Intervention, Individualisation and Insurance: Who is the 'I' who will benefit?

ECIA NSW Chapter 2013 Conference

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Overview

In Australia a new approach to assisting people with disabilities, the National Disability Insurance Scheme (NDIS), now DisabilityCare, is about to be launched. The strengths of this approach include a consistent entitlement to support that is designed to meet the individual's needs and a commitment to choice and control for people with disabilities. The NDIS was primarily developed for adults. The relevance of its approach to the developmental focus of interventions for young children with disabilities and their families is yet to be tested.

This paper has three parts, relating to Intervention, Individualisation and Insurance.

Intervention: In the first part there is a brief scan of the theories and research that are currently driving change in Early Childhood Intervention (ECI) services. This section looks at the different literatures that characterise ECI, the emergence of the ecological model, the recognition of the important role caregivers play in children's development and the important role the played by children themselves.

Individualisation: The second part looks at how these theories and research are changing the service model of ECI based on the experience of Noah's Ark Inc. Noah's Ark is a large Victorian based ECI and Inclusion service that is particularly focused on the years prior to school. This section discusses why Noah's Ark decided to change its services, the consequences of changing to a home visiting model, the challenges of supporting children's development in the home and other everyday settings.

Insurance: The final part considers the development of the NDIS, in terms of the differences in the stated purposes of the NDIS and ECI, the difference between adult perspectives, prioritises and issues and the issues in the early years, how planning is approached and assumptions about access to and use of mainstream services in the development of the NDIS. A key difference is that while adults can set goals according to their interests, young children's goals are focused on their development.

Families face complex issues in adapting to having a young child with a disability. Every family goes through a different process of adaptation, depending on factors such as experience of disability, family social supports and access to resources. Individualised planning for developmental purposes needs to consider supporting family adaptations, promoting the child's development and incorporating evidence based practice. It requires high levels of flexibility and responsiveness as family priorities change, the child's abilities develop and new practices become relevant. Children with disabilities also benefit from the universal developmental opportunities available to all children.

If DisabilityCare is to respond successfully to the needs of families who have a young child with a disability, it must respond to the different stages in the life cycle. We do not know what DisabilityCare will look like in practice and what this means for families who have a young child with a disability. In a period of change it is important to continue to clarify what the underlying theories and research driving the development of ECI have been, how these have been changing practice and what the priorities in the early years are.

Family voices

The experience of having a child with a disability is life changing for families. While much of what is discussed in this paper relates to research and policy, it is important to recognise that at the centre of ECI are families, and to start with their voices. Family voices are not heard by the broader community, although the discussion of the NDIS has brought it much more into the open. While having a child with a disability is highly individualised experience and each family responds according to its own situation and culture, family voices reminds us of the complexity and challenges and the need to find individual responses.

The following voices come from two Noah's Ark reports, *Looking At The World Differently (LATWD)* (2010), for which 12 mothers were interviewed, and *Speaking from experience: The 'hit and miss' of finding information* (SE) (2012), which spoke with 24 parents who have a pre-school age child with a disability. All the parents have used a Noah's Ark ECI service.

The process of getting a diagnosis, except when families already had a child with a disability, was a shock and often proved frustrating.

Initially our world was turned upside down. What does the future hold for her? All you ever want really is a healthy child. Initially I went through a period of thinking why did this happen to me. Why us? But Lily has probably taken us to a place where I never thought that we would go. I'm on more of an even level and that is the way it should be. The other thing about having Lily is that each milestone that she reaches is an achievement and part of her personality is very social and very accepting of things. You just have to learn to deal with it. (LATWD)

I have been told that I am looking for a label for my child but I'm not, I'm searching for an understanding of my child. A label means nothing to me but an understanding of my child means the world to me. (SE)

Parents largely saw themselves as being on their own. Extended families reacted in different ways:

Really just my husband and my parents. But really it is just 'you'. These people come and go and make time for you but it's you by yourself. You are alone! (LATWD)

My parents and in-laws provide ongoing support. But I don't want to bother them too much with my problems as they have their own problems. The kids are hard for them to handle as they are so hyper. They see the differences as a problem with this generation of children and they don't realise that these children have additional needs. They occasionally have them overnight and give us a "little break". (LATWD)

Most mothers experienced pressures on their relationships with their partners, at least initially.

I don't know about other people's husbands but my husband is a big problem that I have to deal with. He has been in denial at all times about my son's autism. At the beginning of assessment time, he kept avoiding taking us to appointments. I could not drive. Services helped me with taxi vouchers so I could get my son to the appointments. When I showed him the autism assessment report, he said to me: 'you are sick, not our son.'(SE)

Now there is a much better understanding of each other's feelings about our son. Now that he has accepted the fact that his child does have autism we're quite good with each other. We're more supportive of each other and we did struggle with the work arrangements for a while, but it is great now. (LATWD)

Experiences outside the family circle can be difficult.

Friends helped. I had friends that would come and would watch my younger child for me so I could take Jack to therapy and that was an enormous support. Another girlfriend used to come every day and check that I was OK. Our social network was the same people and accepting but the wider community stands back. People are not helpful if he has a meltdown and they do not realise there is something wrong until I started signing and then you get the pity look but I would actually rather get the pity look at that stage. (LATWD)

ECI services tended to work out, but parents were cautious in the decisions they make.

The Family Day Care person was gorgeous and she has been with me through the whole process and he has always enjoyed going there. I've been so fortunate with some of the people I've met along the way. With kindergarten I asked around a lot and I stayed with him for all of first term until he was really settled. He has had an exceptional teacher over the two years probably one of the most dedicated teachers you could ever come across. She always asks is there anything she can put into the program that will support him. (LATWD)

Services did not always respond in ways the mother's expected.

You get the feeling that they are working with so many families that you are just another child, another family. But to you it is a personal journey and your emotions are involved and I found a lot of uncaring attitudes and no empathy whatsoever. I remember at [a community health centre] one time rather than assisting me further all they could do was quote me their policies. Rather than suggesting where else I might go it was just 'we can't help you, goodbye.' (SE)

The trouble with Centrelink applications is that it happens at a time when you are very distressed because your child had just been diagnosed. You are coming to terms with what that means for you and them. You apply for it but you don't fit a box…..In the end my paediatrician changed the diagnosis so we would fit. For me it is not about the funding – it's the whole emotional process of going through it and trying to defend your child. It gets out of perspective, rather than being about a small amount of money that they are going to offer you, it is trying to justify that your child has a need and how much you care for them ….It is just recognition that it is part of our life. (SE)

Like all parents, what these mothers wanted was their child to be happy and eventually to lead an independent life. When asked how they saw the child's future they were well aware of the challenges that their children faced.

I just want him to be happy and balanced and to be able to achieve his potential. At the moment that is an unknown quantity. I don't think that it is going to be easy. I can imagine him having a lot of difficulty. Kids can be cruel but as long as he is supported. Teachers teach for a year and I am his mother for life. But it's an unknown quantity at this time. (LATWD)

Intervention

How do we respond to families who have a child with a disability?

Looking back over the last twenty to thirty years there has been a significant evolution of ideas and theories about ECI.

Firstly, a new concept of ECI has been emerging in which health, education and social sciences, particularly psychology are contributing to a more holistic view which combines expertise, as opposed to the relatively different and not always interrelated approaches of the past. Secondly, there has been a progression from intervention mainly focused on the child to an increasingly broad approach, where the focus is no longer solely placed on the child, but also on the family and the community (European Agency for Development in Special Needs Education, 2010).

This section gives a brief overview of how:
- There are two 'literatures' related to ECI.
- The ecological model has become a guiding concept for ECI services
- Recognition of the importance of the role of caregivers has led to a different model of ECI.
- Recognition of the role of the child as an 'actor' in his or her own development is leading to new thinking.

The two 'literatures' related to ECI

While there has been a continuing convergence of the different disciplines of health education and social sciences, as the KPMG report commissioned by FaHCSIA, *Reviewing the evidence on the effectiveness of Early Childhood Intervention* (2011) observes, there are nonetheless two literatures about ECI. While both can be seen to share a common starting point, that "early intervention refers to the strategies, practices and therapies designed to help children with a disability or developmental delay to participate as fully as they are able in social, educational and economic life", the approaches taken to how this is achieved are different. One approach to ECI has seen it as "a service system that mobilises to support children and families with emerging needs relating to a child's disability or developmental delay". The second approach has viewed ECI "as a process, where intervention modifies the natural environments in which children develop – that is, the environments that children inhabit and experience in their everyday lives – to improve the functioning of both children and their families".

