

# Rethinking early childhood intervention services: Implications for policy and practice

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## ABSTRACT

Drawing on a recent major literature review of early childhood intervention services, this paper examines the aims and rationale for early childhood intervention services, and what is known about effective practice. Based on an understanding of how children (including children with disabilities) learn, the aim of early childhood intervention (and indeed of all child rearing) is to ensure that children with developmental disabilities gain the functional skills they need to participate meaningfully in their daily environments. Meaningful participation is the engine of development and the key to attaining a true sense of belonging and a satisfactory quality of life.

The implications of this reconceptualisation of the aims of early childhood intervention services for policy and practice are then considered. The policy implications explored include the question of the compatibility of prevalent funding models in Australia and elsewhere with this new understanding of the aims of early childhood intervention. The practice implications include how to build the capacity of children, families, and mainstream early childhood services, as well as those of early childhood intervention services themselves.

The ideas discussed in this presentation also have implications for our wider society. First, they suggest that we need to go beyond traditional notions of disability and think in terms of the full diversity of human ability. Second, we also need to go beyond traditional notions of inclusion, and think in terms of creating environments that are able to cater for the individual and collective needs of all children and families. Third, we need to go beyond ideas of remediation and rehabilitation, and think instead of building people's capabilities. Ultimately, the goals of early childhood intervention can only be fully achieved through such changes in societal thinking and values.

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## INTRODUCTION

This is the fourth of the Pauline McGregor Memorial Addresses (Johnston, 2006; Moore, 2008; Forster, 2010), and the second that I have the honour to present. Following the lead of Christine Johnston in the first of the addresses (Johnston, 2006), we have been using these opportunities to reflect upon early childhood intervention and its relationship with other services, particularly mainstream services. In the process, we have also reflected upon the needs of children with developmental disabilities and their families, and what their place in the world is, grappling with (and seeking to go beyond) issues of inclusion.

One of the great pleasures of being involved in a national association such as Early Childhood Intervention Australia has been the forming of friendships with interstate colleagues in our collective endeavours to further the cause of early childhood intervention services and the children and families they support. Nothing would give me greater pleasure than to have Pauline McGregor still with us on our journey, contributing with her characteristically forthright but good-humoured views.

## OUTLINE

This paper draws on a recent major literature review of early childhood intervention (ECI) services (Moore, 2011), and on work done subsequently to extend the findings of that review. (A number of colleagues contributed to this work, and their names are listed at the end of the paper). We begin with a brief summary of the key ways in which children develop and learn, and examine whether children with developmental disabilities develop and learn in the same ways as other children. Next, we explore the vital question of outcomes – what goals we are seeking for children, and whether the goals we seek for children with developmental disabilities are any different from those we want for all our children,

This sets the scene for the main body of the paper which examines the aims and rationale for ECI services, and the role of ECI service providers in working with children with developmental disabilities, their families and communities, and the early childhood services they attend. Following this analysis, the paper explores some of the implications of this reconceptualisation for practice, for policy, and for our society as a whole, before drawing some final conclusions.

## HOW CHILDREN WITH AND WITHOUT DISABILITIES DEVELOP AND LEARN

In thinking about children with disabilities, we should always start from what we know about children in general. Thus, in considering how children with disabilities develop and learn, we should start by reviewing what we know about how children in general develop and learn, then explore in what ways the development and learning of children with developmental disabilities differ from these patterns. Also, in considering the needs of children with developmental disabilities, we should begin by reminding ourselves of the needs of children in general, and ask in what ways (if any) these differ for children with developmental disabilities.

Support for this approach comes from psychiatrist Jordan Smoller in his recent book *The Other Side of Normal* (2012). He challenges psychiatry's focus on extreme behavioral abnormalities, which has resulted in a system of classification and diagnosis (the DSM) based on constellations of symptoms. Smoller argues that, without knowing how the brain and mind develop and function, it is impossible to evaluate the validity of these categories of symptoms. He suggests a radically different approach. Rather than seeking to understand the normal by studying the abnormal, he proposes that

'... the best way to study the abnormal is to study the normal. Rather than simply starting at the edges and working our way back, our goal should be to illuminate the full and vast distribution of the normal. As we fill out the centre, we can see the connections to the extremes – how and where the functions of the mind can be perturbed or disrupted.' (p. 335)

Because of the rapid advances in our knowledge of child development and of the genetic and neurological bases of development, we are in a much stronger position to adopt such an approach than before.

## How children in general develop and learn

What, then, do we know about how children in general develop and learn, and the conditions they need to do so? Of the vast amount of knowledge that we have accumulated, we will focus on two key themes only – the importance of early learning environments and role of relationships.

### **Early learning environments**

- Learning starts from birth (Shonkoff & Phillips, 2000), and skills develop cumulatively, so that those acquired early form the basis for later skill development (Cunha et al., 2006).
- Thus, the skills children develop in the early years contribute to a chain of effects that either reinforces and amplifies their initial skills and dispositions, or exacerbate initial difficulties and even produces new ones (Rigney, 2010; Stipek, 2001, 2005; The Marmot Review, 2010).
- Children need multiple opportunities to practice functional skills in everyday environments.
- Because children's learning is cumulative, early functioning is predictive of later functioning - however, behaviour and functioning at any point in time are also more strongly influenced by the immediate social and physical environment than by past experience (Feinstein & Bynner, 2004; Lewis, 1997, 2005. Macmillan et al., 2004; van IJzendoorn & Juffer, 2006).
- The apparent contradiction between these two findings can be resolved by recognising that, for a variety of reasons, children's environments tend not to change: the balance of risk and protective factors is more likely to remain the same than to change significantly (Sameroff et al., 1993).

- While this is not a problem if these environments are positive and stimulating, prolonged exposure to adverse environments can have adverse long-term effects upon children's development and learning (Anda et al., 2006).
- To promote children's learning and development, therefore, we need to ensure that their environments and experiences are optimally nurturing. As Biglan (2012) notes,
 

*'Biological, behavioral, etiological, and intervention evidence converges on a fairly simple and straightforward principle: If we want to prevent multiple problems and increase the prevalence of young people who develop successfully, we must increase the prevalence of nurturing environments.'*

### **Role of relationships**

- In young children particularly, the key environments are relational: children learn through relationships (National Scientific Council on the Developing Child, 2004a; Richter, 2004; Siegel, 2012) - infants and toddlers are hard-wired to use adults' brains to form their own (Siegel, 2012)
- Relationships change brains neurologically and neurochemically, and these changes may be for the better or for the worse (Cozolino, 2006).
- The brain can change its structure and function in significant ways – it possesses a degree of neuroplasticity that is much greater than previously recognized (Doidge, 2007; Begley, 2009; Davidson & Begley, 2012). These changes come about in two ways - through experiences (external input) and through our own thoughts and intentions (internal input)(Davidson & Begley, 2012; Siegel, 2012). However, young children have not yet developed the capacity to modify their own behavior and brain structure through thoughts and intentions – that's one of the things they have to learn from adults – so are much more shaped by the external environmental experiences, especially their relationships with caregivers, than are older children and adults.
- Sensitive and responsive care giving and positive attachments with caregivers are essential for the healthy neurophysiological, physical and psychological development of a child (National Scientific Council on the Developing Child, 2004a, 2004b, 2008; Richter, 2004). Positive attachments are grounded in attunement and responsiveness.
- Caregiving that is inadequate and negligent and attachments that are weak or disrupted result in adverse consequences for the child's survival, health and development (Anda et al., 2006; McCrory et al., 2010; National Scientific Council on the Developing Child, 2005, 2008, 2010; Richter, 2004)
- Nurturant caregiver-child relationships have universal features across cultures, regardless of differences in specific child care practices (Richter, 2004).

