







# Early childhood intervention reform project

Revised literature review December 2010









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Published by Programs and Partnerships Division Department of Education and Early Childhood Development Melbourne Aug 2011

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# EARLY CHILDHOOD INTERVENTION REFORM PROJECT LITERATURE REVIEW (REVISED)

# 1. INTRODUCTION

This paper was commissioned by the Office for Children and Early Childhood Development, Department of Education and Early Childhood Development (DEECD), as part of its Early Childhood Intervention Services (ECIS) Reform Project (Stage 2): *Developing Options and Next Steps*. This Project aims to significantly enhance the efficiency, effectiveness and sustainability of Victoria's ECIS system and improve outcomes for children with a disability or developmental delay and their families. The project will deliver recommendations for comprehensive ECIS reform - including a new service delivery model, new program structure and new funding model - by mid 2011.

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. Services are tailored to meet the individual needs of the child and focused on supporting the child in their natural environments, in their everyday experiences and activities. The services funded through DEECD are provided by government Specialist Children's Services teams and non-government Early Childhood Intervention agencies. 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.

In addition to the services provided by ECIS teams and agencies, the state and federal governments fund a range of complementary programs to support young children with developmental disabilities and their families. These include initiatives to support families (*My Time* parent groups, Family Support Packages), services to support inclusion (Preschool Field Officers, Inclusion Support Facilitators), and funding to support particular disability groups (*Helping Children with Autism* packages). These additional services and supports, together with the ECIS teams and agencies, make up the totality of early childhood intervention provision for young children with disabilities. The findings of the review apply just as much to these additional services as they do to the work of the ECIS teams and agencies. Throughout the review, this combination of services and supports will be referred to as ECIS and allied services.

To support the development of options for future ECIS service delivery, the Department commissioned an update of the previous literature review of research concerning contemporary Australian and international evidence-based service delivery models for children with a disability, developmental delay or additional needs aged 0-8 years. The literature review was meant to build on and update an earlier literature review (Centre for Community Child Health, 2008a) that had been commissioned to inform the first phase of the ECIS Reform Project. There were several reasons why a revised version was felt to be needed. The first was that the timelines for the original review had been tight, and did not allow scope for a systematic search of the relevant literature, or for a detailed comparison of different intervention strategies. As a result, several major aspects of early childhood intervention practice were not covered in the review. while others were only dealt with briefly. The second reason was the ongoing evolution of ideas and practice within the early childhood intervention (ECI) field has resulted in a number of recent developments and reconceptualisations that had not been fully incorporated into the earlier review. Third, the recent developments in government policies and initiatives in the early childhood and early childhood intervention sectors have been so rapid and wide-ranging that the context has shifted appreciably since the preparation of the first literature review. These new developments need to be taken into account

The focus of the literature review is research on contemporary Australian and international evidence-based service delivery models for children with a disability, developmental delay or additional needs aged 0-8 years. In preparing for literature review, a thorough search of the academic and 'grey' literature for the period 2007 onwards was conducted. Databases searched include CINAHL, ERIC, Informit, Medline and PsychInfo. In addition, the review has drawn upon a number of recent papers by recognised ECI authorities that review the current state and future development of ECI services.

The body of the paper is divided into four main sections. The next section, Section 2, presents the general social and policy context that needs to be taken into account when considering the future development of early childhood intervention services. Section 3 focuses on children with disabilities and their families. It begins by summarising the developmental needs and rights of children in general, and then examines how these apply to children with developmental disabilities. The needs of their families are then explored, along with their experiences of professional services and how they can best be supported.

Section 4 looks at early childhood intervention services, beginning with a discussion of definitions and rationales. Next, the outcomes sought by early childhood intervention services are examined, and some service models described. This is followed by a discussion of what evidence-based / practice-based intervention strategies are known to be effective in achieving these

outcomes, and the workforce competencies and skills needed to deliver these strategies.

Section 5 examines early childhood intervention service systems discusses some possible directions and ideas for re-conceptualising early childhood intervention services in Victoria so that they can better support the additional needs of children with disabilities or developmental delay and their families within a universal, inclusive system of early childhood services. The implications of these for policy and practice are discussed.

In the final section, Section 6, the findings are summarised and their implications explored.

# 2. THE SOCIAL AND POLICY CONTEXT

Early childhood intervention (ECI) services do not exist in a vacuum: changes in social conditions and in other services inevitably have an impact on what form the services take and how effective they are. In seeking to reform ECI services, these changes need to be taken into account. It is also true that ECI services cannot be reformed without considering the impact of any changes on the wider system of services for families and young children. Accordingly, this paper begins by outlining how society has changed, the relevance of these changes for services to young children and their families, and how governments have responded to these changes.

# 2.1 The nature and impact of social change

The world has witnessed enormous changes over the past 50 years. These have been so rapid and so far-reaching that they have had a dramatic impact on the physical well-being of the planet (in the form of climate change) as well as on the physical and psychosocial well-being of societies (social climate change) (Moore, 2009a; Moore & Skinner, 2010).

The effect of these changes can be seen in the health and well-being of children and young people. While most children are doing well, there is evidence of worsening or unacceptably high levels of problems in a minority of children across all aspects of development, health and well-being, including mental health, physical health, academic achievement, and social adjustment. These problems are 'disorders of the bioenvironmental interface' (Palfrey et al, 2005) rather than conditions with separate or singular causes, and the developmental pathways that lead to most of these outcomes can be traced back to early childhood.

The profound social changes that have occurred over the past few decades have also altered the circumstances in which families are raising young children – parenting has become more challenging, and the stakes are continuing to rise the more we learn about the importance of the early years and the more we understand about the skills that are needed to function successfully in a complex interconnected world. The current service system was designed at a time when family circumstances were simpler and parenting less challenging, and is struggling to meet all the needs of all families effectively (Moore, 2008a; Moore & Skinner, 2010).

Specific problems faced by the service system include the following (Moore, 2008a):

 The service system is having difficulty providing support to all families who are eligible – there are waiting lists for many services

- Services cannot meet all the needs of families that they do serve no single service is capable of meeting the complex needs of many families
- Families have difficulty finding out about and accessing the services they need – there is no single source of information about relevant services
- Services are not well integrated with one another and are therefore unable to provide cohesive support to families
- Services have difficulty tailoring their services to meet the diverse needs and circumstances of families
- Services are typically focused on and/or funded on the basis of outputs rather than outcomes, and therefore tend to persist with service delivery methods that may not be optimally effective
- Services are typically treatment-oriented rather than prevention- or promotionfocused, and therefore cannot respond promptly to emerging child and family needs
- Child care and early childhood education services are funded and run separately
- Government departments, research disciplines and service sectors tend to work in 'silos'
- Responsibility for provision of services to children and their families is spread across three levels of government - federal, state, and local - with different planning processes and funding priorities
- Most specialist intervention services are already underfunded, and it is looking increasingly unlikely that they can ever be fully funded in their present forms

In the light of these problems, it has become increasingly obvious that the early childhood and family support system needs to be reconfigured to meet the needs of contemporary families more effectively.