The distinction is essential. As the Centre for Community Child Health (2010) has observed:

> *If early childhood intervention is defined in terms of providing children with experiences and opportunities that promote competencies that enable them to participate meaningfully in home and community environments, then the focus will be*

on ensuring that families and other carers are able to provide children with such experiences and opportunities. In other words, the aim will be to ensure that the child's everyday learning environments are optimal.

If early childhood intervention is defined in terms of providing children and families with services, then the emphasis will be on the nature and quality of those services, and on changing the child's behaviour directly rather than on changing the child's learning environments. (p 32)

These different approaches to how ECI is viewed have led to different research literatures. The service orientated literature is child focused and tends to consider strategies designed to change a targeted cognitive, physical, or social area of development, for example a behaviour modification program. Such approaches are often pursued through demonstration projects in academic institutions and study the effect of specific set of strategies intensively implemented by professionals. The use of intensive, targeted interventions and the measurement of specific types change allow the impact of a program to be tested. An example of this type of literature is Roberts J. M. A. and Prior M. A, (2006) *Review of the Research to Identify the Most Effective Models of Practice in Early Intervention for Children with Autism Spectrum Disorders.*

The other type of literature can be found in the Centre for Community Child Health (2010) *DEECD Early Childhood Intervention Reform Project: Revised literature review.* It places ECI in the context of what is understood to effect children's development more broadly. Central to this approach is a view that all children's development occurs primarily within their family and broader social environment and that children with disabilities are no different in this respect. The focus therefore of intervention needs to be on the child's family and broader social context.

These two approaches can be portrayed as dividing the ECI field. In the field practitioners are often seeking to combine aspects of both as they attempt to work with caregivers to create everyday learning opportunities, and work to introduce specific child focus strategies as necessary to address specific issues. It is the influence of the physical and social environment on children's development, and the desire to promote everyday learning opportunities, that is currently changing the way services are structured.

**Why is social environment important?**

The ecological approach developed by Urie Brofenbrenner (1994), which identifies that children's development is influenced by several environmental systems, currently underpins practices in both early childhood and ECI. Its acceptance reflects the resolution of what had been a long standing debate over the relative importance of nature or nurture. Throughout the nineteenth and twentieth century the view of which was most significant kept changing. Some theories stressed the defining influence of the individual's own capabilities. At other times the impact of environment was considered most important.

Arnold Sameroff (2010: 8) proposes this brief history of the fluctuating dominance of the two approaches.

Rough History of Nature - Nurture

Historical era	Empirical advance
1880's – 1940s – Nature	Inherited differences
	Instinct
1920s – 1950s - Nurture	Reinforcement theory
	Psychoanalytical theory
1960 – 1970s - Nature	Ethnology – species differentiation
	Behavioural genetics
	Cognitive revolution
1980 – 1990s - Nurture	Poverty
	Social ecology
2000 - 2010 – Nature	Molecular biology
	Neuroscience

More recently the sciences have resolved this debate by demonstrating that development is the product of a complex interaction in which the child both influences and is influenced by their world, leading to the development of the brain's neural pathways. According to Sameroff, developmental psychology, which had initially focused on the individual, has evolved to accept that in order to understand why an individual has changed it is also necessary to analyse that individual's experience. Behaviour, in general, and development, in particular, cannot be separated from social context. One of the major implications is the importance of the primary caregiver on influencing socialisation. Traditionally the family was seen as the major influence on children. As many children now spend time in out-of-home child care during the early years this also has an impact. Each setting can be seen as making contributions to the development of the child. The following diagram represents a variation of Brofenbrenner's ecological model.

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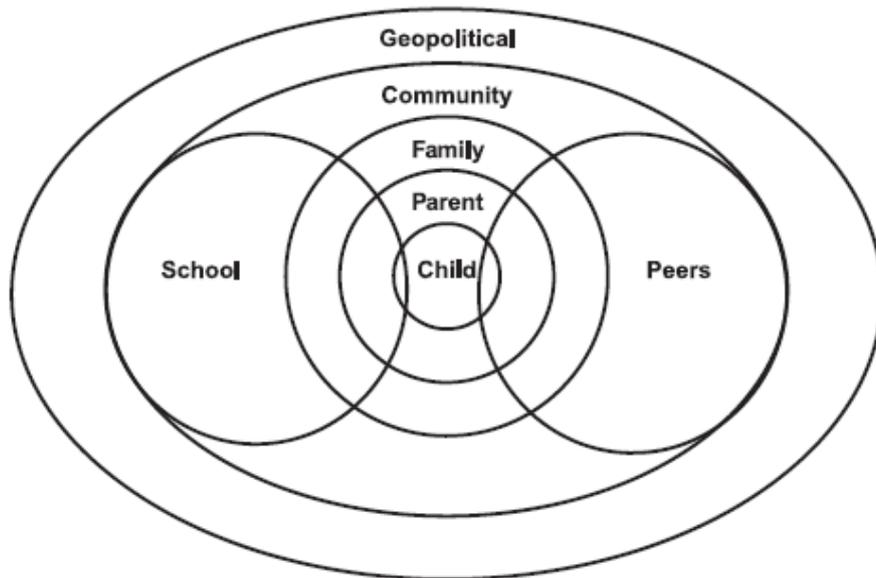
Social-ecological model of context

Rapid development of the sciences related to early childhood development led to President Clinton to commission the report, *From Neurons to Neighborhoods: the science of early childhood,* undertaken by the National Research Council and Institute of Medicine. This project was given the task of a synthesising the range of scientific perspectives. It identified a set of core concepts which are consistent across the sciences, most notably the complex interaction between developing children and their environments.

From Neurons to Neighborhoods also examines the effectiveness of early intervention. In the U.S. the concept of early intervention includes both children with developmental disabilities and children from low income backgrounds. It proposes a theory of change, rather than a model for early intervention. This theory of change can be seen to frame all interventions for young children. The theory proposes that:

- The general principles of development apply to all children and all aspects of development 'unfold' through the interaction between genetic predisposition and the child's physical and social experiences.

- Young children's relationships with their primary care givers have a major impact on their cognitive, linguistic, emotional, social and moral development.

- Caregivers are most supportive when they are warm, nurturing, individualised, responsive and there is a "goodness of fit". Their ability to provide support is influenced by both their internal resources (emotional health, social competence, educational background) and the external circumstances of their lives (family, social network, employment and finances).

- ECI programs have been designed to affect children directly and indirectly. Child focused interventions include developmentally guided educational opportunities or specifically prescribed therapies or both. Caregiver focused interventions varyingly

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combine information, instruction, emotional support, assistance with resources and services. (p 341)

This theory of change has a holistic approach to a child's development, in recognition that all aspects of a child's development are interrelated. Children are driven by their own need to adapt and develop. The course of early childhood development can be altered by interventions that "change the balance between risk and protective factors and thereby "increase the probability of a more favourable developmental trajectory". (p 4)

How is this relevant to children with disabilities?

An example of how this way of thinking can be applied to children with disabilities is Michael Guralnick's (2006) Developmental Systems Approach to Early Intervention. Guralnick's approach identifies the environment created for infants and young children by their family as central to development. It proposes that the family's patterns of interactions with their child create the developmental opportunities that benefit the child. These interactions are a combinations of the quality of the child – parent relationship, the types of experiences that family provides for the child and the general quality and safety of the environment.

