practice Guidelines. Service coordination should be an integral part of an early intervention service.

Governance

Noah's Ark supports the NDIA finding a better balance between participant intake, the quality of plans, participant outcomes and financial sustainability.

As a consequence, Noah's Ark supports the slowing down of the roll out of the NDIS while the purpose of early intervention for young children is clarified and operationalised. The process for implementing transition also needs to be streamlined so that it does not continue to result in long delays in the activation of plans. The long delays in activation disrupts services for young children and their families.

In our view, the most effective way to slow down the roll out is to slow the rate at which new areas enter the NDIS. This approach will also continue to put pressure on the NDIS to be implemented in as timely a manner as possible.

Noah's Ark also supports the NDIA being funded adequately to develop internal capability and expertise.

Conclusion

8.1 Importance of a life cycle approach

The ultimate aim of the NDIS is for people with disabilities and their families to be able to make informed choices about the supports and services they need in order to participate meaningfully in the economic and social life of the community.

This goal is not achievable overnight. When families of young children with disabilities have the diagnosis confirmed and become eligible for services, they are likely to be in a state of some distress and disorientation. They will be unfamiliar with the disability service system and uncertain of their role in relation to professionals. They will also likely to be lacking in confidence in their own abilities to help the child, and tend to defer to the knowledge of professionals.

At this point in time, parents are not well placed to be able to make sound decisions about their own needs or those of the child, or about what forms of service would best meet these needs. It is unreasonable and potentially harmful to expect families at this time to choose services or manage funds to purchase appropriate services in the same way adults might.

One of the tasks of early intervention for young children and their families is to build the understanding, confidence and capabilities of parents in knowing how best to meet the needs of the child and family, and to work in partnership with service providers to ensure that these needs are met. When this is done effectively, by the time families leave the early intervention, their personal circumstances and skills will have altered dramatically. By then, most parents should be familiar with the service system, confident in their ability to help their children, able to articulate their needs, and able to work with professionals as partners. Since early intervention services can work with families over several years, this gives them the time to support families as they gradually gain the skills and confidence they need to manage their child and family needs into the future.

To achieve the goals of the NDIS, an outcomes-focused life cycle approach is needed. This means that, during the early childhood intervention phase in particular, the services that are funded by the NDIS to support families should always be seeking to progressively build the capacity of families (and ultimately of the young people with disabilities themselves) to identify their own needs, build effective partnerships with professional services, and manage the funds allocated to them. These requirements should be clearly stated for the NDIS and providers that cannot demonstrate that they work in ways that achieve these goals should not be accredited.

8.2 The cost of not providing effective ECI services

The NDIS explicitly acknowledges the importance of early intervention in helping ensure the best possible outcomes for people with disabilities and their families. Early intervention can be powerfully instrumental in giving children and families a strong foundation for later development and participation.

What are the risks in not providing support early or not providing such support effectively?

Early childhood intervention has a dual focus – promoting the development and well-being of the child, as well that of the family. At the child level, 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 or not doing so effectively can incur costs in a number of ways:

- In some instances, early childhood 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, the problems will escalate and become increasingly difficult (and costly) to manage, thereby incurring ongoing financial claims upon the NDIS.
- In most instances, however, the child's developmental disabilities are not transient and are sufficiently severe to require ongoing NDIS support. Here, the aim is to 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, which is when their relationship with their caregivers is just developing and most likely to be compromised.

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

Early childhood intervention services also seek to support family functioning and build parent capabilities. When this is not provided, then there are likely to be worse outcomes with associated costs for the family and the wider society. These can take a number of forms:

- The demands of parenting a young 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 tax payers
- Having a young 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 that society has to bear
- These same stresses affect the relationship between parents, resulting in a higher than usual breakdown in parental relationships, with all the associated additional costs of divorce and single parenting
- Children with developmental disabilities are more likely to be neglected or abused, both having adverse effects upon their development and well-being, but also resulting in higher societal costs in the form of child protection and other services

Overall, the failure to provide appropriate and effective support to families can lead to poorer outcomes for parents and families as a whole. These incur additional costs that have to be borne not only by the family, but also by the wider society in the form of support and treatment services to address mental health and family dysfunction. These personal and social problems also reduce the capacity of family members to contribute productively to society as active citizens, workers and tax payers.