All developed nations have recognised the need to address the changed circumstances in which families are raising young children and to reconfigure early childhood and family support services. In Australia, federal and state governments have responded to this challenge with a range of initiatives and polices, as described in the next section.

# 2.2 Current National and State reforms

In Australia, there have been a number of federal initiatives over the past decade or so. Some have been driven by a growing awareness of the ways in which some people within society are failing to benefit from the changed social and economic conditions and are therefore achieving poorer outcomes. This has, in turn, led to general public policy initiatives in Australia and elsewhere to address

social exclusion and promote a truly inclusive society. Other initiatives have focused on the needs of young children and their families, and ways of integrating early childhood and family support services.

The move towards more integrated service delivery has been driven by a growing awareness of how fragmented services for young children and their families are, and how that fragmentation undermines the capacity of the service system to support children and families effectively (Moore & Skinner, 2010). The fragmentation of services is particularly problematic for the families of children below school age because there is no universal service that all families use during these years. All children are known to the service system at birth and at school entry, but the contact they have with early childhood and other services between those two points varies greatly. As a result, the service system cannot respond promptly to issues as they arise and may only become involved later when the problems have become more entrenched and severe. The lack of a universally used early childhood service has been one of the problems that moves to integrate services are intended to address.

At a national level, the Council of Australian Governments (COAG) has endorsed a number of national policies and initiatives aimed at young children and families.

## These include:

- Funding for new, integrated Children's Services
- Development of new Quality National Standards and a revised Accreditation system
- Workforce reform agenda
- Development of a national Early Years Learning Framework

At a federal level, there has also been one important recent initiative that specifically addresses the needs of children with disabilities:

• The *Helping Children with Autism* package (Department of Families, Housing, Community Services and Indigenous Affairs, 2008).

This has since been followed up by a related initiative, due to commence in July 2011:

 The Better Start – Early Intervention for Children with Disability initiative (Department of Families, Housing, Community Services and Indigenous Affairs, 2010) for children diagnosed with a sight or hearing impairment, Down syndrome, cerebral palsy or Fragile X syndrome.

At the state level, there was a change of government while this report was being prepared, and the incoming government has yet to confirm which policies and

initiatives it will support. The former Victorian government had a number of major policies and initiatives, including the following:

- The Victorian Early Years Learning and Development Framework (DEECD, 2009a) is designed to help families and early childhood education and care professionals to work in partnership to promote the learning and development of children aged 0-8. The framework describes the key knowledge and skills that children will acquire during this stage and identifies how children best acquire these building blocks of future development.
- Transition: A Positive Start to School (DEECD, 2009b), which aims to improve children's experience of starting school by providing families, early childhood educators and Prep teachers with information about the learning and development needs of individual children who are starting school. The process includes a partnership protocol for early childhood services, early intervention services, preschool field officers, and schools to work together in implementing transition support plans for children with significant disabilities and their families.
- Improving Victoria's Early Childhood Workforce: Working to give Victoria's children the best start in life (DEECD, c) focuses on supporting the development of the early childhood workforce including early childhood educators, early childhood intervention workers, Maternal and Child Health nurses, preschool field officers, inclusion support facilitators, Aboriginal early childhood workers and Best Start facilitators. It focuses on actions to respond to increased demand for qualified early childhood educators, improve the quality of services and meet the challenges of integrated practice.
- Towards a health and wellbeing service framework: A discussion paper for consultation (DEECD, 2010b)

In addition, there were a number of initiatives that specifically addressed the needs of young children with disabilities. These included:

- The Autism State Plan (Department of Human Services, 2009a) which was developed in partnership with Autism Victoria to strengthen services and support and build new and better approaches to meeting the growing and complex needs of people with Autism Spectrum Disorder across the life course.
- Better Opportunities, Better Outcomes: Strategic directions for Victorian services and supports for children and young people with a disability or developmental delay and their families (DEECD, 2010c) is a policy framework to support the learning, development and inclusion of all children and young people with a disability or developmental delay and their families through a more holistic, life-cycle approach to the diverse and changing needs of

children and young people with a disability or developmental delay and to the needs of their families.

- The Statement of principles for children and young people and their families (Department of Human Services, 2009b) builds on the overarching policies and articulates the specific vision, principles and actions that will guide the Department of Human Services' Disability Services division in providing supports to children and young people with a disability and their families.
- The Early Childhood Intervention Services Quality Assurance Framework will strengthen the quality of the existing early childhood intervention services across Victoria. It will cover outcomes for children, families and community, program standards, best practice guidelines for workers, and an evaluation and performance monitoring system to support ECIS accountability.
- The *Disability Survey Scoping project* (DEECD, 2010d) has been undertaken in response to the very limited statewide data that exists for children living with disabilities and their families, and will ultimately lead to the development of develop a survey to gather this data on a regular basis.

The various policies and initiatives undertaken by governments in Australia and elsewhere share a number of common features (Moore & Skinner, 2010). These include:

- integrating early childhood services
- finding more effective ways of reaching vulnerable children and families
- ensuring that all children arrive at school ready to learn
- shifting services to a promotion / prevention focus
- reducing child protection rates
- monitoring children's development and well-being more effectively
- improving the quality of early childhood services
- increasing the use of evidence-based practices

The scope and intent of these significant reforms for the early childhood and early intervention sectors, provides some optimism that a fragmented, diverse and disconnected system could be transformed into a universal systems approach of high quality connected services for all children and families. However, there is one other common feature of all these policies and initiatives share: none of them have succeeded as yet in making significant improvements in child and family outcomes (Moore & Skinner, 2010). One reason for this is that our efforts to alter the circumstances in which families are raising young children are relatively modest so far, and have not been in place long enough to begin to counteract the effects of social climate change. Another reason is that we have not yet clearly identified how to reconfigure the service system so as to support families more effectively.

# 3. CHILDREN WITH DEVELOPMENTAL DISABILITIES AND THEIR FAMILIES

In order to place the review within the contexts of the broader field of early childhood, two related questions provide the focus for discussion in this section of the paper:

- 1. What do all children and families need if they are to develop, learn and flourish?
- 2. What support do all families need to raise their children well?

There are several reasons why it is important to identify the needs and supports common to all children and families as the first stage in this review paper:

- Current and future approaches in mainstream and early childhood intervention concerned with policies, funding, service and practice provision need to be based on these identified outcomes and needs if they are to meet expectations.
- The early childhood intervention literature stresses the notion that all children and all families have universal needs in common with children with developmental disabilities and their families. Communities benefit when they are able to support the needs of all children and their families. Meeting these shared needs should be a focus for policies, funding and planning in early childhood services (Moore, 2008b; McLoughlin & Stonehouse, 2006).
- Identifying the common or shared needs of all children and families helps to bring in to relief the additional needs of children with a disability or developmental delay and their families.