While a child with a disability benefits from good patterns of interaction, a child with a disability also introduces additional stressors which may undermine these interactions. The additional pressures on the family include the need to process unexpected information as well as potentially complex interpersonal and family distress brought about by individual reactions and cultural attitudes to disability. In addition, there can be substantial resource needs, for example both in time, to attend and follow up appointments, and materials, to make home modification. Parents may feel challenged by the task of raising a child with a disability and begin to doubt their abilities. (pp10 -14) This process can be represented as follows:

Child characteristics   **Family patterns of interaction**   **Outcomes**

Stressors
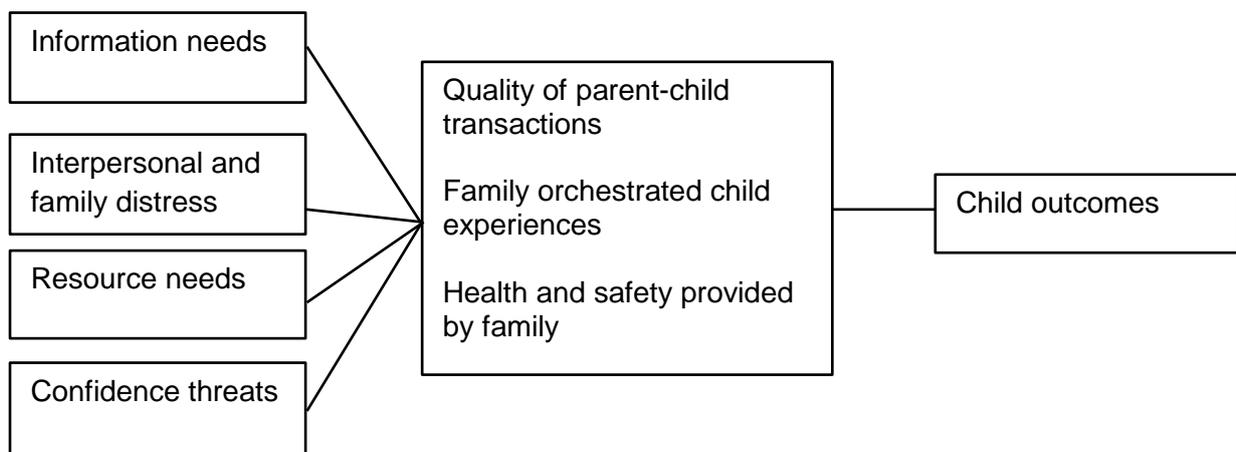
There are increasing levels of complexity added to this situation if families face other challenges, for example, from the economic situation of the family, the family's social networks and so forth.

The model proposed by Guralnick reflects both the broader changes in understandings about child development and a growing body of research evidence emerging from the ECI field itself. The importance of families and the study of family centred-practice in ECI has been central to its development over the past three decades.

Odom and Wolery (2003) brought this range of evidence together in identifying a set of key principles which had an evidence base, including:

- Families and homes are primary nurturing contexts.
- Strengthening relationships is an essential feature of early intervention
- Children learn through acting on and observing their environment.
- Adults mediate children's experiences to promote learning.
- Children's participation in more developmentally advanced settings, at times with assistance, is necessary for successful and independent participation in those settings.
- Early intervention practice is individually and dynamically goal oriented.
- Transitions across programs are enhanced by a developmentally instigative adult.
- Families and programs are influenced by the broader context (p 166).

These practices reinforce the importance of caregivers relationships with a child. The convergence of the early childhood and ECI literatures continues, for example in Guralnick's (2011) more recent work on what makes early intervention work.

In 2008 the Office of Special Education Programs brought together a Working Group, which included Carl Dunst, Mary Beth Bruder, Robin McWilliam, amongst others, to develop a set of Practices and Principles in Natural Environments. The term natural environments had been adopted to represent those places where young children normally went with their caregivers. The brief of the Working Group was to develop key principles and practices for working through families and other caregivers. It proposed that the purpose of early intervention was to build upon and provide "supports and resources to assist family members and caregivers to enhance children's learning and development through everyday learning opportunities". The principles that were identified included:

1. Infants and toddlers learn best through everyday experiences and interactions with familiar people in familiar contexts.
2. All families, with the necessary supports and resources, can enhance their children's learning and development.
3. The primary role of a service provider in early intervention is to work with and support family members and caregivers in children's lives.
4. The early intervention process, from initial contacts through transition, must be dynamic and individualised to reflect the child's and family members' preferences, learning styles and cultural beliefs.

5. Individual Family Support Plan outcomes must be functional and based on children's and families' needs and family-identified priorities.
6. The family's priorities, needs and interests are addressed most appropriately by a primary provider who represents and receives team and community support.
7. Interventions with young children and family members must be based on explicit principles, validated practices, best available research, and relevant laws and regulations.

The last three points warrant additional comment. The idea of functional goals introduces the idea that families set specific goals which are relevant to their everyday needs and activities. The idea of a primary provider arises from proposition that if the service seeks a deeper engagement with a family, then this is more effectively channelled through one person, rather than a whole staff team or multiple services. Making the process of ECI to families is essential if families are to have control over their involvement.

How do children influence their environments?

While *Neurons to Neighborhoods* highlighted the important role that caregivers have in their child's development, it also reported on the important role that children play as active participants in this development. There is an intrinsic human drive to explore and master one's environment. This inborn drive is a feature of all human development and continues throughout the life cycle. Soon after birth, children begin to learn about the world by creating their own knowledge based on their early experiences. Environments that provide opportunities and supports for growth support this natural drive. Unsupportive environments hinder it. (National Research Council and Institute of Medicine, 2000: 27)

The Australian Early Years Learning Framework (EYLF), (DEEWR, 2009) is based on this understanding of early development. Drawing on scientific research, the practice expertise of the field, and the philosophy of the UN's Convention on the Rights of the Child, it recognises both the importance of the relationships between the child and their caregivers and the active role children play in development. The themes of Belonging, Being and Becoming express the emerging identities, developing skills and new understandings that occur as children interact with their world. The outcomes identified by the EYLF emphasise the way in which a child develops within a social context.
These outcomes are that children:
- have a strong identity
- are connected to and contribute to their world
- have a strong sense of wellbeing
- are confident and involved learners
- are effective communicators.

This way of thinking is not necessarily new to either the early childhood or ECI fields. Writing about the evolution of Activity-Based intervention from the 1970's Pretti-Frontzak and Bricker (2011) observed how their centred based program was influenced by the inclusion of typically developing children.

Fortunately, this program included typically developing children as well as children with disabilities and was probably the first inclusive program for young children with disabilities in the country. The typically developing children taught program staff two valuable lessons. First, children's motivation is critically important. Young children living in reasonable environments are self-directed and frequently object to overt adult management and control. Thus, when faced with an uninteresting, non-meaningful, adult-directed task, the typically developing children in the program often refused to cooperate and sought ways to free themselves from such unwanted constraints. Second, children considered to be developing typically are often neither engaged by nor interested in pursuing a task or activity because they are provided with a tangible reward; rather, what the typically developing children deemed interesting and meaningful served to involve them and maintain their participation. These observations in concert with the intervention and research staff's growing appreciation of ecological theory moved them to better understand the critical nature of the learning context. (p.7)

Greater attention is being paid to supporting children with disabilities to develop through following their own interests. Dunst, Trivette, and Cutspec, (2007) have reported on a study involving 50 infants, toddlers, and preschoolers in six U.S. states designed to compare the relative effectiveness of interest-based learning vs. adult-directed learning. Using the Developmental Observation Checklist Scales (Language, Cognitive, Motor, Social) as the measure the study found that the children who were supported to explore their interests developed more quickly.
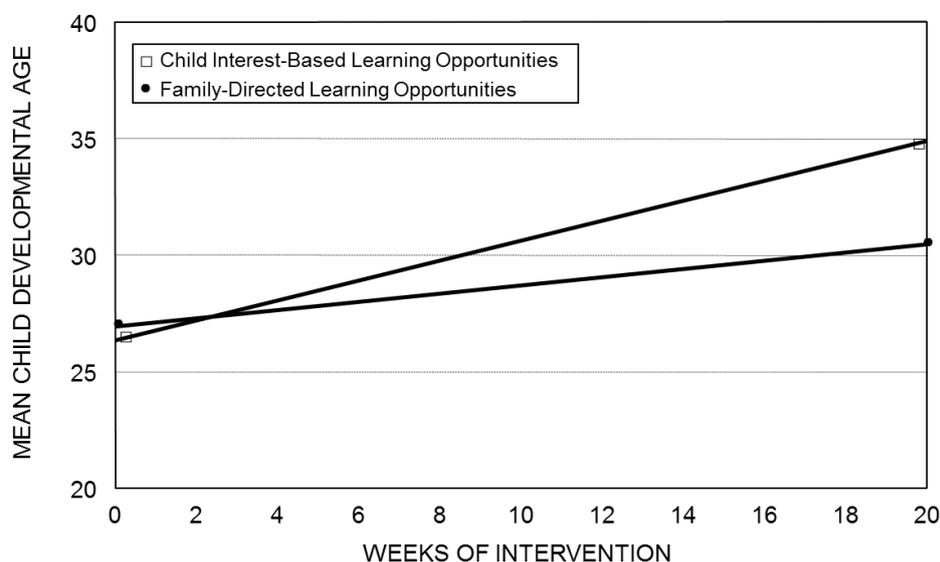
Relative Effectiveness of Two Contrasting Approaches to Natural Learning Environment Intervention Practices

This suggests that learning for children with disabilities is similar to other children's learning and that the balance between adult directed activities and child initiated activities adjusted.