## How children with disabilities develop and learn

Do all these findings apply to children with disabilities? Do they learn in the same ways as other children? Are relationships just as important for them? The short answer to all those questions is *Yes* (King et al., 2002; Moore, 2009; Warren & Brady, 2007).

In a recent analysis of the importance for development of relationships and attachments, Moore (2009) explored the evidence that these are just as important for children with disabilities as they are for all other children. He summarised the evidence thus:

- The nature and quality of their key relationships are critical for children's development, and the key features of these relationships – particularly attunement / engagement and responsiveness – are especially important for early childhood development and the establishment of secure attachment.
- These same general features of development and learning apply to children with disabilities and to those without. However, while children with disabilities have the same developmental needs as other children, they may have difficulty having these realised because of the nature of their disabilities.
- For many children with disabilities, the neurological structures on which relationships are based are intact and they are therefore subject to the same positive and negative possibilities as other children. If warm and responsive caregiving is provided, then positive attachments will develop, forming a secure basis for future learning and development. If the child does not receive such caregiving, then their learning and development may be compromised.
- Children with disabilities often initiate interactions less frequently and give cues that are more subtle and difficult to read. Some parents and caregivers tend to compensate by becoming more directive in their interactions. Others develop compensatory or therapeutic parenting techniques that evoke a positive emotional climate in the relationship, until their children become positively emotionally responsive to them.
- An important goal of intervention is to help caregivers to become good observers of children so that they can recognise their cues and respond contingently, and thereby build secure attachments. (Moore, 2009)

The implication of this evidence is that supporting parents and caregivers in developing positive and responsive relationships with children with developmental disabilities from as early an age as possible should be a major focus of early childhood intervention services. There is good evidence that parents, even those with challenging or unresponsive children, can be taught to be highly responsive in ways that enhance their child's development (Warren & Brady, 2007). All those involved in working with young children with disabilities – parents, caregivers, early childhood interventionists – should seek to establish relationships with these children that reflect the key qualities of effective relationships. It is the combined effect of such relationships that will ensure the effectiveness of interventions (Moore, 2009).

We have established that children with developmental disabilities develop and learn in the same basic ways as other children. The next question to be addressed is what outcomes we want for our children, and whether the outcomes we want for children with developmental disabilities are the same as those we want for all children.

## OUTCOMES FOR CHILDREN WITH DEVELOPMENTAL DISABILITIES

All effective endeavours are based on a clear understanding of the outcomes that are being sought. Without such an understanding, one's efforts are less focused and less effective (Friedman, 2005; Hogan & Murphey, 2002). This is true of endeavours such as early childhood intervention: unless we can be clear about what outcomes we are trying to achieve for children with developmental disabilities and their families, then our efforts to help them be diffuse and unfocused, and therefore less consistently effective (Bailey et al., 2006; Dunst & Bruder, 2002).

In considering what outcomes we want, we need to recognise that the choice of outcomes is always based on values, whether they are the values of the individual, the family or the wider society. Although our choices may be informed by evidence or research, in the end we do not base our decisions solely or primarily on these. Instead, what we want for our children is based on what outcomes – behaviours, achievements, states of being – we value above others.

Just as we should base our understanding of the needs of children with developmental disabilities on those of all children, so we should base our goals and outcomes for children with developmental disabilities on those we hold for all children. We will begin therefore by considering some of the emerging thinking about outcomes for children in general.

Our ideas and values often change over time, as a result of variety of factors – changes in social conditions, new evidence or understanding of child development, shifts in societal thinking etc. For instance, there have been an ongoing evolution of ideas about concepts such as well-being (Ben-Arieh, 2010), quality of life (Samuel et al., 2012), and disability (Bach, 2007; Turnbull & Turnbull, 2003; Odom et al., 2007; WHO, 2001, 2002).

One such change has been in thinking about the outcomes we want for children. These are increasingly being formulated in terms of *developing capabilities* (rather than 'reaching potential'), *meaningful participation* (as opposed to social exclusion or marginalisation), and *quality of life*. Each of these concepts will now be examined in turn.

### **Developing capabilities**

One common way of thinking about outcomes for children is that we want all children to 'reach their potential'. There a number of problems with this formulation. Who can say what any child's potential is (so that we will know when they have reached it)? Potential for what? Are all potentials (potential accomplishments or learnings) equally valuable? Who determines which potentials we should be encouraging – the child, the family, the wider society, or all of them?

A more helpful way of thinking about the outcomes that we want for children is that we want them to have the *functional capabilities* to participate meaningfully in all aspects of their lives. This notion of functional capabilities is similar to the Capabilities Approach championed by the economist and Nobel Prize laureate Amartya Sen (1985, 2005) and the philosopher Martha Nussbaum (2011) (see also Clark, 2005; Robeyns, 2005). For Sen (1985), ‘The primary feature of well-being can be seen in terms of how a person can ‘function’, taking that term in a broad sense.’ (p. 197). Similarly, in Sen (2005), he defines capability as ‘the opportunity to achieve valuable combinations of human functionings — what a person is able to do or be’. In her account of this approach, Nussbaum (2011) says it is based on a very simple question: *What are people actually able to do and to be? What real opportunities are available to them?* She sees the answer to these questions in terms of capabilities, which are freedoms or opportunities to choose and to act. Capabilities are ‘not just abilities residing inside a person, but also the freedoms or opportunities created by a combination of personal abilities and the political, social and economic environment.’ (p. 20). Thus, capabilities in this sense are not innate, but nurtured (or not nurtured, as the case may be) by prenatal and postnatal environments and experiences. These capabilities are ‘the innate faculties of the person that make later development and training possible’ (p. 24). The flip side capability is *functioning*: a functioning is ‘an active realisation of one or more capabilities’ (Nussbaum, 2011, p. 25)

Nussbaum cautions against equating this approach with the idea that people’s political and social entitlements should be proportional to their innate intelligence or skill. Instead, she argues that

‘.. the political goal for all human beings in a nation ought to be the same: all should get above a certain threshold of combined capability, in the sense not of coerced functioning but of substantial freedom to choose and act. That is what it means to treat all people with equal respect. So the attitude toward people’s basic capabilities is not a meritocratic one – more innately skilled people get better treatment – but, if anything, the opposite: those who need more help to get above the threshold get more help.’ (p. 24).

This conclusion is – that those who those who need more help to develop their capabilities should receive it – is one that resonates strongly with the literature on inclusion of children with developmental disabilities in mainstream settings. It has long been recognized that providing such children with access to mainstream programs and settings is a necessary but not sufficient condition for them to benefit from such opportunities: as well as access, they need specific additional supports to enable them to gain the same benefits as other children (Buysse, 2011; Odom et al., 2002; National Professional Development Center on Inclusion, 2011).

### **Meaningful participation**

The reason why children need to develop functional capabilities is *to participate meaningfully in all aspects of their lives*. In the World Health Organization’s International Classification of Functioning, Health and Disability (2001), participation is defined as ‘involvement in a life situation’ (p. 10). In a joint statement on early childhood inclusion, the Division for Early Childhood and the National Association for the Education of Young Children (2009) in the US identify participation as one of the



three defining features of inclusion in early childhood settings. In this statement, participation means 'using a range of instructional approaches to promote engagement in play and learning activities, and a sense of belonging for every child.'