# 3.1 Children's developmental needs and rights

The past several decades have seen tremendous progress in understanding child development, particularly neurological development. Previously, brain development was viewed as the product of a genetically predetermined maturational pathway, and the relationship between brain and behavioural development was regarded as unidirectional; that is, the structural maturation of the brain was thought to enable the functional developments manifested in behaviour (Stiles, 2009). The models that have emerged suggest that this development is dynamic and, from the very beginning, involves the continuous interaction of genetic, organismic, and environmental factors (Gopnik, 2009; Sameroff, 2009; Shonkoff, 2010; Shonkoff et al., 2009; Sroufe, 2009; Stiles, 2009; Worthman et al., 2010).

Of particular importance for early childhood intervention services is our growing understanding of how children learn. Sameroff (1994) argues that the theoretical base used in early childhood intervention also needs to include a conceptualisation of development and how children learn: 'Unless one understands how development proceeds, there is little basis for attempts to alter it, either through prevention or intervention.'

As summarised by Moore (2010a), the key facts about child development that are particularly relevant for early childhood intervention are as follows:

- Children develop through their relationships with the important people in their lives
- Sensitive and responsive care giving is a requirement for the healthy neurophysiological, physical and psychological development of a child.
- Relationships change brains neurologically and neurochemically, and these changes may be for the better or for the worse
- The attachments that children form with parents and caregivers create the central foundation from which the mind develops
- Skills develop cumulatively, so that those acquired early form the basis for later skill development (which is one of the reasons why behaviour and functioning at one point in time is predictive of later behaviour and functioning)
- But behaviour and functioning at any point in time are also strongly influenced by the immediate social and physical environment, regardless of earlier levels of behaviour and functioning
- Children's ongoing learning is a product of the interaction between learnings and patterns of behaviour arising from earlier environments and experiences, and the child's adaptation to the current environment
- Early behaviour and functioning are predictive of later behaviour and functioning to the extent that children's environments remain unchanged
- Changing children's environments is therefore critical for children's ongoing learning and development
- Children's ongoing learning depends upon having repeated opportunities to practice developmentally appropriate skills in everyday situations with support ('scaffolding') from attuned and responsive caregivers
- Children are active participants in their own development creating effects on others and their environment by the way they initiate and respond. The effects are cumulative and bi-directional, sequentially impacting interactions and learning for all partners.

What do all children need if they are to develop, learn and flourish? A synthesis of recent attempts to identify the key experiences that children need to promote

their general development (Brazelton & Greenspan, 2000; Gerhardt, 2004; Greenspan & Lewis, 1999; Guralnick, 1997, 1998; Hallowell, 2003; Lally, 2000, 2007; Marty et al., 2005; Ramey & Ramey, 1992, 1999; Richter, 2004; Shonkoff & Phillips, 2000; Siegel, 2001) suggests that we can best promote children's development by providing them with

- close and ongoing caring relationships with parents or caregivers
- adults who recognise and are responsive to the particular child's needs, feelings and interests
- adults who are able to help children understand and regulate their emotions
- adults who are able to help children understand their own mental states and those of others
- adults who are able to help children negotiate temporary breakdowns and ruptures in relationships
- protection from harms that children fear and from threats of which they may be unaware
- clear behavioural limits and expectations that are consistently and benignly maintained
- opportunities and support for children to learn new skills and capabilities that are within their reach
- opportunities for children to develop social skills through regular contact with a range of adults and other children
- opportunities and support for children to learn how to resolve conflict with others cooperatively
- stable and supportive communities that are accepting of a different families and cultures

## Other more basic needs include

- healthy physical environments, including clean air and water, and protection from environmental toxins
- safe physical environments that provide adequate opportunities for play and exercise
- adequate nutrition, particularly during pregnancy and infancy
- housing that is stable, healthy and uncrowded

This list is couched in terms of needs, but it could just as easily be regarded as a list of children's rights. As Philips (2001) has noted, there is debate in the early

intervention literature about whether the term 'rights' is emphasised rather than the term 'needs'.

Since Australia and most other nations ratified the United Nations' Convention on the Rights of the Child (1989), there has been increasing interest in using a rights-based approach to underpin or conceptualise early childhood theory and research (Davis et al., 2007; Edwards et al., 1998; Rinaldi, 2006; Siraj-Blatchford & Clarke, 2000; Woodhead, 2005). Children's rights as enshrined in the UN Convention are formally agreed standards which could be viewed as ethical imperatives for signatory countries (Alderson, 2000). The 54 Articles of the Convention encompass four comprehensive areas of rights or needs for all children:

- prevention (mostly health matters)
- protection (against exploitation and neglect)
- provision (includes access to children's services, clean water and shelter)
- participation (a voice for children and their right to be heard)

From an ECIS perspective, a key principle of the UN Convention's principle is that 'all children have the right to participate fully in and to benefit from educational experiences and play a full part in society.'

Dahlberg and Moss (2005) argue that, at best, documents such as the UN Convention provide for minimal conditions and are removed from the particular social, cultural, political and economic contexts of children and families' everyday lives. They recommend that rights should be used as a tool and not as an icon – that is, as a way for making child and family rights visible and legitimate through advocacy and action. Similarly, Bach (2002) contends that a rights-based approach is insufficient to achieve 'valued recognition' and that action through solidarity must follow from any rights' declarations if all children and families are to achieve social inclusion and valued recognition.

Cuskelly and Hayes (2004) argue that children with a disability can only become fully participating members of their communities when society develops measures 'to reduce the handicapping effects of impairment and disabilities' (p. 31). Reducing these handicapping barriers is central to becoming an inclusive society, community or service. Communities benefit when every member's dignity is valued and every member is able to participate meaningfully (Bach, 2002).

How, then, can we reduce the handicapping effects of impairment and disability? To understand this, we need to begin by considering the changes that have occurred in conceptualisations of disability and the challenges faced by children with developmental disabilities and delays.

# 3.2 Children with developmental disabilities

# Changing models of disability

(The following section draws upon a literature review recently completed by the Centre for Community Child Health to inform the DEECD's Disability Scoping Survey Project).