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Individualisation

In 2003 Noah's Ark Inc.'s commenced changing to a more individualised service model. The main changes were from centre based programs, that ran groups for children based on age and developmental stage, to a home visiting program where individual goals were set with parents and implemented in the child's everyday environment. By taking the service to the home, it was intended to respond to families individually and modify the service to suit their wishes or needs. This change process is still continuing. The translation of theory to practice is not straight forward. The implications of change are often only be fully understood once the change has commenced. This section will focus on:

- Why change?
- What were the consequences of home visiting?
- How are we supporting developmental opportunities in the home?
- What are other opportunities exist in everyday settings?

Why change?

When Noah's Ark embarked on its change process it was guided by a mixture of philosophy and science rather than a master plan. Noah's Ark at that time was a hybrid. It worked from 17 locations across regional and metropolitan Victoria. Approximately one third of the organisation had originated out of the Toy Libraries which had been the initial model for the organisation. One third of the organisation focussed on inclusion. One third of the organisation was an amalgamation of a number of smaller services which came together in the Western suburbs of Melbourne. It was the team in the West that led the change.

With the benefit of hindsight it can be observed that the literature provided two possible paths. One led into the highly intensive programs that had been established in the Universities. The second path led into working with caregivers as the principle influence over their child in everyday settings. Both sets of research converged on the need to give children greater opportunities to practice skills consistently than was possible in our group programs.

Philosophically we were much more inclined to want to work in ways which supported the child to be part of the family and part of the community. Supporting inclusion and the rights of children with disabilities to participate in the community were strong currents in the organisation.

Practically we wanted to become more flexible in responding to families. As greater efforts were made to reach all families who had a child with a disability there were problems with fixed program structures. Some parents preferred not to participate in playgroups. Some families were choosing to send their child to 4-year-old kindergarten rather than our specialised program. Even more intensive centre based programs appeared less family friendly. The momentum was towards going to where the families were.

Pragmatically we didn't have the resources to implement an intensive professional program even if we had been that way inclined. While the lack of resources challenges all practice, it eliminates fidelity to many of the intensive programs that feature in the literature. Mobilising more resources through families and communities appeared the best way to create more learning opportunities.

A tipping point was a visit by Dr. Mary Beth Bruder to the ECIA Conference in Tasmania in 2002. She presented on the importance of working in what she called natural environments. The organisation decided it had to test this new approach. The change led to vigorous debate amongst the team. Partly this was the uncertainty of moving into the unknown and leaving behind long established practices.

What were the consequences of home visiting?

To guide the process of changing to a home based service we worked intensively with Bernadette Glass, who had worked with St Luke's in Bendigo on their strength-based training. As the name implies this approach aims to work with families from the perspective of what they are doing well. Bernadette came from a background of working with families involved in child protection, so she had experience of working with families from a low socio-economic background who had complex issues to deal with. Once staff started home visiting they were exposed to a new set of experiences, including:

The shock of poverty: while many staff had worked in the region for a long period of time, the experience of visiting homes and seeing the quality of the houses and how few resources some families had still took considerable adjustment

A different type of relationship: as parents started to get to know staff, and staff asked parents open ended questions, parents began to talk about a wider range of issues and circumstances than they had previously discussed in the centre, which led staff to question their boundaries

Safety and OHS: meeting families at home raised new issues, for example the presence of aggressive male partners and the very poor conditions in some houses

Cultural complexity: staff had to learn the appropriate behaviours for visiting the homes of families who followed particular cultural and religious practices or in other cases meet in neutral locations

Role clarification

We started home visiting with the model that one member of the staff team would become the primary home visitor for a family. They were to be the point of contact for the organisation. As a result staff became more involved with families and their lives and goals. This meant many more issues stared emerging from the parents. Some staff took to this role with great gusto, while others felt that their work with children was being compromised. This led to a process of role clarification. What was the role of an ECI worker, or what we came to call, the Transdisciplinary Key Worker?

What proved helpful most helpful was to see the role as a sets of five skills, as indicated below.
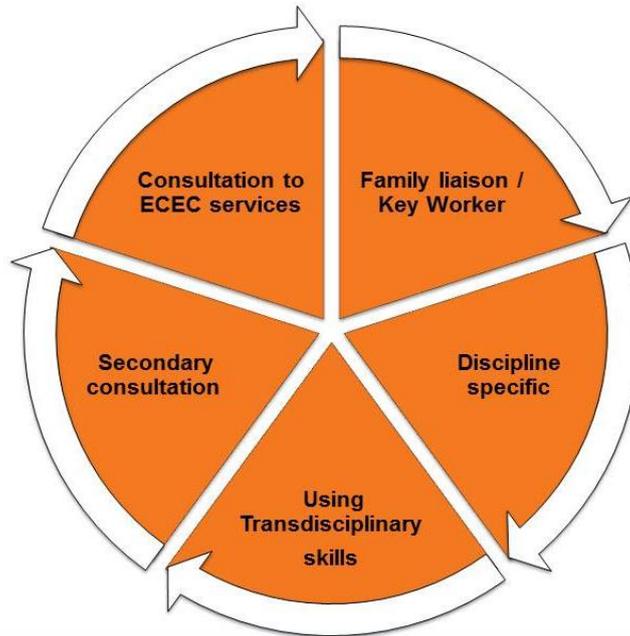
Family Liaison: This section represents skills in working with families through their issues and goals arising from having a child with a disability.

Own discipline: Our staff include Occupational Therapists, Physiotherapists, Speech Pathologists, Teachers, Psychologists and Social Workers and to the extent possible staff work with those children who will most benefit from their professional background.

Transdisciplinary: In the home visiting model staff used skills and knowledge they had picked up from working with colleagues from different professional backgrounds to deal with relatively straight forward issues or implemented a strategy recommended or demonstrated by someone from another profession.

Secondary Consultation: Staff could be called on by their colleagues to provide advice or conduct on a joint home visit to assist with issues that required their specific professional background.

Consultation to ECEC services: As children spend considerable time in children's services, at the request of parents, visits occurred at children's services where support and suggestions were offered.

This role is more complex than the traditional ECI professionals' role. It is not a role in which the focus is evenly split across the five areas. It requires professionals to prioritise, with families, what their focus is and then to refocus as the goals change. Staff are expected to

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be competent in their own discipline and expand into areas like using transdisciplinary skills as their experience grows.

The Key Worker

While clarifying the ECI role was helpful, it was actually the Key Worker, or family liaison, component of the role that needed most attention. There were two major issues. How did we prepare staff to undertake this role? How did we clarify the boundaries? This led to discussions with staff about their experiences, a review of the literature and, after much iteration, producing a book called *The Key Worker: Resources for Early Childhood Intervention Professionals (*Alexander and Forster, 2012). This describes the family liaison component of our ECI role in terms of:

Emotional support: The reality for many parents who have a child with a disability is that this is neither what they expected or wanted, which can initially lead to different emotional responses including self-blame, recriminations, family divisions and other disruptions. Unless these emotions are acknowledged and validated then it is more difficult for families to shift their focus to their child.

Information and Advice: When families enter the world of disability their previous knowledge and skills may be of little help in finding out the information they now need about their child or for their family. There can be a deluge of information, often in a professional language which is difficult to understand or in a form which makes it is difficult to find what is relevant. Control over information provides families with options and choices.

Identifying and addressing needs: After the initial reaction families start to address their immediate needs, as a family and for their child, and start a process of adaptation which may go through many stages.