What evidence do we have that participation is important for children? Law et al. (2006) have summarised the research regarding participation, and conclude that participation in everyday environments is vital to the health, development and quality of life of all children. Does that include children with disabilities? King et al. (2002) see participation and quality of life as the principal long-term outcomes of intervention services for children with disabilities: 'Participation in activities is the *context* in which people develop competencies, gain an understanding of their strengths and abilities, form friendships and relationships, and make a contribution to their worlds.' Participation is both the ultimate goal of intervention services and the context in which children develop, and is thus both a process and an outcome (King et al., 2002). Children with disabilities face many obstacles and restrictions in the life experiences and opportunities needed for the development of capabilities that will enable them to participate meaningfully (King et al., 2002, 2003; Law et al., 2006). To overcome these obstacles and restrictions, they need inclusive environments (that is, environments that are accessible, accommodating, socially supportive and non-discriminatory) and specific supports from families, early childhood professionals and early childhood intervention services.

Why *meaningful* participation? Participation is more than being present in different environments – the person must be actively engaged and their involvement must be more than tokenistic. For participation to be meaningful, the person's role and contribution must be valued by all those involved in the activity, including the person themselves.

## **Quality of life**

The reason we want children to be meaningful participants in everyday environments is because meaningful participation is the engine of development and the key to attaining a true sense of belonging and a satisfactory quality of life. The concept of quality of life is one that has been invoked increasingly in discussions of outcomes for children (Axford, 2008; King et al., 2002, 2003; Roche, 2001; Rosenbaum, 2008). The World Health Organization (WHOQOL Group, 1995) has defined quality of life as 'individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns' (p. 1405). In this definition, quality of life is a broad ranging concept, multi-dimensional, and subjective.

Is quality of life a useful concept to apply to children with disabilities? Despite the multidimensional and subjective nature of the notion of quality of life, King et al. (2002) argue that it provides a useful conceptual framework from which to consider the outcomes of services and supports offered to people with disabilities. The components of quality of life are the same for people with and without disabilities. These have been described in terms of the life domains of *being*, *belonging*, and *becoming* (Raphael et al., 1996; Woodill et al., 2004), the same three domains that serve as a framework for Australia's Early Years Learning Framework (Council of Australian Governments, 2009). In a related formulation based on interviews with

adults with disabilities (King et al., 2003), people attain meaning (and thereby perceive their lives to have quality) through *doing* (being engaged in meaningful activities), through *belonging* (having secure relationships with others), and through *achieving self-understanding* (a set of beliefs or values that guide how one lives).

Participation is clearly central to quality of life. As Rosenbaum (2008) notes,

‘To the extent that people are able to do the things that are important to them, to participate in whatever ways enable ‘engagement’, their quality of life is probably better than were they thwarted in ‘participating’.

When we succeed in helping children gain the skills that enable them to participate meaningfully in the key environments in their lives, we improve the quality of their lives. Meaningful participation and satisfactory quality of life are what we want for *all* children, not just those with disabilities or developmental delay. However, to improve the quality of life for children with disabilities, we need more than tolerance or acceptance: ‘The vision is one of true participation and integration, where environmental supports, positive community attitudes, and strengths of individuals converge to support people in pursuing their own goals and reaching their potential’ (King et al., 2002).

Studies of quality of life of people with disabilities have revealed an apparent paradox (Albrecht & Devlieger, 1999): many people with serious and persistent disabilities report that they experience a good or excellent quality of life when to most external observers these individuals seem to live an undesirable daily existence. This is also true for children. A European study of self-reported quality of life of 8–12-year-old children with cerebral palsy found they had similar quality of life to children in the general population in all domains except schooling, in which evidence was equivocal (Dickinson et al., 2007). The authors comment:

Is it surprising that subjective quality of life of children with cerebral palsy is similar to that of the general population? Possibly, from the perspective of a non-disabled adult imagining what it would be like to be disabled, but probably not from the perspective of a child whose sense of self from birth incorporates their impairment and who embraces growth, development, and living with the same excitement as most children.

Rosenbaum (2008) supports this interpretation, noting that children’s functional status (as distinct from their ‘limitations’) is not automatically an impediment to a self-experienced quality of life that is comparable to that of other children of their age. He also points out that we should not assume that these non-disabled peers are all ‘normal’ or ‘able-bodied’ or ‘typical’. In other words, functional abilities (and limitations thereof) should not be equated with self-described quality of life. Rosenbaum suggests that we need to challenge the assumption that the lives of children with chronic conditions are impoverished and of lesser quality. An emphasis on ‘possibilities’ and ‘what can be’ would reflect a healthy approach to understanding and celebrating life’s variations, including those that lead to disability. Here we see clear parallels with the capabilities approach of Sen and Nussbaum.

## Conclusion

To conclude, a number of strands of thought converge to suggest that the overall outcome we want for children, with or without developmental disabilities, is that *they gain the functional skills or capabilities they need to participate meaningfully in their daily environments.*

It will be noted that this formulation only refers to two of the key concepts just discussed – developing capabilities and meaningful participation. This is because the third concept – quality of life (including a sense of belonging) – is subjective and is one of those goals (like happiness) that is best approached obliquely rather than directly (Kay, 2010). Being satisfied with one's quality of life and feeling that one belongs are by-products of the other outcomes, namely, gaining the functional skills to participate meaningfully. If we succeed in helping children develop the functional skills they need for their daily environments and in ensuring that these environments accommodate and value their involvement, then the children will come to feel that they are accepted and are more likely to report that they are satisfied with the quality of their lives.

Although we want the same goals for children with and without developmental disabilities, it is obvious that, for children with developmental disabilities, developing the functional skills they need to participate meaningfully in their daily environment can be problematic. For a start, there is the question of access (or, in Nussbaum's terms, opportunities): in order to begin to build functional skills, such children need ready access to the relevant environments, and that is not always guaranteed. Secondly, mastering the necessary functional skills (or capabilities) is more of a challenge for them, and additional supports and specialist help are needed; again, these are not always guaranteed. The existence of these problems do not, of course, mean that the goals we have identified are inappropriate for children with developmental disabilities, but simply alerts us to the challenges that must be overcome if we are to help them achieve these goals.

Having previously established that children with developmental disabilities develop and learn in the same basic ways as other children, we have now shown that the outcomes we want for children with developmental disabilities are the same as those we want for all children: to gain the functional skills or capabilities they need to participate meaningfully in their daily environments.

With these general thoughts in mind, we will now examine the rationale and aims of early childhood intervention services. (The account that follows is an elaboration of ideas first presented in Moore, 2011).

## RATIONALE AND AIMS OF EARLY INTERVENTION SERVICES

### Rationale for early childhood intervention

As already noted, all children (including those with disabilities or developmental delays) develop through their relationships with the key people in their lives and through the experiences and learning opportunities provided by the environments in which they spend their time. Initially, children's main learning environment is the

family, with early childhood education and care (ECEC) services and community settings playing an increasingly important role as the children grow older. While early childhood intervention (ECI) service providers can play an important role in supporting children with disabilities or developmental delays and their families, they have a limited role to play in the everyday lives of these children. ECI service providers have limited direct time with children with disabilities or developmental delays and their parents and are not one of the main providers of early learning environments. The bulk of the child's learning occurs *between* home visits or other sessions with professionals, not *during* them.

Seen in this light, the overall aim of ECI is ***to ensure that the parents or other key caregivers are able to provide young children who have disabilities or developmental delays with experiences and opportunities that promote the children's acquisition and use of competencies which enable the children to participate meaningfully in the key environments in their lives.***

The term 'environment' as used here refers to the relationships, experiences and learning opportunities provided in particular social and physical settings.

## **Defining early childhood intervention**

The field of early childhood intervention continues to evolve, reflecting developments within its own practices as well as related developments in other fields. This has led to progressive reformulations of how it is defined and what its central aims and purposes are (eg. Dunst, 1985, 2000, 2012).