Over the past 20 to 30 years, there has been a paradigm shift in the way that we define and conceptualise disability (Brown, 2007; Brown & Radford, 2007; Edwards & Fisher, 2008; Odom et al., 2007; Schalock et al., 2010; Turnbull & Turnbull, 2003; World Health Organisation, 2001, 2002). This involved a shift from a deficit model of disability to a social model. The World Health Organisation (2002) describes these two models in the following terms:

- The historical 'deficit' model which views disability as a feature of the person, directly caused by disease, trauma or other health condition, which requires treatment or intervention, to 'correct' the problem with the individual (Bach, 2007; Turnbull & Turnbull, 2003)
- The more recent social model of disability, which sees disability as a sociallycreated problem due to the attitudes and other features of the society that do not accommodate the individual with a disability (Bach, 2007; Turnbull & Turnbull, 2003; World Health Organisation, 2001, 2002)

In fact, disability is always an interaction between features of the person and features of the overall context in which the person lives, so that neither model is adequate on its own. Recognising this, the WHO International Classification of Functioning, Disability and Health (ICF)(2002) distinguishes between impairment, activity and participation:

- *impairments* refer to the actual body functions and structure how a person is affected at a physical level
- activity refers to the impact of these upon the person's ability to do certain activities - what restrictions the impairments place upon the person's ability to do things
- participation refers to the person's ability to participate as they would like within family and community settings - what restrictions the social environment placed upon the person's capacity to participate in life activities

Building on its ICF classification system, the WHO has also developed a version for children and young people – the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) (Simeonsson et al., 2006; WHO, 2007). The ICF-CY expanded the coverage of the ICF to cover the body functions and structures, activities, participation and environments specific to infants, toddlers, children and adolescents. The ICF-CY is designed to record

characteristics of the developing child and the influence of environments surrounding the child. This version can be used by providers, consumers and all those concerned with the health, education, and well being of children and youth, and provides a common and universal language for clinical, public health, and research applications to facilitate the documentation and measurement of health and disability in child and youth populations.

According to Simeonsson (2009), this classification system can now be seen as a universal tool for the documentation of disability. Many studies have demonstrated the importance of measuring activity limitations distinctly from chronic conditions and impairments (eg. McDougall et al., 2004). By taking into account the social aspects of disability and the impact of the environment on a person's functioning, the ICF-CY reframes the notions of 'health' and 'disability – every human being can experience a decrease in health or functioning and thereby experience some degree of disability. Considering disability as a universal experience is consistent with the growing understanding of the attributes that those with and without disabilities share, and the lack of a clear dividing line between the two groups.

Further, there is a developing understanding that many, if not all, disabilities are points randomly placed on a continuum of normality (Armstrong, 2010). This is obviously true of intellectual disabilities, as measured or defined by IQ scores, but it is also true of other conditions, such as autism. The strongest case for this continuum conceptualisation of ability / disability has been put by Armstrong (2010) who champions the notion of neurodiversity – that vast natural differences exist from one brain to another in a host of mental functions. From this perspective, instead of regarding traditionally pathologised populations as disabled or disordered, the emphasis in neurodiversity is placed on differences. Mindful of how this argument might appear to some people, Armstrong maintains that this is not merely a new form of political correctness. Instead, he suggests that research from brain science, evolutionary psychology, anthropology, sociology and the humanities demonstrates that these differences are real and deserve serious consideration. For instance, Skuse et al. (2009) have shown that the social and communication disorders characteristic of autism are continuously distributed in the general population, although boys have mean scores 30% higher than girls. This shows that many children have mild autistic 'symptoms' without ever having enough problems to attract specialist attention. Similarly, using data from a large longitudinal study of twins to explore the genetic and environmental origins of learning abilities and disabilities in the early school years, Kovas et al. (2007) pointed out that the 'abnormal' was part of the normal distribution: low performance is the quantitative extreme of the same genetic and environmental influences that operate throughout the normal distribution.

These developments in thinking suggest that society should be providing appropriate levels of support to enhance the lives of people with disabilities, rather than requiring them to develop certain skills and behaviours in order to

participate inclusively in relationships and community settings (Schalock et al., 2010; Turnbull & Turnbull, 2003). The 'equal opportunities' model reflects these developments, aiming to give everyone, irrespective of differences, equal opportunity to succeed within society as it exists, as well as removing the barriers that exist in policy and practice which prevent children from participating in early childhood programs (MacNaughton, 2006).

Underlying this shift in thinking is the question of who should adapt: should people with disabilities have to adapt to the environment in order to participate in society, or should the environment be adapted to enable them to participate? In his discussion of 'neurodiverse' individuals (eg. those with autism, attention-deficit disorders, intellectual disabilities – all disorders of neurological origin that may represent alternative forms of natural human difference), Armstrong (2010) argues that it should be seen as a two-way process: success in life is based upon adapting one's brain to the needs of the surrounding environment, but also depends upon modifying one's surrounding environment to fit the needs of one's unique brain. In addition, it is about finding one's niche:

While it is true that individuals have to adapt to the world around them, it is also true that the world is very large, and that within this complex culture of ours, there are many 'sub-cultures', or micro-habitats, that have different requirements for living. If individuals can discover their particular 'niches' within this great web of life, they may be able to find success on their own terms. (pp. 16-17)

For neurodiverse individuals, finding or constructing one's niche includes lifestyle choices and assistive technologies tailored to their individual needs. Assistive technologies refer to a wide range of tools - including computer hardware, software and peripherals - that enable individuals with disabilities to perform tasks that they were previously unable to accomplish. Armstrong notes that the experience of a positive niche directly modifies the brain, which in turn enhances its ability to adapt to the environment. The brains of young children are especially 'plastic' or susceptible to stimulation from the environment during the first few years of life, so niche construction in the earliest years of life should be a major priority for parents and other caregivers of neurodiverse children.

# The developmental needs and rights of children with disabilities

The Australian and international early childhood intervention literature provides clear evidence of the additional needs and supports required by children with disabilities and developmental delays if they are to flourish and enjoy fulfilling lives within inclusive communities. These children have rights and share needs in common with all children and families, but have additional needs that require attention if they are to become participating members of society.

In a recent analysis of the importance for development of relationships and attachments, Moore (2009b) 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. 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.

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. 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, 2009b).

Evidence that how parents interact with children with disabilities is important for their long term development comes from studies by Siller & Sigman (2002, 2008) of children with autism. Siller & Sigman (2002) examined the behaviours that caregivers of children with autism show during play interactions, particularly the extent to which the caregiver's behaviour was synchronised with young children's focus of attention and ongoing activity. They found that the more successful

caregivers of children with autism were in synchronising their behaviours to their children's attention and activities during play interactions in the early years, the greater the children's joint attention and language development over a period of 1, 10, and 16 years. In a subsequent study, Siller & Sigman (2008) evaluated the patterns of longitudinal change in the language abilities of 28 children with autism during early and middle childhood. Results from applying a series of multilevel models showed that children's rate of language growth was independently predicted by (a) children's responsiveness to others' bids for joint attention and (b) parents' responsiveness to their children's attention and activity during play. Both predictive relations could not be explained by initial variation in global developmental characteristics, such as IQ, mental age, or language abilities.

While children with developmental disabilities have rights and share needs in common with all children and families, unless there is acknowledgement both of their rights and their additional needs, they will face exclusion and limitations in reaching their potentials and overall wellbeing (Bach, 2002; Guralnick, 2005; Kemp & Hayes, 2005; Wachs, 2000). While high quality early childhood programs can support the needs of all children, they are not sufficient on their own as a means for ensuring authentic inclusion of children with disabilities or developmental delay and their families (Brown et al, 1999; Grace et al, 2008; McLoughlin & Stonehouse, 2006).