Advocacy: Parents have to develop the skills to become an advocate for their child, whether dealing with the public or accessing services for their child.

Service Coordination: Learning to coordinate and utilise services can make a significant contribution to reducing family stress, given the many additional services a child with a disability might require.

The Key Worker resource includes a brief literature review, a summary of best practice and a competency checklist. One of the key roles it has played is in helping define boundaries. For example, it is within the role to discuss a family's emotional response to having a child with a disability, but it requires different professional input if those reactions escalate to the point where it is more appropriate for parents to seek marriage counselling.

In effect in the Key Worker resource we were dealing with the stresses that Guralnick (2006) identified.

How are we supporting developmental opportunities in the home?

In their book *Developmental Parenting,* Roggman, Boyce and Innocenti (2008) describe three models of home visiting services:
- child focused model
- parent focused model
- parenting focused model.

Child focused: a practitioner plans and implements specific child learning opportunities which are similar to those offered in an enriched early childhood learning environment directly with the child while the parent observes so she can imitate the activities later.

Parent focused: the practitioner works on meeting the family's basic needs, making referrals to other services, developing a relationship with and providing emotional support to the parent and giving information about child development of a general nature.

Parenting focused: the practitioner's central role is to assist parents to support their children's development by focusing on the parent-child interactions, using the resources available in the home and identifying ways the parent can enjoy the activities with the child (p 7-10).

Perhaps inadvertently, as we moved to a home visiting service the issues raised by families meant that the service became more parent focused. While it is essential to respond to what challenges parents, it is important to keep also looking at how to support a child's developmental opportunities. The strength of a home visiting model is the opportunity to support positive relationships between parent and child and to support the family to create opportunities that support the child to develop new skills.

Improving parent child interactions

Noah's Ark is currently pursuing three approaches to improve parent child interactions, which are related to attachment, collaborative partnerships and coaching.

Attachment: For a number of years we have been training staff in a program called Make The Connection (MTC) which was developed in Canada by The First Three Years (ND), with the support of Ayala Hanen Manolson, the founder of the Hanen Centre. The Hanen Centre has worldwide recognition for its communication programs which have a strong focus on how parents interact with their children. These programs, with one exception, can only be run by Speech Pathologists. MTC uses many of the same principles, but with a focus on providing parents with ways to develop their relationship with their child. Good attachment between parent and child is the basic building block for all parenting.

Collaborative partnerships: We are commencing a project with the Parenting Research Centre in Melbourne to develop resources to support staff and parents work together. These resources aim to better equip staff with a greater knowledge of adult learning theory and ways to support adults to change their behaviour or develop new skills. One of the premises

of working with parents in everyday settings is that parents have the capacity to support their child in learning or developmental opportunities. A challenge for anyone taking up new tasks is that this means reprioritising or giving up old ones. Most people know of something they should do to live a healthier life, but that does not mean they change what they are doing. Supporting adults to change is an important task in creating better learning opportunities.

Coaching parents: Currently we are also doing some work on how we can coach parents to work with their child, rather than work directly with children, with Dathan Rush and M'Lisa Sheldon, who have documented their approach in *The Early Childhood Coaching Handbook* (2011). If the focus of our work is strong, positive parent child interactions, then the focus needs to stay on the development of these interactions, as opposed to a visiting professional interacting with the child herself. Everyone has the experience of being a novice. We might have understood that we were going to swim and how we were meant to do it. We might have watched someone swimming. The first time anyone actually tries to swim it is quite a different experience. The coaching model is about parents having the opportunity to practice ways of interacting with their child with someone who can offer support and provide feedback. It is a powerful form of adult education.

Improving learning opportunities

Improving developmental opportunities has been the core of ECI services and is therefore the most rich in knowledge and the most complex to formalise. In terms of Noah's Ark approach we have formalised the use of the Canadian Occupational Performance Measure as the main planning and measurement instrument, but beyond this there are different approaches adopted by different teams.

One of the opportunities offered by working in everyday environments is the chance to make goals that reflect achieving things that are helpful in everyday life. McWilliam(2010) suggests that it is important to set functional goals that reflect things that are important in everyday life like the child's engagement, their progress towards independence and their social abilities. He points out that there has been confusion between assessments done for eligibility, which traditionally have looked at cognitive, communication; motor, adaptive and social development and assessments done to assist improve family. McWilliam has proposed a routines based interview as a method of collecting sufficient observations over time and across contexts to identify to identify those changes that would be significant. The criteria for functional goals are that they need to:

- Reflect priorities of families
- Be useful and meaningful
- Reflect real life experience
- Be free of jargon
- Be measureable (p 101 – 102)

Some of our teams are using the routines based approach or variations of it. The approach taken by Pip Campbell (2009) is simpler and gets families to identify how things are progressing in different times of the day, as the following part form indicates.

ROUTINE/ACTIVITY	EXPECTATIONS				COMMENTS	SATISFACTION				
	Exceeds	Meets	Occasionally Meets	Does not meet		Very	Is OK	Somewhat	Not	Did Not Ask
BATHTIME										
MORNING ROUTINE (getting up, getting dressed, bathing/washing)										
BEDTIME (getting ready for bed, going to bed, sleeping)										
MEALTIMES (appetite, level of assistance)										

What is helpful in this approach is that it identifies two types of intervention opportunities, those that arise when things are not going well and those that arise when things are going well. The former leads to more adult directed interventions. The second presents opportunities to explore children's interests.

Adult directed or scaffolded activities happen around situations, like toileting, when a specific outcome is required.

Child interest driven activities are useful in areas like language development where every day experiences like a walk in the park can form the basis of encouraging the use of description and expression.

Evidence based practice

It is in the implementation of different approaches to supporting a child's development that the two literatures about Early Intervention reconnect. The skills that practitioners bring to supporting children's development are often an eclectic collection of things learnt through study, things learnt from mentors and things learnt from experience. These approaches draw on what is being learnt through the evaluations of demonstration programs.

Sam Odom and Ann Cox are currently formalising this approach through National Professional Development Center on Autism Spectrum Disorders, which is a multi-university center to promote the use of evidence-based practice for children and adolescents with autism spectrum disorders. They are identifying the practices that underpin the programs that have good evidence about their effectiveness.

An example is the practice of prompting. They have identified that there are a number of studies that indicate the effectiveness of prompting in the domains of academic and language/communication.

Effective prompting strategies include:

- *Least-to-most prompts*: in which a prompt hierarchy is used to teach learners with ASD new skills
- *Simultaneous prompting*: in which the cue (i.e., a signal to learner to use target skill) and controlling prompt (i.e., prompt that ensures that the learner will use the target skill successfully) are delivered simultaneously
- *Graduated guidance*: in which a prompt is used to ensure the learner use these skill correctly is gradually removed the prompt during a teaching activity. (Neitzel, J., & Wolery, M. (2009)

Consideration is also given to what settings prompting be effectively used in. While the evidence-based studies were conducted mainly in clinic-based settings or in one-to-one teaching sessions with learners with ASD and did not demonstrate the use of prompting in more naturalistic settings such as during ongoing classroom routines and activities, in the home, or in community-based settings, they conclude that 'each of the prompting procedures could be adapted for use in these settings'. (National Professional Development Center on Autism Spectrum Disorders)

What are other opportunities exist in everyday settings?

The other area in which Noah's Ark has been active is in supporting children to benefit from attending ECEC services. Outside the home, ECEC services provide one of the best everyday environments which children with disabilities can develop, practice and master new skills.

While some parents report that their children have very successful experiences in ECEC, anecdotally the experience remains variable. The challenges to children's successful inclusion include:
- Attitudes and beliefs of adults
- Flexibility or otherwise of programs
- Availability of professional support or mentoring
- Availability of information and resources.

There are at least three approaches to improving the developmental opportunities children with disabilities have in ECEC. These are:
- Development and adaptation of the ECEC program
- Strengthening support from visiting consultants
- Developing individualised programs.