Early childhood intervention has usually been defined as the provision of various multidisciplinary services to children with disabilities and their families. An alternative way of defining early childhood intervention is that it involves providing children with experiences and opportunities that promote their acquisition and use of competencies that enable them to participate meaningfully with others and with their environment.

The difference between these two definitions may appear to be just a matter of emphasis, but it has important implications:

- 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.

On the other hand ...

- 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.

Thus, the aim of ECIS is not so much to be the major agent of change through direct work with children, but to work with and through the children's caregivers to ensure that the children's everyday environments provide them with the opportunities and experiences that will enable them to develop the functional skills to participate meaningfully.

This same logic leads to the recognition that the learning environments that children experience outside the home are just as important for their development as their home environments. Therefore, the learning environments provided by early childhood programs are properly regarded as being major settings for early childhood intervention, not just as desirable additions.

In working with early childhood services, the task of ECI services is the same as in working in home environments: to work with and through the early childhood staff to ensure that the early childhood environment provides children with developmental disabilities with the opportunities and experiences that will enable them to develop the functional skills to participate meaningfully in the same social and learning activities as the other children.

The definition and rationale just outlined represent a significant evolutionary shift in ECI service philosophy and practice, the culmination of changes that have been building for some time. This involves a shift from thinking of ECI service providers as direct agents of change for children to recognising that they are not major providers of direct services to children, and that they need to focus instead on ensuring that the environments in which young children do spend their time are able to act as agents of change. Specifically, this means ensuring that family and community and ECEC service professionals are able to provide children with the relationships, experiences and supports they need to develop the functional skills that will enable them to participate meaningfully in those environments.

If ECI service providers do not make this shift in thinking, then they will continue to think of themselves as the major agents of change and persist in using intervention strategies that do not promote the development of functional skills or of meaningful participation effectively. This leads to service-centred rather than family-centred models of practice. In a service-centred approach, families are encouraged to think that their children are best helped by specialist providers working directly with their children rather than by ECI teams working with them to promote their children's learning in everyday environments. It is only a short step from such service-based thinking to market-based models of provision, in which professionals market their direct child-focused services to parents. In such circumstances, it is understandable that many parents believe that the professionals can do a better job than they can, and that the services they buy are preferable to those provided by non-fee-paying services that use a family-centred approach.

Others who have argued the same point about the dangers of thinking of ECI in terms of services include Carl Dunst (Dunst, 2000, 2007, 2012; Dunst et al., 2005, 2006) and Robin McWilliam (McWilliam, 2010a; 2011; McWilliam & Scott, 2001). McWilliam and Scott (2001) argued that we should view and conduct early intervention in a way that de-emphasises professional *services* and emphasises the *support* that professionals can provide. The major purpose of early intervention is to enhance the competence and confidence of children's caregivers so children had the greatest likelihood of developing to their maximum potential. Conceiving of early intervention primarily as a mechanism for providing support is an alternative to conceiving of early intervention as a mechanism for providing services.

Dunst (2000, 2007, 2012) contrasts two conceptualisations or definitions of early childhood intervention. In one, ECI is defined in terms of the learning opportunities provided to infants and toddlers that are intentionally used to influence changes in the children's behavior and development. In the other definition, early child intervention is defined in terms of the services provided by qualified professionals to infants and toddlers and their families. He argues that this latter definition is detrimental to the adoption of best practices and is inconsistent with contemporary evidence about the kinds of experiences and opportunities young children need to develop optimally (Dunst, 2012).

Evidence to support this view – that it is better to define early childhood intervention in terms of experiences provided to children than in terms of services provided – comes from studies by Dunst and colleagues (Dunst et al., 2005, 2006). The first of these (Dunst et al., 2005) found that conceptualising participation in everyday activity settings as a type of intervention rather than as settings for professionals to conduct their interventions leads to an increase in the number of learning opportunities that children are provided. The second study (Dunst et al., 2006) found that when practitioners showed parents how to use everyday activities as sources of naturally occurring learning opportunities, the parents reported more positive and less negative well-being. In contrast, when the practitioners themselves implemented their interventions in everyday activities, the parents reported less positive well-being and even negative well-being in some instances.

## **Working with children**

One of the key features of child development (including the development of children with developmental disabilities) is that their ongoing learning depends upon the nature and quality of their environments. Initially, children's main learning environment is the family, with early childhood programs and community settings playing an increasingly important role as they grow older.

The key point to note is that children's main learning environments do not include specialist services such as those provided by ECI professionals: children spend the majority of their time with their families in everyday routines and activities. While ECI providers can play an important role in supporting children with disabilities and their families, they have a limited role to play in the everyday lives of these children. With existing caseloads and levels of funding, ECI providers have limited direct time with children with disabilities and their parents and therefore are not one of the main

providers of early learning environments. The one or two hours a week that ECI professional may be able to spend in direct contact with children represents less than 3% of their waking hours. The bulk of the child's learning occurs between home visits or other sessions with professionals, not during them.

The rationale for working with children is summarised in Table 1.

**Table 1: *Rationale for early childhood intervention with children***

- Since children's development is shaped by the environments in which they live, then we need to ensure that these environments are as fully supportive as they can be of children's learning and development.
- Since young children's main learning environments are the family, ECEC services and other community settings, then these are the environments that need to be able to support children's learning and development.
- Since ECI services are not major providers of environments, experiences and learning opportunities that children need, then their job is to work with and through those that can provide them – families, ECEC service providers and community settings.

In focusing on children, the role of ECI providers has the same core features regardless of environment in which they are working. This role is summarised in Table 2.

**Table 2. *Role of ECI providers in working with children***

- In partnership with parents, the role of ECI providers is to:
- promote positive attachment between children and their parents/caregivers through attuned and responsive caregiving
  - identify children's functional/developmental capacities and needs
  - analyse the child's home environments and identify what adaptations are needed to ensure the child's full participation/engagement in activities
  - analyse the child's home environments and identify what learning opportunities exist or can be created to maximise the child's practice of key skills
  - support parents in implementing adaptations and maximising learning opportunities for the child
  - monitor the impact of these strategies on the child's developmental and functional skills and child's participation/engagement in activities
  - strengthen the capacity of universal services to meet the needs of all children through fully inclusive programs

## Working with families

A major focus of ECI work has always been supporting families of young children with developmental disabilities/delays. This continues to be central to ECI work, and includes the following key aspects:

- As noted earlier, the prime goal in working with families is to ensure that they are able to provide young children who have disabilities or developmental delays with experiences and opportunities that promote the children's acquisition and use of competencies that enable them to participate meaningfully in the key environments in their lives. The task for ECI professionals is to identify what strategies and experiences will work for the particular child in the particular family circumstances, and to work with the family to build these into daily routines.
- Another major task is helping the families develop caring and responsive relationships with their children. This is a central task for all parents, but can be particularly challenging for parents of children with disabilities or developmental delays. Such children have the same relational needs as other children, and depend upon attuned and responsive caregiving for their development. The role of the ECI professionals is to support families to provide attuned, responsive and intentional caregiving whilst adapting to any challenges and to the impact of their child's disability or developmental delay.
- A third major task is to address the stressors that are typically associated with parenting a child with disability or developmental delay: the need for information about their child's health and development; the interpersonal and family distress that can result from having a child with a disability or developmental delay; threats to the parents' confidence in their ability to meet their child's needs; and additional resource needs resulting from having a child with a disability or developmental delay. The role of ECI professionals is to provide information, support and resources in a collaborative, timely and effective manner.