# 3.3 Families of children with disabilities

Just as children with developmental disabilities can be regarded as having the same basic needs as children without disabilities, so their families should be understood as having the same core needs as families of children who do not have disabilities, being more like these families than different from them. An illustration of this comes from a study by Zuna et al. (2009) in which the Family Quality of Life Scale, developed for use with families who had children with disabilities, was used with families of children who did not have disabilities. When the items specifically addressing disability-related supports were removed, families of children without disabilities perceived the family quality of life construct in a similar fashion as families of children with disabilities.

There is a considerable body of research that has addressed the experiences and development of families of children with developmental disabilities. A recent summary of this evidence (Bailey, 2007) draws the following conclusions:

 General knowledge about how families function and develop over time is applicable to families of children with disabilities. That is, in order to understand what happens when families face extraordinary challenges, such as those inherent in raising a child with a disability, it is helpful to know about typical family development and adaptation.

- The family environment influences the development and behaviour of children with intellectual and developmental disabilities. A large body of research has shown that both direct variables, such as responsivity within the parent-child interaction or the valence of maternal expressed emotion, and indirect variables, such as family climate or financial resources, play important roles in children's development and behaviour.
- The experience of having a child with an intellectual or developmental disability almost inevitably has a significant impact on the family. However, families vary widely in the ways they respond to disability and different family members may respond differently.
- Factors that can influence adaptation to disability vary from family to family.
  However, two child variables are consistently shown to be associated with
  family adaptation across numerous studies, disability types, and forms of
  family adaptation child behaviour problems and child health. Most studies
  show that positive family adaptation is much more difficult to achieve when
  children exhibit a high rate of behaviour problems and are in poor health.
- The nature and quality of social support available to families and family members has been repeatedly demonstrated as critical to positive adaptation. Social support comes from a variety of sources both proximate (e.g., spouse, in-laws, parents) and distal (e.g., friends, religious institutions, parent support groups, community services) to the family. Positive family adaptation, as measured by a wide range of variables, is more likely to occur for individuals or families that have strong informal support systems.
- Although there is some evidence that informal supports can be more important predictors of family wellbeing, formal interventions and professional services are also beneficial.
- Families exist in cultural and socio-political contexts that influence their beliefs, perceptions, and practices. A wide range of sociocultural studies, using varied theories and methods, have shown that cultural and sociopolitical contexts shape families' coproduction of meanings and practices related to intellectual disability; families' experiences, responses, accommodations and adaptations to disability, and how their understandings and experiences are shaped within larger social institutions and inequities, such as poverty and minority status.

Another recent review, this time of sociocultural studies of families of children with intellectual disabilities (Skinner & Weisner, 2007), made the following points:

Creating developmental opportunities for children with disabilities takes
families beyond the confines of the home to interactions with a number of
individuals, agencies, and policies. Families' ability to garner resources,
navigate a path through bureaucracies, link agencies and information, fight for
their child's services and rights, and access sources of support in these
endeavors may significantly affect their child's developmental trajectory.

- Families may have little need to reflect on or articulate understandings of
  disability until having a child with a disabling condition. Then parents often
  seek explanations and interpretations of the condition in relation to their lives.
  Families may create their own personal understandings of "genetic disorder"
  or "mental retardation" or of the child who is affected, but these
  understandings are not private. They are shaped by, and sometimes forged in
  opposition to, different cultural models and discourses of disability that
  parents encounter in different communities—for example, the medical
  profession, the early intervention system, or parent advocacy groups.
- Once a developmental delay or disability has been identified, families then are faced with making sense of the condition in relation to cultural models of disability. There are two dominant models: the medical model and the "minority" or social model of disability. The medical model views disability as a problem located in the individual, whereas the social model defines disability as a social construct located not in the individual but in the environmental barriers and discriminatory practices of society. The medical model is predominant in the initial phase of diagnosis and treatment. However, as they experience their child and interact with other parents, support groups, and sensitive professionals, parents come to recognise "difference" instead of 'abnormality',' and sometimes challenge medical knowledge that assigns a label of 'normality' or 'pathology' to their child.
- Another important aspect of the experiences of families of children with
  disabilities concerns the ways in which they adapt to meet the child's needs.
  Family adaptation involves managing the day-to-day routines of all members,
  and keeping the family going. Adaptations, or accommodations, are changes
  made or intentionally not made to the family's daily routine of activities due, at
  least in part, to the child with disabilities. Such routines may range from quite
  troubled and struggling, to coherent, balanced, and meaningful. They are
  more likely to be sustainable when there are high levels of social and
  interpersonal connectedness and sharing within the family, and lower family
  workloads in dealing with the child.
- It is important to recognise that a child with developmental problems does not necessarily mean a family with problems. Families make a wide range of accommodations, or functional responses to having a child with developmental delays (scheduling activities, arranging care, organising mealtimes, play, family visits, support services). This does not necessarily lead to exceptionally high levels of stress, emotional problems, or family difficulties.

Weisner (1997) stresses the importance of the everyday routines of life for development:

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Everyday routines are made up of activities and practices, which in turn include five features as a minimum definition: goals and values, motives and emotions, tasks to be performed in that activity, a script for normative or appropriate conduct (the right ways to do that activity), and who the people are who should be participants. A child's participation in these linked activities in a local ecology is the single most important influence on development, and children are prepared to learn from and respond to activity settings. (p. 182)

This has implications for practice. Professionals who ask parents about everyday life with a child with disabilities can plan and implement interventions that will better support the family's daily routine. As Bernheimer & Weisner (2007) point out, no intervention will have an impact if it cannot find a slot in the daily routines of an organisation, family, or individual. One focus of work with families of children with disabilities is helping them establish sustainable routines that are adapted to the child's needs. Tools for doing this include the Routines-based Interview (McWilliam, 2010a, 2010b) and the Ecocultural Family Interview (Weisner et al., 1997). General strategies for gathering information about routines have been described by Woods and Lindeman (2008), and a specific tool for examining the sustainability of family routines has been developed by Llewellyn et al. (2010).

One of the factors noted above is that having a child with an intellectual or developmental disability almost inevitably has a significant impact on the family. In the first instance, this impact is primarily emotional. The feelings that parents commonly experience are well documented (eg. Barnett et al., 2003). Initial reactions often include feeling devastated, overwhelmed, and traumatised by the news; being in a state of shock, denial, numbness and disbelief; experiencing a sense of loss for the 'hoped-for child'; and having grief reactions similar to those experienced by individuals who lose someone through death. Parents may also have feelings of guilt, responsibility, and shame; be angry at the medical staff and professionals involved with the child; or have decreased self-esteem and self-efficacy as their sense of themselves as effective providers and protectors are severely challenged. Marital and other family relationships can become severely strained, especially if family routines are disrupted and new routines are proving hard to establish.