The development and adaptation of ECEC programs

There are a number of ways ECEC programs might develop and adapt. At the community level there is the broad challenge developing services that can meet the needs of all children. The concept of universal design is helpful in this context. The term 'universal design' came into currency through its use in architecture. It is the concept that a building should be designed in such a way that it is accessible to anyone. It should not need to be modified later on. This idea has been adopted in approaches such as universal design for learning. The principles of universal design have implications for ECEC services' culture,

curriculum, pedagogy and physical design. Are services designed for every child, including children with disabilities, or were they designed for the 'mainstream', whatever that term means today? This is a very difficult area for ECI to influence, although reform to children's services is essential to achieving the inclusion of all children. These themes are explored in more depth in Virginia Buysse's (2012) recent work on a framework for improving inclusive early education opportunities for children with disabilities.

Where Noah's Ark has attempted to have some influence is through its staff who visit ECEC services. Both Inclusion Support Facilitators and ECI professionals offer support to staff in ECEC services who are seeking to better include a child with additional needs. The work that we have done is more directly relevant to Inclusion Support Facilitators, but it also has relevance to ECI.

We wanted to find a way where we could introduce evidence based information into the types of decisions that were being made about including a particular child. What we understood was that the issue was likely to be pressing and the time available was likely to be limited. We also wanted to work in a capacity building way in which the staff in the services were identifying the issues and suggesting possible solutions.

We developed a set of tools that eventually became a book, *Participating and Belonging: Inclusion in Practice (Webster and Forster, 2012).* Sixteen areas of practice that supports inclusion were identified. For each area of practice we developed a brief Overview, a summary of research and practice knowledge put into an Australian context, a two page Tip Sheet, the essential components of the practice, and a Checklist to identify which practices are already in place. It was the two page tip sheet was the main tool. It has one page on the practice and one page of illustrative stories.

Inclusion Practices

Program Practices that Support Inclusion
- Transitions
- Individualised Programs
- Physical Environment
- Equipment and Toys
- Children's Relationships
- Staff Teams

Resources to Support Inclusion
- Families
- Consultants
- Training
- Mentoring and Support
- Funding Programs

Inclusion Readiness
- Leadership
- Quality Programs
- Enrolment
- Full Participation
- Parent Involvement

Quality Inclusive Children's Programs

Intervention, Individualisation and Insurance: Who is the 'I' who will benefit?

Participating and Belonging: Inclusion in Practice is organised into three sections which have a different focus and these are: Inclusion Readiness, Resources to Support Inclusion and Program Practices to Support Inclusion. This is illustrated above.

- Inclusion readiness highlights the pivotal role of the manager, owner or coordinator/director and identifies the need for consistent and equitable processes and strong parent involvement. The practices areas include Leadership, Quality Programs, Enrolment, Full Participation and Parent Involvement.
- Resources to support inclusion focus on ensuring that the right resources are in place to support educators, children and families. The practice areas include Families, Consultants, Training, Mentoring and Support, and Funding Programs.
- Program Practices that support inclusion recognises that once the resources are in place it may be necessary to look at how the program can be adapted to support inclusion. The practice areas include transitions, individualised programs, physical environment, equipment and toys, children's relationships and staff teams.

Strengthening support from visiting consultants and developing individualised programs

One of the interesting system challenges for ECEC is that while there is acknowledgement about the benefits for children with disabilities from linking with other services involved with the child, there is no clarification about what that relationship might look like. This would appear to be negotiated on an individual basis. While there is a mandate from the Inclusion and Professional Support Program for Inclusion Support Facilitators to visit Commonwealth funded services, it is not their role to focus on specific children. One of the best explorations of this role is by clarifications of the role to date has been by Dinnebeil and McInernery (2011) who describe the role in terms of the:

- Consultant
- Coach
- Assessor
- Service coordinator
- Team member.

This type of approach needs to be clarified for the Australian context.

Noah's Ark Transdisciplinary Key Workers use a range of approaches to supporting the development of individualised programs in ECEC services and we have not attempted to formalise these to date. The use of functional goal setting may be useful in this environment, as well in the home.

Insurance

Early Childhood Intervention and the NDIS (DisabilityCare Australia)

DisabilityCare is a scheme that proposes major changes to how people with disabilities are supported and has significant implications for ECI. The Productivity Commission report that recommended its establishment identified a wide range of issues with current arrangements including:

- Patchy and inequitable coverage for people with and who acquire a disability
- Long waiting lists and poor use of early intervention
- A fragmented approach that lacked clear responsibilities or adequate planning.
- People with disabilities, their families and carers treated in ways that are disempowering, provide little choice, are devaluing and give little confidence about the future.
- Are inefficient, economically unsustainable and has insufficient engagement with the community.
- Provides poor information, has poor data and a poor evidence base.

At the centre of the reform is a significant change in funding models. Instead of government funding organisations to provide services, it is proposed that the government funds people with disability to purchase services. It is intended that this approach gives people with disabilities more choice and control over the services they receive.

Since the release of the *Disability Care and Support* report there has been rapid progress towards implementation, including the development of the NDIS Agency, the identification of the launch sites and the passing of enabling legislation. This has been undertaken with amazing speed. In shortening the timelines initially proposed by the Productivity Commission for the development of a scheme of such significance size and importance, it has not been possible to explore every dimension of support and care to people with disabilities. It will be a challenge for both the new Agency and other stakeholders to balance continuing to address these complexities while dealing with the necessities and expectations created by implementation.

This section addresses some of the issues arising from the NDIS for young children with disabilities and their families. It considers:

- Are the purposes of the NDIS and ECI the same?
- What are the differences between adult perspective, prioritises and issues and issues in the early years?
- How is planning understood in the NDIS and ECI?
- What assumptions about access to and use of mainstream services are made in the NDIS?

Intervention, Individualisation and Insurance: Who is the 'I' who will benefit?

Are the purposes of the NDIS and Early Childhood Intervention the same?

The NDIS was initially proposed with a very specific notion of Care and Support. The Productivity Commission report outlined the type of things that it saw as examples of what was relevant, including:

- **Aides & appliances and home & vehicle modifications**
- **Personal care** (bathing, dressing, personal hygiene, eating, mobility exercises etc)
- **Community access supports** (supporting social independence)
- **Respite** (short-term and time-limited breaks, including for carers)
- **Specialist accommodation support (** group homes, alternative family placement)
- **Domestic assistance** (meal preparation, domestic tasks, banking, shopping, appointments)
- **Transport assistance (** individual or group transport services)
- **Supported employment services and specialist transition to work programs**
- **Therapies** (occupational and physiotherapy, counselling, behavioural interventions)
- **Local area coordination and development (case** management, geographical area)
- **Crisis/emergency support**
- **Guide dogs and assistance dogs**　　　　(Productivity Commission 2011a, p 21)

While many of the terms used by the productivity Commission resonate with the early years, they mean different things. Young children generally have high support needs and the support needs of young children with disabilities are often more characteristic of an age than a disability. Some children do have very high support needs. Some families use respite. Therapies are relevant across the life span. What have been viewed as Support and Care in the NDIS include many things that are not characteristics of ECI programs. What has been central to ECI is not immediately evident in Support and Care. The process of providing Support and care is clearer when there is a demonstrated need. In ECI there always been the intention to work in a preventative way which stops needs emerging.

Early Intervention in general is a challenge for a scheme like an NDIS. The Productivity Commission identified the difficulties an NDIS would inevitably have to face in choosing or targeting early interventions to be funded or purchased. While it is possible in principle, by identifying interventions that are safe and work and that are likely to yield the highest benefits or have lowest costs, this is less easy to put into practice. To determine what early interventions should be funded the NDIS will need to determine:

- *What standard of evidence is required in deciding whether or not to fund or purchase a particular intervention?*
- *How should the evidence be obtained?*
- *How would the funding of proven interventions sit with the funding of other disability supports? (Productivity Commission 2011a, p 628)*

By contrast to the language of Support and Care, the language used in describing the purpose of ECI has had a strong emphasis on family supports, developmental supports and school entry. The NSW Department of Ageing, Disability and Home Care (ADHC) website describes ECI in the following terms:

Early Childhood Intervention services provide specialised support and services for infants and young children with developmental delay or disability. These services can include therapy, education, inclusion support in early childhood services, formal and informal family support, and the provision of information and support for transition into school systems. (ADHC)

The Victorian Department of Education and Early Childhood Development (DEECD) website has a similar approach.