The ability of ECI professionals to support families in these ways depends not only on their technical knowledge and skills in working with children with disability or developmental delay, but also upon their personal qualities and skills in building positive working relationships with parents. The manner in which ECI professionals engage families is as important as their knowledge of appropriate strategies for working with children. Key skills for working with families include relationship-based practice, family-centred practice, and empowerment and strength-building approaches.

In addition to supporting families to provide optimal learning environments for their children, ECI providers also have an important role to play in supporting the family as a whole and all its members. This work has a dual focus. On the one hand, family functioning is shaped by a range of factors in the family's external environments – the supportiveness of their personal and community networks, access to community services and facilities, and the quality of their physical and built environments. On the other hand, family functioning is also shaped by a range of family-specific resource factors. Some of these involve access to material resources such as



income, housing and transport, while others are personal or relational issues such as parental mental and physical health, drug and alcohol issues, and family violence. In the field of early childhood intervention, practitioners are reporting an increasing number of families with multiple risk factors (Watson & Gatti, 2012). Unless addressed, all of these factors can undermine a family's capacity to support their children effectively.

In addressing the external environmental influences, the rationale for work with families is summarised in Table 3.

**Table 3. Rationale for helping families address external environmental influences**

- Since family functioning and development are shaped in part by immediate external environments, then we need to ensure that families' external environments are as fully supportive and inclusive as they can be
- Since the immediate environments for families are their family and social networks, their physical and built environments, and the community settings in which they live, then these are the environments we need to work with, with a view to building the supportive capacity of social and community networks, and promoting inclusive and family-friendly neighbourhoods and services
- Since ECIS is not one of the major providers of the families' social, physical and community environments, then its job is to work with and through those who are major providers – social networks, community services, and other formal services.

An important goal is to enhance the quality of life of the entire family so that it is better able to meet the needs of all family members (Turnbull et al., 2007a, 2007b; Zuna et al., 2009, 2011). Families experience a satisfactory family quality of life when they are satisfied with what they have attained, and feel empowered to live the lives they wish to live. As with children, the capacity of families to participate meaningfully in community life is a central feature of a satisfactory family quality of life. In the case of families, participation can take many forms, including social, economic, civic and recreational participation. In each of these areas, families of children with disability or developmental delay can face barriers to participation. To enable families to participate more effectively and enjoy a more satisfactory quality of life, additional supports and adaptations may be needed on the part of community services and facilities.

Family functioning is also affected by internal resource factors specific to each family. In addressing these factors, the rationale for work with families is as follows:

**Table 4. Rationale for helping families address internal resource factors**

- Since family functioning and development can be undermined by lack of access to material resources and by various personal and relational problems, then we need to seek to ensure that these personal and resource issues are addressed
- Since these personal and material resource issues usually cannot be addressed through community-based services, then we need to ensure that families have access to appropriate specialist support services
- Since ECIS does not have the capacity to address the various material and personal resource issues that can undermine family functioning, then it needs to work with and through the various specialist services that can provide them.

The role of ECI providers in helping families address both external environmental influences and internal resource factors is summarised in Table 5.

**Table 5. The role of ECI providers in working with families**

In partnership with parents, communities and other services, the role of ECIS providers is to:

- help families identify their needs, both in relation to the family as a whole and to the needs of the children (particularly those with disabilities or developmental delays)
- help families mobilise resources and access services to address their needs and those of their children
- help families build positive social support networks
- work with communities and community-based services to build family friendly services and community environments
- work with other relevant family services to provide integrated support to address parental and family stressors
- support parents in meeting the needs of their children – specifically children with disabilities and developmental delays (see rationale for working with children)
- promote the capacity of other community-based and specialist services to support parents in their caregiving roles.

## **Working with early childhood services**

A key feature of the rationale for ECI services is the notion of *participation*: the ultimate aim of ECIS is to enable children with disabilities and developmental delays to participate meaningfully in the key environments in their lives – family environments, ECEC programs, and community settings and. Traditionally, the main focus of ECI has been the family environment, with the aim of supporting the family as a whole and promoting the family's ability to meet the child's needs. Increasingly, this task is being reframed to take account of family routines, embedded learning opportunities, and the child's meaningful participation in family activities.

With regard to a major early childhood environment – ECEC – the issue of participation has usually been couched in terms of *inclusion*. ECI and other disability services have pushed for children with disabilities and developmental delays to have access to the same services and opportunities as other children, and have supported such inclusion in various ways.

This advocacy is based on the understanding that full inclusion is a necessary component of learning to participate meaningfully in community life and is essential for the development and participation of children with disabilities and developmental delays. Inclusion in universal ECEC services is critical because children need to experience more developmentally advanced settings if they are to learn the skills for successful and independent participation in those settings. The skills cannot be taught effectively in other contexts and then transferred – skills for specific contexts are only learned by participating in those contexts.

Full inclusion involves more than access. For children with disabilities, simply attending an early childhood program or a community facility is not enough to ensure that they benefit from the experience. Benefits only accrue when the child develops skills that allow them to participate meaningfully in the activities. Children with disabilities or developmental delays generally have more complex learning needs, which means developing these skills and engaging and participating in a meaningful way in these settings will depend heavily on the presence of significant relationships and the provision of supportive learning opportunities and experiences.

So, in addition to working with families and communities, ECI services have a major role to play in working with ECEC services. ECEC settings become increasingly important as children get older, providing essential experiences with other children and with caregivers other than their parents. These experiences are just as important for young children with disabilities or developmental delays as they are for other children, and the learning environments that children experience outside the home are just as important for their development as their home environments. Therefore, the learning environments provided by ECEC services are properly regarded as being a major setting for early childhood intervention, not just as a desirable addition. This will mean the task of ECIS is the same as in the home: to work with and through ECEC professionals to ensure that the ECEC environment provides children with a disability or developmental delay with opportunities and experiences to enable them to develop the functional skills to participate meaningfully in the same social and learning activities as the other children.

While there is a powerful rationale for children with a disability or developmental delay having access to the same experiences and services as other children, there are many barriers to them being able to participate meaningfully. These barriers arise in part from the nature of a disability or developmental delay, and the specific difficulties these children have in learning, mobility, communication or socialisation. However, the barriers also reflect the problems that universal ECEC services have in knowing how to provide such children with the experiences they need to become full participants in the program's activities. For young children with a disability or developmental delay, attending a universal ECEC service is a necessary but not sufficient condition for the experience to be truly beneficial. For the ECEC

environment to be able to build children's functional and participatory skills, a range of adaptations, strategies and resources are likely to be needed.

As is the case when working with families, there are three major tasks for specialist ECI professionals when working with universal ECEC services:

- As already noted, the prime goal in working with ECEC services is to ensure that they are able to provide young children who have a disability or developmental delay with experiences and opportunities that promote the acquisition and use of competencies that enable the children to participate meaningfully in the program's activities. The task for ECI professionals is to identify what strategies and experiences will work for the particular child in the particular ECEC setting, what supports or adaptations are needed, and then to help the early childhood professionals build these strategies and supports into their program's daily routines.
- Another major task is helping the ECEC professionals to develop caring and responsive relationships with the children. This is a central task with all the children, but can be particularly challenging with children who have a disability or developmental delay. It is just as important for ECEC professionals to be able to provide such children with attuned and responsive caregiving as it is for the children's parents to do so.
- A third major task is to address the challenges that universal ECEC professionals often face when working with children with a disability or developmental delay – the need for information about the child's health and development, the threats to the ECEC professional's confidence in their ability to meet the child's needs, and the additional resource needs associated with a particular child.