While some (eg. Bruce & Schultz, 2001) have emphasised the traumatic nature of this experience, recent evidence (eg. Blacher & Hatton, 2007; Flaherty & Glidden, 2000; Hastings & Taunt, 2002; Ochiltree & Forster, 2010) suggests that not all parents of children with disabilities are traumatised, and in time many succeed in adjusting well to the challenges of rearing a child with disabilities. Indeed, there is also evidence that some families do more than adjust or adapt to the challenges, but ultimately transcend them, emerging stronger for the experiences (Bayat, 2007; Blacher & Hatton, 2007; King et al., 2006; Linley & Joseph, 2005; Schwartz, 2003). For early childhood intervention staff, this

highlights the importance of responding to the parents' initial distress and confusion in ways that acknowledges (but does not amplify) the feelings, while also keeping a focus on positive hopes, perceptions and experiences (Gallagher et al., 2002; Hastings & Taunt, 2002; Muir et al., 2008).

Despite the evidence of positive adaptations, families of children with developmental disabilities are at greater risk of a number of social and psychological stresses. These include mental and physical health problems (Murphy & Christian, 2007; Sloper & Beresford, 2006), marital problems and divorce (Glenn, 2007), poor housing (Joseph Rowntree Foundation, 2008), and increased expenses coupled with reduced income (because of constraints upon both partners working)(Sloper & Beresford, 2006). Australian studies (eg. Edwards et al., 2008; Ochiltree & Forster, 2010; Owen et al., 2002). have confirmed these findings.

Families who receive early childhood interventions services can vary widely in the family demographics and resources, as well as in the extent and nature of the child's disabilities. This was one of the findings of the National Early Intervention Longitudinal Study (NEILS) (Hebbeler et al., 2007), which was initiated in the late 1990s and is the only nationally representative US study of early intervention services.

In Australia, evidence of this diversity comes from the Department of Families, Housing, Community Services and Indigenous Affairs (2007) and the Australian Bureau of Statistics (2008) who have summarised the data regarding the population of children with disability and their carers in Australia:

- In 2003, almost 320,000 children aged 0-14 years had a disability. Almost all
  of these children lived in family households, as opposed to institutions.
  Around 4% of all children aged 0-14 years had a profound/severe disability.
  These children needed assistance all or most of the time with self-care,
  communication or mobility.
- Children may have more than one type of disability. In 2003, the most common types of disability among children were intellectual disabilities (59% of children with a profound/severe disability) and sensory/speech disabilities (53%).
- In 2003, there were around 285,000 Australian families (13% of the total) with children aged 0-14 years, 7% having a child with a profound/severe disability.
- In 2003, of all families with at least one child with a disability, 69% were couple families and 31% were one-parent families. One-parent families that have a child with a disability may be at increased risk of disadvantage.

- In 2003 there were approximately 57,800 primary carers of children with disability (12% of all carers), including approximately 54,600 who were the primary carers of children with severe or profound core activity limitations.
- The majority of primary carers of children with severe or profound core activity limitations were mothers (91%)
- In 2003, the majority (62%) of primary carers of children with severe or profound core activity limitations were not in the labour force (compared with 37% of all mothers of children of the same age). Of those who were, 27% were employed part time and only 11% full time. These carers were less likely to be employed full-time when the child they cared for was 0–4 years (2%), compared to when the child was aged 10–14 years (11%).
- Reflecting in part the differences in employment by parents, the incomes of families with a child with a disability were generally lower than were incomes of families without a child with a disability. Families with a child with a disability may be affected not only by reduced income but also by the increased costs associated with the child, such as health care, special diets and equipment needed for their care.
- Families with a child with a disability were more likely to be living in areas of greater socioeconomic disadvantage and were more likely to be renting than either owning or paying off their own home.
- Most primary carers of a child with a severe or profound core activity limitation reported that their relationship with the child was either unaffected (44%) or was closer (37%) as a result of their caring role.
- However, around 36% of carers reported that their relationship with their spouse was strained, that they were losing touch or lacked time together alone. One-quarter (25%) reported that they had lost, or were losing, touch with friends, and around 39% reported that they had less time to spend with other family members.
- Respite care services provide alternative care arrangements for children with a disability so that parents can take a short-term break from their caring role. Over half (55%) of primary carers of young children with disabilities had never accessed respite care and felt they did not need it. However, about two-fifths (38%) felt they needed more respite care than they received, and a further 16% had never received respite care, but felt they needed it.

An Australian survey of the nature and impact of caring for family members with a disability (Edwards et al., 2008) found that there were significant emotional costs for all family members - the primary carer, the person with a disability and other family members - associated with caring. Carers raising children (both children who have a disability and those who do not) were at particular risk of worse mental health outcomes. Carers and their families experience higher rates of both physical and mental health problems. Although most carers had

supportive people around them, there was a substantial minority of carers (one in five) who had no assistance from other people in caring for the person or people with a disability. For the majority of carers who did have support, the support provided was not without some issues attached.

A similar picture emerges from studies overseas (Murphy & Christian, 2007; Sloper & Beresford, 2006). Sloper & Beresford (2006) summarised the current circumstances of UK families with disabled children in the following terms:

- The profile of disabled children in the United Kingdom is changing. More
  disabled children and young people live in the UK than ever before, and the
  number of children with the most severe or complex needs—such as those
  with autistic spectrum conditions or with complex health and nursing needs—
  is also increasing.
- The needs of families with a disabled child, which involve input from professionals working in many different agencies, are often unmet.
- Around 55% of families of disabled children live in poverty; they have been
  described as 'the poorest of the poor'. It is within these constrained financial
  circumstances that families have to meet costs associated with bringing up a
  disabled child, which are estimated to be three times those of bringing up a
  non-disabled child.
- Unlike in other families, paid work is not the potential solution. The child's care needs, multiple appointments with healthcare professionals, and lack of child care affect parents' ability to work. Mothers with disabled children are much less likely to have paid employment than other mothers.
- Parents with disabled children have higher levels of stress and lower levels of wellbeing than parents with non-disabled children. Factors influencing levels of stress include the child's sleep and behaviour problems, families' material resources, parents' employment situation, social support, unmet service needs, and parents' coping strategies
- Some interventions have improved children's sleep and behaviour problems and parental stress. However, many parents report that they want but do not receive help in these areas.
- Living in suitable housing and having appropriate equipment to assist with activities of daily living are also key factors promoting families' wellbeing. Yet most families report problems with their housing and unmet needs for equipment.
- Disabled children and their families often lack suitable local leisure facilities and accessible transport, and they often face hostile attitudes of staff and members of the public. These factors prevent them from taking part in activities as a whole family.