Early Childhood Intervention Services (ECIS) support children with a disability or developmental delay from birth to school entry and their families. ECIS provides special education, therapy, counselling, service planning and coordination, assistance and support to access services such as kindergarten and child care.

The overall aim of these services is to provide parents and families with the knowledge, skills and support to meet the needs of their child and to optimise the child's development and ability to participate in family and community life. All services are provided using a family-centred approach, recognising the importance of working in partnership with the family. (DEECD)

The Australian Government programs Helping Children with Autism (HCWA) and the Better Start for Children with Disability Initiative (Better Start) have less focus on family support but share the focus on school entry. According the Families, Housing, Community Services and Indigenous Affairs' (FAHCSIAa) website:

The Early Intervention funding under the Helping Children with Autism (HCWA) package is aimed at providing increased access to Early Intervention for children aged up to six years with an ASD. The funding supports the delivery of multidisciplinary evidence based Early Intervention to facilitate improved cognitive, emotional and social development prior to a child starting school. (FAHCSIAa)

The Better Start initiative Information for parents and carers describes its purpose as:

This targeted early intervention during a child's pre-school years aims to complement existing Commonwealth and state and territory services to help children have the best possible preparation for school. (FAHCSIAb)

The NDIS does have some broader aims about improving the future of people with disabilities, but its focus continues to be different to the traditional focus of ECI programs. In the recently released *Principles to determine the responsibilities of the NDIS and other service systems* the Council of Australian Governments was keen to distinguish the roles of the NDIS and education. It states that the NDIS will be responsible for early interventions for a child with a disability (or development delay) which are:

- *specifically targeted at enhancing a child's functioning to undertake activities of daily living (not supports, such as school readiness programs, which are specifically for the purpose of accessing a universal service, such as education); and*

- *likely to reduce the child's future support needs which would otherwise require support from the NDIS in later years, including through a combination and sequence of supports (not including medical and health treatments outlined in the health interface).* COAG (2013)

It is difficult to be definitive about the NDIS at this time, given the unknown nature of its operational guidelines. What we know is that ECI is being included in the launch sites and in process its purpose is being changed. It may be semantics. In practice ECI may continue to have a similar role to that it has played in the past. It may also be the case that gaps will emerge if these different purposes prove real.

What are the difference between adult perspectives, prioritises and issues and issues in the early years?

The NDIS has a strong focus on adults. The fact that less attention is paid to children should not be a surprise. Young children represent a small part of the general population. While the Australian Government has had a significant role in services for adults, it has only recently became involved in early childhood development generally, and young children with disabilities in particular. The national reforms to early childhood services that saw the emergence of a unified approach to early childhood education and care, and the identification of an EYLF, were first put forward in the Australian Labor Party's Policy Platform for the 2007 election (ALP, 2007). *Helping Children with Autism* was announced in 2007, The by Mal Brough (Press release, 2007) as a Howard Government initiative.

The perspectives, priorities and issues that are important to adults who have a disability have driven much of the thinking behind the NDIS. These are not the same as the issues in the early years. For example a central feature of the NDIS is that it needs to redress the disempowerment experienced by adults who limited control or choice over the services they use or how they organise their lives. Young children with disabilities are not disempowered in the same way. It could be said they are at the start of a process that will lead to their disempowerment as adults. The following table attempts to identify some of the major differences between the focus that has traditionally been taken in ECI and the adult orientated approach adopted for the NDIS.

	Early Childhood	Adults	Comment
Underlying concepts	*Prevention*	*Individualised/ Personalisation*	The notion of being disenfranchised does not apply to a young child as what is about to happen to them is what is what leads to exclusion
Decisions	Parents	Individual with disability	It is the accepted community norm and legal right of parents/guardians to be making decisions for their child, whereas for adults it is important that the individual drive the decision making and others do not make decisions for them.

Type of decision	Developmental	Interest based	The main concern in the early years is to promote the child's capabilities in the best possible manner and decisions about what to do need to be informed by the developmental interests of the child, whereas the adult can make decisions arising out of their own interests and preferences.
Planning needs	Rapidly changing priorities	Longer term goals	The planning needs for young children are rapidly changing because of the changing circumstances of the family and the changing developmental needs of the child and the fact that children grow and change quickly during this period in general.
Services involvement	Necessary	Optional	There is the need for children to engage with services that support the development of children and children with disabilities specifically in order to ensure that the develop their capacities because parents / guardians do not have knowledge about atypical child development.
Community involvement	Increasingly structured: Child care, Preschool, school	Individual choice	Social interaction with peers is an essential way in which children develop and this is supported for all children through the community infrastructure of Early Childhood Education and Care settings.
Outcomes	Same as all children	Broad, to accommodate individual goals	Through the development of the Early Years Learning Framework there is now an agreed set of outcomes to guide all children's development. In the adult sphere we expect greater autonomy.
Duration	Short term / finite	Long term / indefinite	The early childhood phase is a distinct period of life prior to school which lasts for up to 6 years, but which may be less than one year where a disability is identified. Adulthood broadly extends from school completion.
Workforce	Skilled	Flexible	The workforce required to support child development has historically included therapists and teachers, with other supports including carers. Adults may support from people with a wider range of backgrounds.

It should not be unexpected that what is expected for adults through these reforms do not align with the experiences of families who have young children with a disability. In any service area there is the need to take into account the life cycle and make appropriate adjustments.

How is planning understood in the NDIS and ECI?

The central driver to the NDIS model is individualised care planning. This approach to planning is intended to identify future and immediate goals, devise strategies to respond to these goals and match these to the available resources.

Under the *National Disability Insurance Scheme Act 2013* there are detailed considerations given to the development of an individualised plan. It requires plans that:

- Are directed by the participant towards achieving his or her individual goals, needs and aspirations and are underpinned by the individual's right to exercise control over his or her own life;
- Consider and respect the role of family, carers and other significant persons as well as strengthen and build capacity of families and carers to support participants who are children
- Consider the availability of informal support, support services and support from the community and advance the participants inclusion and participation in the community. (p 35)

This type of approach to person centred planning is not new. For example a resource book *Working in Person Centred Ways* developed by The Department of Ageing, Disability and Home Care & The Consortium for Person-Centred Approaches outlines the rationale for such an approach in the following terms.

Person centred approaches can mean that people with disabilities have better lives. That means having:

- *a real home*
- *a meaningful week*
- *purpose*
- *family, friends and acquaintances*
- *growth and self-development*
- *social groups to belong to*
- *people treat you as an individual*
- *control over the direction of one's life and future*
- *good health*
- *a belief system*
- *safety, security and justice.*

As in the NDIS more broadly, while there are overlaps with the early years, the focus in this resource is towards adults.

Proponents of person centred planning like Simon Duffy and Helen Sanderson emphasise that it is important to change the approach to planning with a person with a disability. People with disabilities live in different circumstances. The care manager's role needs to change according to the capabilities of the person with a disability, or their supporters to drive the planning process. Interventions should be as light, or non-taxing, as possible.

They propose a Five Gear Model of Care Management, which has the following steps:

- Gather Information
- Design Service
- Develop Services
- Solve Problems
- Review & Learn

The process starts with gathering information about the person, their needs, their objectives and their community. The amount of work required at this stage depends on existing knowledge or need to be developed in a more detailed way. Once there is shared understanding of the present situation and what needs to change, then possible solutions can be identified. If the person has significant support needs then an individual service will need to be designed. Some people will be able to do this themselves or with help from others, in which case the care manager's role is to evaluate whether the proposed service is a sensible way of meeting the agreed needs.

If the person cannot design the response then the care manager becomes more involved in helping making it happen. Once a service has been designed then its implementation needs to be worked out. More imaginative and community-focused services require the most negotiation and development. If the individual, their family, their friends or other service providers can do most of the work in implementation then the case manager has a limited role. If not, then the care manager has to take on the practical responsibility of putting the service into practice. Once the service is in place, the care manager may still need to be involved to help solve problems, manage risks and reduce conflict. Involvement at this stage will depend on what other supports are in place. Once the plan has been implemented then it is the care manager's responsibility to review support services and to ensure that any lessons are learnt.