As is true of work with families, the manner in which ECI professionals engage ECEC professionals is as important as their knowledge of appropriate strategies for working with children. To help the children, ECI professionals need to be able to build positive working relationships with these colleagues. Key skills for working with ECEC professionals include relationship, teamwork and consultancy skills.

The rationale for ECI work in ECEC settings is summarised in Table 6.

**Table 6. Rationale for ECI work with early childhood education and care settings**

- |  |
|--|
| <ul style="list-style-type: none"><li>• Since children's development is shaped in part by the environments children experience, then these environments need to be as fully supportive as they can be of learning and development</li><li>• Since one of the main learning environments for young children is that provided by universal ECEC; then we need to ensure that these environments are able to effectively support the learning, development and meaningful participation of children with developmental disabilities</li></ul> |
|--|

- Since ECI services are not major providers of the group early childhood environments and experiences that children need, then their job is to work with and through those that can provide them – universal ECEC providers.

The role of specialist ECI providers in their work with ECEC settings is summarised in Table 7.

**Table 7. The role of ECI providers in working with ECEC settings**

In partnership with early childhood professionals, the role of ECIS providers is to:

- promote positive attachment between early childhood professionals through attuned and responsive caregiving
- identify children’s functional/developmental capacities and needs
- analyse the child’s ECEC environments and identify the adaptations needed to ensure the child’s full participation/engagement in activities
- analyse the child’s ECEC environments and identify what learning opportunities exist or can be created to maximise the child’s practice of key skills
- support ECEC staff in implementing adaptations and maximising learning opportunities for the child
- monitor the impact of these strategies on the child’s developmental and functional skills and child’s participation/engagement in activities
- strengthen the capacity of universal services to meet the needs of all children through fully universal inclusive programs.

## **Working with community programs and settings**

A key feature of the rationale for ECI services is the notion of *participation*: the ultimate aim of ECI is to enable children with developmental disabilities to participate meaningfully in the key environments in their lives – family environments, early childhood services, and community programs and settings. This section focuses on children’s participation in the third of these – community programs and settings.

Most young children and their families make use of a range of community programs, facilities and settings in their local area. *Community programs* include Maternal and Child Health services (including mother and baby groups), community playgroups, and a range of community-based programs provided by Local Government Authorities and non-government agencies. *Community settings* include facilities such as libraries, swimming pools and parks, but also include streets, shopping malls and public spaces. These programs and settings provide children and families with a range of experiences that can contribute significantly to their development and quality of life.

Inclusion in community programs and activities is important, both for the child and the family. When children and their families can access all aspects of community life

and services relevant to their stage of life, no matter what their circumstances, then the community is inclusive.

However, if these programs, facilities and built environments are difficult to access, navigate or of poor quality, then this can deprive children and families of valuable social and learning opportunities and compromise their quality of life.

The experiences provided through community programs and settings are just as important for children with a disability or developmental delay as they are for other children. In the case of community programs and settings, the key issues for children with a disability or developmental delay and their families are *access* and *participation*. While there is a powerful rationale for children with a disability or developmental delay and their families having access to the same experiences and services as other children, there are many barriers to them being able to participate meaningfully. These arise in part from the nature of the child's disability or developmental delay, but also reflect the problems that community services have in knowing how to cater for such children and their families. Barriers take several forms:

- *attitudinal barriers* – these include lack of understanding or acceptance of a disability or developmental delay on the part of community services or other community members
- *structural barriers* – these include services or settings that are not physically adapted or equipped to allow access for children with various disabilities or developmental delays
- *family barriers* – these include lack of confidence in being able to negotiate on their child's behalf, or transport or financial difficulties.

There are three major tasks for specialist ECI professionals when working with community programs and settings:

- The prime goal in working with community programs and settings is to ensure that children with disabilities, developmental delays or additional needs and their families are able to access them. This can be achieved by addressing attitudinal and structural barriers to access and by promoting community awareness and acceptance of disability and developmental delay. The important role that ECI providers can play is to act as advocate for particular children, working with community and local government services to raise their awareness of the needs of the child and family, and the benefits they can gain from being part of the same community activities as other children and families.
- Another major task is helping community programs and settings create the conditions that will allow children with a disability or developmental delay and their families to participate in the activities and make full use of the facilities. The contribution that ECI professionals can make is to identify what supports or adaptations are needed for the particular child in the particular community setting or service, and then to help the relevant staff build these strategies and supports into their program's structure and routines.

- A third major task is to strengthen the capacity of universal community services to be fully inclusive. This involves designing programs and settings that are planned from the outset to cater for children with the full range of abilities, needs and backgrounds.

As is true of work with families and ECEC services, the manner in which ECI professionals engage community program providers is as important as their knowledge of appropriate strategies for working with children. To help the children, they need to be able to build positive working relationships with these colleagues. Key skills for working with community programs include relationship, teamwork and consultancy skills.

The rationale for early childhood intervention service provision in working with community settings and programs is summarised in Table 8.

**Table 8. Rationale for ECI work with early childhood education and care settings**

- Since children’s development is shaped in part by access to and participation in the different environments they experience, then all these environments need to be accessible to and able to support the participation of all children.
- Since some of the main learning environments for young children are those provided by universal community programs and settings, then we need to ensure that these environments are as accessible and as fully supportive of the participation of children with a disability or developmental delay as they can be.
- Since ECI services are not major providers of the community environments and experiences that children need, then their job is to work with and through those that can provide them – community programs and service providers.

The role of ECI providers in their work with community programs and settings is summarised in Table 9.

**Table 9. Role of ECI services in working with community programs and settings**

In partnership with community services providers, the role of ECIS providers is to:

- promote community understanding and acceptance of children with disabilities or developmental delay and their families
- advocate for the rights of children with disabilities or developmental delay and their families to have full access to community programs and settings
- promote the quality of life of young children with disabilities or developmental delay and their families through access to the same community services and experiences as others
- analyse the community environments and identify what adaptations are needed to ensure particular children’s full participation/engagement in activities

- support community staff in implementing adaptations that will allow the child's full participation
- monitor the impact of these strategies on the child's participation/engagement in activities
- strengthen the capacity of universal community services to meet the needs of all children through fully inclusive services

## Summary

This concludes our comprehensive analysis of the rationale and role of early intervention services. The key features of the ECI outcomes framework just presented are as follows:

- It is based on an understanding of the key ways in which children develop and learn – through early learning environments and through caregiving relationships
- It is based on a clear statement of the outcomes being sought - to ensure that children with developmental disabilities gain the functional skills or capabilities they need to participate meaningfully in their daily environments
- It recognises the limitations on what ECI professionals can do achieve these outcomes directly, and the importance of them working with and through those who spend most time with the child
- It recognises that any environment in which children spend time constitutes a setting for early childhood intervention
- It recognises the importance of working with other services to help families address the external and internal resource factors that can otherwise undermine their capacity to support their children effectively

Some of these features are also evident in some of the other comprehensive frameworks that have been developed for ECI services. These include the following:

- Michael Guralnick's developmental systems model (Guralnick, 1997, 2001, 2005)
- Carl Dunst and Carol Trivette's integrated framework model (Dunst, 2000, 2004; Dunst & Trivette, 2009)
- Robin McWilliam's support-based home visiting model (McWilliam & Scott, 2001; McWilliam, 2010)
- Sam Odom and Mark Wolery's unified theory of practice model (Odom & Wolery, 2003)
- Gillian King's Life Needs model (King et al., 2002) and Relational Goal-Oriented Model (King, 2009)

Next, we explore the implications for practitioners of adopting the ECI outcomes framework presented here.