Parents frequently report the need for a break from caring. Such a break can provide time for themselves and their partners, and time to spend with their other children. Services that provide short term breaks can reduce mothers' stress, but many carers report that the complexity of obtaining and managing respite arrangements can be so great that it is not worthwhile making the effort. Children for whom provision is most inadequate include those with complex health needs or with challenging behaviour or autistic spectrum disorders and children from minority ethnic families.

It is clear from this evidence that families of children with developmental disabilities are faced with many challenges that place them at risk of poor outcomes for themselves and their children. However, many such families are able to meet these challenges and even transcend them, drawing on their own personal resources, the support of family and friends, and the help of specialist services. The sections that follow explore family experiences of professional help, and what additional supports these services can provide.

# 3.4 Family experiences of professional services

As noted earlier, although there is some evidence that informal supports can be more important predictors of family wellbeing, formal interventions and professional services also have an important role to play. Appropriate training, support, and help giving practices can improve maternal styles of interacting with their children to enhance language and cognitive development, decrease depressive symptoms and other forms of psychological distress, and improve self-efficacy beliefs and other important family outcomes (Bailey, 2007).

Features that are important for effective early childhood intervention services include the nature of the relationship between the professionals and parents, the degree of control that parents have over the form of service they receive, the extent to which parents are actively and meaningfully engaged in the program activities (regardless of the setting), and the ease with which parents are able to integrate strategies into daily family routines (Moore, 2005). *How* programs are delivered is as important as *what* is delivered. Thus, the use of family-centred helpgiving is associated with more positive and less negative parent, family, and child behaviour and functioning (Dunst, Trivette & Hamby, 2007).

However, all attempts by human services providers to help those in need run the risk of doing harm, and early childhood intervention services are no exception to this. For instance, one of the findings from a recent NSW study of resilience in families that have a young child with disabilities (Muir et al., 2008) was that how they were treated at the time of their child's initial diagnosis can have a long term impact. What doctors or other practitioners say at this time or at any other key transition point such as entering into an early intervention service for the first time can have a lasting effect on family expectations, confidence and overall sense of

control. As one mother, who the researchers identified as having fewer resilience resources to draw on, expressed it, 'You have meetings, but other than that, you don't really have that much control at all' (Muir et al., 2008).

Professional services can also add to family stress by making too many demands upon their time. When providers are not sensitive to the realities of daily family life, they increase the stress levels of parents and the likelihood that they will carry through the program concerned or make use of services in general. In practice, the evidence suggests that services do not always consider these factors, and instead recommend intervention strategies that are not easily integrated into family life (Moore & Larkin, 2006).

Services can also be experienced by families as counterproductive, generating conflict and guilt. A UK study by Rix et al. (2008) found that the activities that generated conflict were those where the child did not feel in control, which they did not enjoy, and at which they did not feel competent. Parents also suggested that these feelings were often engendered by the developmental, target-driven strategies at the heart of much of the current early intervention process in the UK.

Services can also be hard to access. The experiences of Australian families who have children with a disability or developmental delay vary also according to where they live - remote, rural, inner city or outer suburbs - each context presenting different challenges and sometimes benefits such as access to a wider range of support services (McLoughlin & Stonehouse, 2006; Tannous & Katz, 2008). A Victorian study into the rates of early intervention services in very preterm children with developmental disabilities has found that children of 'higher social risk were less likely to receive EI services' (Roberts et al., 2007, p.1). The findings in this study indicate that the most vulnerable children are underserved. The researchers argue that a more broad developmental screening program is necessary as part of a program of preventative services.

Parents also have difficulties when services are poorly coordinated. Parents of children with disabilities often have to deal with a significant number of health, medical and early intervention specialists or practitioners on a regular basis, and may also have regular dealings with non-disability services such as child protection units, Centrelink or Indigenous services (Muir et al., 2008). Some families experience problems from a lack of communication between such services, and conflicting advice, and a constant threat that current services may be withdrawn (Glenn, 2007). These factors can lead to added stress, in an already difficult situation. Where professional support works well, it co-ordinates the range of services that parents' deal with, and is an important source of emotional and practical assistance (Glenn, 2007).

An extensive survey of Australian families of children with disabilities (Owen et al., 2002) found that such families struggled with the complex and fragmented

services available to them. This was particularly so for families with children with severe or profound disabilities who had to negotiate an extremely complex service system. Assistance with coordination or integration of services on a local basis, and in a culturally sensitive manner, was a priority for many families. Many parents also experienced a lack of congruence between the needs of their child and family as a whole, and the services they are able to access. The service system was not always attuned to family needs, or failed to appreciate the importance of maintaining the functioning of the whole family and addressing the needs of each member - including the children with disabilities - in a balanced way.

From this brief summary of parents' experiences of professional services, it is apparent that, while professional help can be very helpful to families, it can also create problems for them when it is delivered in ways that make parents feel disempowered, when services do not consider the demands they are making on families, and when services are hard to access or poorly coordinated.

The next section explores what specific forms of services families of children with disabilities need.

# 3.5 Supporting families of children with disabilities

The following discussion is a brief overview of these additional needs of families of young children with disabilities, and the commensurate supports that have been identified in many studies.

**Emotional support and counselling.** All parents of children with disabilities need personal and emotional support, particularly at times of stress (such as diagnosis). Some parents may be able to get the support they need from their personal support networks, but many will benefit from the emotional support that caring professionals can provide. In addition, some parents require access to affordable (free, low cost or means tested) initial and ongoing counselling to help them cope with a range of feelings or emotions including grief, guilt, loss, anger, helplessness or depression, all of which may occur in the context of love and concern for their child. Counselling needs to be made available as soon as possible after a child's disability or delay is identified or when a professional such as general practitioner is aware that there is a serious developmental concern about the child. Transition times for parents and children, such as at the time of initial diagnosis, or when a child starts attending an early childhood service, have been identified as times where counselling support could help ameliorate families' feelings of increased vulnerability (Grace et al., 2008; Muir et al., 2008; Orsmond, 2005).

**Social support.** There is strong evidence that the nature and extent of families' personal social networks are linked with a wide range of outcomes for parents

and children (Armstrong et al., 2005; Cooper et al., 1999; Crnic & Stormshak, 1997; Thompson & Ontai, 2000). Social support is just as important for families of children with disabilities as it is for other families (Barakat & Linney, 1992; Bailey, 2007; Bromley et al., 2004; Dunst et al., 1997; Glenn, 2007; Khine, 2003). There is also good evidence that contact with other parents of children with disabilities can be a valuable source of support for families (Kerr & McIntosh, 2000; Singer et al., 1999; Turnbull & Turnbull, 2000). This contact can take many forms, from opportunities to meet informally as well as more formally organised parent-to-parent programs (Law et al., 2001; Santelli et al., 2001; Turnbull & Turnbull, 2000). A local example is the MyTime program, a peer support program for parents of children with a disability or chronic medical condition, developed by the Parenting Research Centre, and in supported with a national network of agencies and facilitators.