While the stages in any case management or consultancy role moves through similar steps, the focus in ECI has been quite different. As the Ageing, Disability and Home Care (ADHC) website informs parents, the types of planning supports parents might get through ECI are highly informative and include:

- finding out about your child's disability and needs
- support you to help your child learn new skills
- developmental and learning activities for your child
- opportunities for your child to interact with other children
- play based activities to develop new skills for your child
- information about and help you to connect with other professionals in the community such as staff in preschool and child care settings, psychologists, case managers speech pathologists, educators, physiotherapists and occupational therapists
- support to be involved in the activities and experiences that all children and families enjoy
- support to develop networks with other parents, health professionals, service providers and their local community. (ADHC)

Planning in ECI starts with the immediate needs of families to find out about their child, begin a different type of parenting experience and find ways to reengage with the community around the general early childhood experience. Early childhood is characterised by constant and rapid change. Parents are constantly finding out about their child's developing capabilities, helping the child develop new skills, introducing new activities, arranging social interaction, while dealing with their own stresses. ECI has a long history of dealing with this

process through Individual Family Support Plans. How the planning process required by the NDIS intersects with the planning cycle required within ECI will be important to resolve.

What assumptions are made about access to and use of mainstream services in the NDIS?

An area that is yet to be clarified is how children with disabilities will be supported in ECEC services. The NDIS has been careful to distinguish itself from education. It does recognise that ECEC has a role for children with disabilities:

> *The early childhood education and care sector will continue to be responsible for meeting the education and care needs of children with a development delay or disability, including through inclusion supports that enable children to participate in early childhood education and care settings.* COAG (2013)

Under the new National Quality Framework (NQF) there is the strongest indication policy intention yet that children with disabilities will benefit from ECEC services, including a broad commitment to inclusion. In the Early Years Learning Framework inclusion is defined in the following terms:

> *Inclusion: involves taking into account all children's social, cultural and linguistic diversity (including learning styles, abilities, disabilities, gender, family circumstances and geographic location) in curriculum decision-making processes. The intent is to ensure that all children's experiences are recognised and valued. The intent is also to ensure that all children have equitable access to resources and participation, and opportunities to demonstrate their learning and to value difference. (DEEWR, 2009)*

More recently Early Childhood Australia and ECIA (2012) developed a Position Statement on the inclusion of children with a disability in early childhood education and care to further the importance of children with disabilities participating in ECEC services. That position is as follows.

> *Our position is that children with a disability have the same rights as all children and additional rights because of their disability. They share with all children the right to be valued as individuals and as contributing members of families, communities and society.*
>
> *Every child is entitled to access and participate in ECEC programs which recognise them as active agents in their own lives and learning, respond to them as individuals, respect their families as partners and engage with their diverse backgrounds and cultures.*
>
> *This means that ECEC services and support professionals must be resourced and supported to the level required to fully include children with a disability and to achieve high quality outcomes for all children.*

Intervention, Individualisation and Insurance: Who is the 'I' who will benefit?

While there has been policy progress in this area, there are significant concerns about whether these are being put into practice. The Productivity Commission (2011b) report on the *Early Childhood Development Workforce* warned that there were significant gaps between the ECEC opportunities for children with additional needs and those available to other children. It suggested that to reduce these gaps, priority needed to be given to children with additional needs in the implementation of the ECEC reforms. This has not happened to date. The Productivity Commission noted that the limited data available on the ECEC workforce for children with additional needs made it difficult for governments' to develop effective policy development or workforce planning. In particular it noted the lack of professional support to assist staff in mainstream ECEC services. Better access to professional development programs was suggested for both general staff and the generally unqualified staff who provide extra support for children with high additional needs. Funding arrangements, including its often short term nature, lag in payments to services and onerous administrative processes were not helpful. (p 147)

There are two immediate challenges for an NDIS model in the context of ECEC services. The first is that it may not recognise the level of self-advocacy that is required by parents to find a suitable service for their child. Even in the compulsory school system there are enough anecdotes about discrimination to suggest it is a major problem. In the non-compulsory early years and with a mixed set of providers the potential of exclusion is much greater.

The other issue goes to who supports ECEC staff in providing an individualised program for a child with a disability in an ECEC service. At present the system of professional support is far from comprehensive. ECI has been playing an increasing role through supporting children with disabilities in everyday settings. Will the distinction that the NDIS is drawing between support and care and education support this into the future?

Conclusion- Who is the 'I' who benefits?

This paper has explored three areas. It has described the theories and research that have been driving change in ECI services, explored how services have been developing through using the experience of Noah's Ark Inc as an example and commented on the differences between the adult and early childhood experience that needs to be accommodated in a NDIS, DisabilityCare. That seemed to be the best way to illuminate the interesting intersection at which we have now arrived. New thinking about how children develop has been driving a new way of providing services for children with disabilities, with the emphasis on the role of caregivers providing learning opportunities. This development is now caught up in a major restructure of services for people with disability with its orientation towards choice and control and creating markets. It is not yet clear how this will resolve itself as the operational guidelines for DisabilityCare have not been released and the scheme is still clarifying how it will operate.

There are clear benefits for children with disabilities from services that mobilise resources to support children's developmental opportunities in everyday settings. The influence of caregivers on the development of young children is clearly established across the early childhood sciences and field. The process of effectively working with caregivers to increase children's developmental opportunities is continuing to be refined.

There are also clear benefits for families and children from a national insurance model that eliminates waiting periods and attempts to better match resources to a child and family's need. There are also benefits from parents of children with a disability having greater choice and control over services, as there are benefits for anyone using a service. How this is done in a way which reflects the demands on families who a young child with a disability is yet to be clarified.

There are also some risks. The first risk lies in responding to challenge to early intervention generally identified by the Productivity Commission. It has argued that establishing the evidence base justifying early interventions will be a difficulty. This is certainly the case in ECI, where its fragmented development across the different jurisdictions has also been characterised by an absence of investment in research and development. There has been no investment in developing either a national approach or making a common evidence base available. By comparison the early childhood field, granted it is very recently, has had the opportunity to undertake a major consolidation through the development of the National Quality Framework (NQF). In the U.S. the equivalent to Early Childhood Intervention Australia, the Division of Early Childhood, is funded to produce a national publication called *DEC Recommended Practices: A Comprehensive Guide* (Sandall, Hemmeter, Smith and McLean, 2005) which reviews evidence based practice for use by practitioners. This type of investment is needed.

Secondly, there is a danger that support for ECI that only functions in homes and cannot outreach into ECEC services will leave children with disabilities without the supports they need to benefit from ECEC. The Productivity Commission has identified the risk that they will not gain the same benefits from the introduction of the NQF and the introduction of a universal 4-year-old program. Indeed, they risk being left behind in these developments.

Realising the developmental opportunities available to children with disabilities through children's services is an important part of working through caregivers to enhance children's development.

Thirdly, there are the questions of workforce and market development. The principle of establishing markets in the design of the NDIS has significant implications. How this is applied will lead to quite different futures. To date there has been little discussion on this topic. There has been significant debate elsewhere, for example, about what are known as 'vendor services' and about service coordination in the U.S. These focus on similar mechanisms to those proposed by DisabilityCare and the different ways they have been applied in different States and the consequences. It would be useful to have an open debate on these issues.

Finally there is the question of whether the broader challenges identified by families who have a child with a disability are going to be met. One of the reoccurring themes from parent interviews is the complex and fragmented nature of the services available to children with disabilities. While planning through a Key Worker, planner or care manager may assist families to negotiate their way through the maze of services, this assistance is not changing the environment. While every department and program continues to independently add its disability support element and create its own eligibility criteria the maze continues to grow. The grouping of programs within DisabilityCare may reduce some elements of this, but that is only part of the answer. The larger picture is yet to be seen.

In a time of great goodwill and exciting opportunities, there is reason to be optimistic that DisabilityCare will bring great benefits to families who have a child with a disability. That said, there is a need for great vigilance on behalf of families who have a young child with a disability and ECI. Decisions may be made that reduce the scope of ECI. Decisions may be made that reduce the opportunities children with disabilities have in ECEC services. If the workforce and market are not managed well then the landscape of ECI could look entirely different in a decade. There is no reason for complacency, given how much is still left to be done to ensure all families can enjoy the early years and be confident that their child will have support, care and a meaningful role in the community. DisabilityCare, at its best, will make a significant contribution, but it, by itself, will not be enough.

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