## IMPLICATIONS FOR PRACTICE

The ECI outcomes framework is just that – a framework, not a full service model. It needs to be populated by evidence-based strategies that are consistent with the aims and rationale of the outcomes-based framework. Strategies that are not consistent with the framework – that achieve different outcomes – should not be used. This includes strategies that may have been proven to be effective, but do not achieve the desired outcomes identified in this model.

So, what do we know about intervention strategies that are effective in meeting the outcomes that have been identified? There have been some efforts to draw up lists of effective ECI strategies, such as those by Odom and Wolery (2003) and McWilliam (2012). In addition, Dunst and colleagues have developed a systematic way of identifying effective practices, and have found a number that meet their criteria (Dunst et al. 2002, 2004; Dunst, 2009).

It is beyond the scope of the present paper to identify definitively all the strategies that are compatible with the outcomes-based framework, but it is possible to nominate some strategies that are candidates for inclusion on a final list. Here are some examples:

### *Strategies for working with children*

- Building on children's interests (Dunst & Swanson, 2006; Dunst et al., 2011)
- Parent-mediated everyday learning opportunities (Dunst & Swanson, 2006)
- Community-based everyday child learning opportunities (Dunst et al., 2010)
- Response-contingent child learning and parent contingent responsiveness (Dunst et al., 2007, 2008)

### *Strategies for working with families*

- Family-centred practice (Dunst & Trivette, 2009; Trivette et al., 2010) and family-centred care (Kuo et al., 2012; Kuhlthau et al., 2011)
- Capacity-building practices (Dunst & Trivette, 2009; Trivette & Dunst, 2007)
- Home visiting (McWilliam, 2012)
- Routines-based approaches (McWilliam, 2010; McWilliam et al., 2009)
- Coordinating services (Bruder, 2010; Bruder & Dunst, 2006)
- Key worker and transdisciplinary service delivery (Forster & Webster, 2012; McWilliam, 2011)

### *Strategies for working with other settings*

- Coaching (Shelden & Rush, 2010)
- Consultation (Buisse & Wesley, 1994)
- Engagement strategies (McWilliam & Casey, 2008)

As already indicated, this list is indicative rather than definitive. For inclusion on a final list, each of these strategies will need to be tested against the model. The above list is also incomplete in that it does not include any disability-specific or discipline-specific intervention strategies. Further work will be needed to identify any strategies that are specific to individual disabilities or disciplines.

## Challenges

What are the challenges to be faced in adopting the ECI outcomes framework? Three challenges stand out.

**Challenge 1: Direct therapy and professional skills.** When presented with the rationale and role definitions described above, one of the first challenges that occurs many ECI practitioners concerns their professional hands-on skills: if their principal role is to work with and through others, what does this mean for their specialist skills? Under what conditions and for what reasons do they work directly with children?

The challenge posed by the outcomes-based framework presented in this paper is that, if the principal role of the ECI worker involves the transfer of their specialist knowledge to others rather than the provision of direct therapy to the child, does that mean ECI practitioners should not work with children at all? If that were the case, how would practitioners develop the skills that they are supposed to transfer to others? Clearly, practitioners *do* have to work with children, in some capacity or other. Equally clearly, they cannot rely solely on direct work with children to achieve the ultimate outcome of meaningful participation in everyday environments. Yet therapists tend to feel that the work they do is not 'real' unless it involves hands-on work with the child (Lawlor & Mattingly, 1998; McDonald, 2012).

More work needs to be done on this issue, so that therapists can be clear about why, when and how they work directly with children. A start has been made by Case-Smith and Holland (2009) who argue that what we need is a blend of direct and consultative services according to need. They see the goals of direct, individualised services as being

- to establish a relationship between the child and therapist that facilitates particular performance goals;
- to offer, in addition to the teaching staff, support of the child's social-emotional growth;
- to gauge how to adapt an activity to provide a 'just-right challenge' to a particular child; and
- to obtain evaluation data about the child's performance that can be used to make decisions about revising his or her program.

In other words, direct work with a child is usually a means to an end, a way of getting to know the child in order to be able to help parents and early childhood practitioners provide appropriate experiences and learning opportunities. Further work is needed in this area to disentangle these complex issues, but the rationale provided by Case-Smith and Holland provides a useful starting point in understanding how we meet this challenge.

**Challenge 2: Key worker and transdisciplinary service models.** A related issue concerns the role of individual specialists in transdisciplinary teamwork: if ECI teams adopt key worker or transdisciplinary models, what is the role of the ECI specialists when they are not the key worker? To some professionals, working indirectly through

a key worker or primary support team member feels like an abrogation of their responsibilities. However, from the perspective of the families themselves, the delivery of support through a key worker can be a way of making the task of meeting their child's needs much more manageable, making it more likely that they will be able to provide the child with the kinds of learning opportunities and experiences they need.

**Challenge 3: Centre-based group programs.** Another challenge concerns the practice of running centre-based programs for groups of children with disabilities and their parents. As with individual therapy, the question is how this general strategy achieves the overall outcomes being sought. This is an open question: if centre-based group programs can be shown to be an efficient and effective way of ensuring that children everyday learning environments are optimally supportive and inclusive, then they will continue to have a role to play. Analysing exactly how such group programs 'work' is a task that still needs to be tackled.

There is no doubt that the outcomes-based framework presented in this paper has profound implications for ECI practice and presents considerable challenges for traditionally-trained ECI professionals. Some professionals may experience these challenges as threatening their professional identity and skills, while others will interpret the framework as providing exciting new ways of using their skills to better effect. What should be clear is that the framework does *not* imply that there is no need for the professional skills of the various specialist disciplines that work in ECI services. On the contrary, these skills are needed just as much as ever. However, what is implied is that the *ways* in which these skills and knowledge are deployed will differ from some of the more traditional ways in which ECI services have operated.

This section has looked at practical implications of the outcomes-based framework, and identified a number of tasks that still need to be addressed. These include the following:

- Identify intervention strategies that have been proven to be effective, and test each one against the outcomes-based framework.
- Compile a list of those strategies that can be shown to be consistent with the framework, showing exactly how each one contributes to the overall outcomes and to the specific roles of ECI professionals within the framework.
- Identify any additional intervention strategies that are specific to particular disabilities or to particular disciplines.
- Develop protocols for key worker / transdisciplinary practice that clearly specifies the roles and responsibilities of ECI team members when acting as a member of a transdisciplinary team.
- Review the program logic and the research evidence for the efficiency and effectiveness of centre-based group programs to establish what role they might play in the range of services provided within an outcomes-based framework.

Next, we consider what implications the ECI outcomes framework has for policy, both in the general early childhood sector and the ECI sector specifically.

## IMPLICATIONS FOR POLICY

Three policy issues stand out.

**First, it is important to be clear about what outcomes we are seeking.** It is important to clarify outcomes for all children – in Australia, the national Early Years Learning Framework does this and is also consistent with the outcome approach articulated in this paper. Therefore we should build on this framework in planning and delivering services for children with developmental disabilities.

**Second, it is also important that we have clear statements of the philosophy and practices on which services are to be provided.** At present, Australia lacks any national statement of the aims and philosophy of ECI services. Recent national agreements reached through the Council of Australian Governments – on the national Early Years Learning Framework, the National Quality Framework for Early Childhood Education and Care, and the National Framework for Protecting Australia's Children – are proving to be enormously helpful in achieving greater consistency across jurisdictions and in providing leadership and guidance. It is time for a similar agreement to be sought regarding ECI service provision.

**Third, it is also important that the funding models used support this philosophy and practice.** Funding models can support or undermine the delivery of best practice intervention. For instance, Dunst (2012) has argued that the way that federal legislation in the US is framed encourages a service-oriented mode of delivery that is not in line with best practice and has stifled genuine progress in the field.

In Australia, the situation is mixed, with variations between states and between state and federal governments. In many instances, funding is allocated to agencies on a per capita or block grant basis. There is no requirement or expectation that the agency gives each family the same level of service, equivalent to the per capita funding. Instead, the agencies make decisions as to how the total money should be spent, giving more service to families with complex needs and less to families with fewer needs.

A different approach was adopted by the federal Department of Families, Housing, Community Services and Indigenous Affairs in its *Helping Children with Autism* (HCWA) Package (FaHCSIA, 2008) and *Better Start for Children with Disability* initiative (FaHCSIA, 2011). These initiatives are based on a new market-based and individualised approach to funding early intervention services, with the funding allocated to families rather than services. While the ECI sector has welcomed this additional funding, there are a number of problems with the funding model:

- The funding is not available for all children with disabilities.
- The funding is category-based, that is, dependent upon children being classified as falling into a particular disability category.
- The funding encourages a service-oriented conceptualisation of early childhood intervention, rather than an outcomes-based model.

- There are insufficient quality controls to ensure that the services offered are consistent with best practice, or with the logic outlined in this paper.
- The funding places unfair demands upon parents at a time when they are particularly vulnerable and will have difficulty making properly informed decisions.
- The funding is independent of the current ECIS system and adds an unwelcome layer of complexity to an already complicated system.
- Each family receives the same allocation of funding regardless of need.
- There are not enough trained and skilled practitioners to meet the demand for service.

This is a formidable list of concerns about a well-intentioned but ultimately misconceived policy. In the light of the argument presented in this paper, a particular concern is the third point: that the funding encourages precisely the wrong service orientation, focusing on the provision of direct services by therapists rather than them working with and through those who are the major providers of the children's learning environments. It is to be hoped that this unhelpful emphasis can be rectified when this funding is incorporated into the forthcoming National Disability Insurance Scheme.

## IMPLICATIONS FOR SOCIETY

The ideas discussed in this presentation also have implications for our wider society.

**First, the reconceptualisation of ECI services presented in this paper is applicable to many other services and settings.** Early learning environments and caregiver relationships are important for all children, and the quality of those environments and relationships play a major role in contributing to children's development, well-being and quality of life. Therefore, the logic of the analysis presented in this paper applies to most other services to young children and their families. The only early childhood that provides extended time with young children are the ECEC services; all other services for children and all family support services spend limited time with families, and therefore need to think about how they can ensure that the home care and learning environment can be enhanced, and the family caregiving skills strengthened in order to achieve the aims of their particular services.

**Second, we need to go beyond traditional notions of disability and think in terms of the full diversity of human ability.** All human abilities and characteristics fall on continua, and there are no clear dividing lines between what is normal and abnormal. This is why the determining the eligibility of children for special education or early childhood intervention services is such a fraught business. Instead of trying to draw arbitrary cut-off points that distinguish the 'disabled' from the 'normal', we should acknowledge what Spanish disability advocates Javier Romañach and Manuel Lobato (2005) have called our *functional diversity* (see also Patston, 2007). Others who have made a similar case include disability advocate Kathie Snow in *Disability is Natural* (2001), psychologist Thomas Armstrong in *Neurodiversity* (2010), and psychiatrist Jordan Smoller in *Beyond the Normal* (2012).

This means that we need to ground our understanding of the extremes of functioning and behaviour in terms of 'normal' development, building our knowledge from the centre outwards rather than working back from the extremes. The astonishing growth in our knowledge of human development and functioning – at genetic, neurological, psychological and sociological levels - is providing an increasingly strong basis for such an enterprise, and may well revolutionise the way we understand, classify and manage the extremes of functioning and behaviour, including the developmental disabilities that are the focus of early childhood intervention services. (eg. research on the common aetiologies of autism, schizophrenia and intellectual disabilities – see Smoller, 2012). The findings cited earlier regarding what we know about how children in general develop and learn are just a hint of the riches we might gather from such an approach.

***Third, we need to go beyond traditional notions of inclusion, and think in terms of creating environments that are able to cater for the individual and collective needs of all children and families.*** This means designing everything – policies, laws, institutions, services, facilities and technologies – on principles of universal design (Conn-Powers et al., 2006; Story et al., 1998). This means building them from the ground up to be able to cater for everyone in society, the complete spectrum of abilities, cultures, and circumstances. In other words, what we need is universal societal design.

***Fourth, we need to go beyond ideas of remediation and rehabilitation, and think in terms of building people's capabilities.*** This means focusing what each person is actually able to do and to be, and what real opportunities are available to them.

***Fifth, we need to explore how to go beyond categorical approaches to disability and focus instead on the common functional needs across disabilities.*** In the categorical approach, funding, service provision and treatment methods are based on diagnostic categories, and advocates of different disability groups compete with one another for public money. This approach ignores the commonalities between categories of disabilities. As Ronen et al. (2011) have argued,

This is because of the increasing evidence across various chronic conditions that it is difficult to attribute better or poorer health outcomes solely to the biological aspects of a disease and its medical treatment. ... Many additional factors influence overall well-being in children and adolescents with chronic disorders, including a child's psychosocial adaptation, their skills in problem solving, coping skills in adverse situations, social communication, educational issues, and delivery of services. Yet, there is as much variation in how these factors manifest within a specific condition as across conditions.

A non-categorical approach to chronic conditions addresses the variation and diverse factors affecting health by emphasizing the commonalities across disease categories. In this perspective, limitations of daily functioning are seen as common manifestations of impaired health rather than being specific to particular etiologies.

... The non-categorical approach makes it possible to examine the impact of various neurological conditions throughout development by studying child and family adaptation as well as the impact of various conditions on education and social development and their influence on later adult life.<sup>11</sup> This approach also allows us to construct health outcome models that assess outcomes between, as well as within, conditions.

Moving from a categorical approach to disability to one that focuses on common functional needs across disabilities is a challenging prospect, but one that is more likely to achieve the aim of ensuring that children with developmental disabilities gain the functional skills to enable them to participate meaningfully in their daily environments.

## CONCLUSIONS

Our latest rethinking of the goals for children with (and without) developmental disabilities is based on the growth in our understanding of child development and learning, on changing values, and on changing social conditions. Is the world ready for this emerging vision?

There are some indications that society may be moving in a direction that will support this. If we take a long-term perspective (over hundreds or even thousands of years), some scholars have detected some encouraging long-term trends. In his book *The Empathic Civilisation* (2009), the economist Jeremy Rifkin has identified a general trend towards greater social empathy. In *The Better Angels of Our Nature* (2011), the psychologist Steven Pinker sees a trend towards less violence, and in *The Emotional Life of Nations* (2002), the psychohistorian Lloyd de Mause describes the progressive improvements in our treatment of children over millenia.

If we take a somewhat shorter perspective (last 50 years), we can detect trends towards more balanced relationships between those in authority and general citizens, and between service providers (such as doctors and allied health professionals) and consumers. We have also seen the emergence of person-centred and family-centred models of service delivery, and, more recently, the trend towards individualised approaches to service delivery in medicine and other areas.

If societies are not changing in these ways, then they need to. This is because we live in a densely interconnected world that is becoming increasingly diverse, exposing us to a greater variety of cultures, beliefs, practices and abilities. In such a world, interdependence will be the norm, and collaboration will have to become a central practice, empathy a central virtue, and universal design (social, economic, educational) a central feature.

Ultimately, the goals of early childhood intervention can only be fully achieved through such changes in societal thinking, values and practices.

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