Information. Families need access to information concerned with their child's diagnosis, assessment, treatment, interventions and other matters such as genetics or available resources. The timing (immediate and ongoing), level of complexity, type (written or verbal) and amount will depend on each family's particular contexts and changing circumstances. Research with families has shown that many families feel frustrated or confused by either a lack of coherent information or by information overload (Bailey & Powell, 2005; Guralnick, 2005; Moore & Larkin, 2006; Muir et al., 2008; Shonkoff et al., 2000). Information may need to be available in a language other than English or translated verbally if that is not possible. Information may also be required for siblings and extended family members such as grandparents (Carpenter & Russell, 2005; Siraj-Blatchford & Clarke, 2000). Strategies for gathering and giving information to families have been described by Woods and Lindeman (2008).

Learning their role. When parents first come in contact with ECI services, it is likely that they will have little or no knowledge of such services or of disability prior to the referral of their child (Woods & Lindeman, 2008). They will never have heard of or experienced the principles of family-centred practice, natural environments, team decision making, or care provider—implemented approaches. If a family has had any prior experience, it is likely to be with a medical, a clinical, or an educational model, with expectations for team members to diagnose and prescribe a treatment, do therapy, teach, or give homework. In order that parents can participate, they need to have a clear description of what the program entails and what their roles are (Woods & Lindeman, 2008), as well as the research evidence that supports these roles.

Strength-building and empowerment. Parents of children with developmental disabilities want and need to (re)gain control over their lives, and to develop their capacity to meet the children's needs. To help them do this, practitioners need to use strength-building and family-centred practices (Pilkington & Malinowski, 2002; Saleebey, 2006; Turnbull et al., 2000). Training programs, such as those developed at St. Luke's in Bendigo (McCashen, 2004), are now available. In

building parental capacity, the aim is to strengthen parents' confidence and competence in providing their children with learning experiences and opportunities known to be effective in promoting children's development (Dunst, 2007a). Building such parental skills is most effectively done by involving parents in informed decision-making and in taking action to obtain whatever resources or goals they have chosen (Dunst, Trivette & Hamby, 2007).

Parent-child relationship support (Moore, 2009b). A key aspect of effective intervention with young children with disabilities is helping parents and other caregivers develop responsive and engaged relationships with the children. Such relationships are essential for all children, including those with disabilities, but may be harder to establish with children who have certain disabilities. A range of programs have been developed to promote positive parent-child relationships, including interaction coaching (McDonough, 2000), the Responsive Teaching approach developed by Gerald Mahoney and colleagues (Mahoney & MacDonald, 2007), the Early Start Denver Model developed by Sally Rogers and colleagues (Vismara et al., 2009; Vismara & Rogers, 2008), and the Relationship Development Intervention developed by Steven Gutstein (Gutstein, 2001, 2007; Gutstein & Sheely, 2002). In addition, Kassow & Dunst (2007) have identified the characteristics of intervention practices most associated with enhanced parental sensitivity.

Additional demands and resources. There needs to be practical recognition for the additional daily demands made on families when a child has a disability or developmental delay. Research has identified that these families have additional demands placed on their time, stress levels, energy, finances and relationships with partners as they attempt to provide the best interventions for their children as well as meeting the needs of siblings, other family members, work commitments and their personal needs (Guralnick, 2005; McWilliam, 2005; Muir et al., 2008; Orsmond, 2005; Tannous & Katz, 2008). As noted earlier, research has also identified that these families face additional difficulties in establishing and maintaining family routines which are recognised as one of the foundations for stable, happy, meaningful and productive family life (Keilty & Galvin, 2006; Gallimore et al., 1989). Practical supports might include:

- Time access to affordable (fully funded, low cost or means tested) family or parent time out or family relief services; services or consultations for their child available at one, central location; flexible work arrangements
- Stress and energy levels access to affordable (free, low cost or means tested) stress management programs, exercise programs or nutritional and dietary advice at a local community health service, integrated child and family hub or a local hospital
- Financial basic financial support such as carer payments indexed annually and additional funding through subsidies or tax relief to enable access to a range of services that can support their capacities as parents and to ensure

that every child with a disability or developmental delay can access appropriate services and resources

- Partner relationships ongoing access to locally provided, affordable partnership guidance counselling services
- Family- support from trained family-centred early intervention consultants could help all family members in making appropriate accommodations to ensure that family appropriate routines are established and sustained (Keilty & Galvin, 2006; Llewellyn et al., 2010; McWilliam, 2005, 2010a, 2010b).

Coordinated care and support. An issue repeatedly highlighted in the literature is the need for effective care coordination for families of children with disabilities (Drennan et al., 2005; Sloper, 1999). The more health or development problems a child has, the more services they receive and the more service locations they have to access. Parents report that in this circumstance services are less familycentred, and essential information and services are hard to obtain (Greco et al., 2007). Numerous research studies have found that parents want a single point of contact with services and an effective, trusted person to support them to get what they need. The key worker model is one way in which this need can be addressed (Care Coordination Network UK, 2004; Drennan et al., 2005; Greco et al., 2004; Mukheriee et al., 1999). This is a method of service delivery involving a person who works in a guide role with families. This person acts as a single point of contact for a family, helping the family to coordinate their care, not only within the healthcare system, but also across systems (education, social services, financial resources, recreation, transportation, etc). The main concept of the key worker's role is to empower parents by providing them with support, resources and information tailored to meet their individual needs. There is good evidence that parents of children with disabilities prefer working with a key service provider to working with different team members or services (Sloper, 1999) and that provision of a key worker is associated with a number of positive benefits for the family and their children (Liabo et al., 2001). Comparisons of different key worker models show that a strong predictor of family outcomes is the extent to which key workers carry out the various aspects of key working, namely provision of emotional support, information about services and the child's condition, advice, identifying and addressing needs of all family members, speaking on behalf of the family when dealing with services, co-ordinating care, improving access to services and provision of support in a crisis (Sloper et al., 2006).

Timely diagnosis, assessment, monitoring and feedback. Children with a disability or developmental delay need ongoing comprehensive, authentic, contextualised, assessment and monitoring processes and feedback for their families which is not always driven by the need to gain access to a particular service or type of funding. Families have reported being frustrated by the need to have their child assessed repeatedly in order to show that the child has a disability as part of eligibility for funding or to access a service. In addition, it can take up to a year for some families to obtain agreement from professionals that

their child is eligible for funding and to gain access to an early intervention service (Gavidia-Payne et al., 2006; Grace et al; 2008; Muir et al., 2008). Key features or principles of best practice in early intervention assessment processes have been identified by Bagnato (2007), Guralnick (2005), Hanft & Pilkington (2000), Meisels & Atkins-Burnet (2000), Moore (2005), Shonkoff et al. (2000) and Williamson et al. (2006).

# Access to early childhood and early childhood intervention services.

Children with disabilities and their families need access to local and affordable early childhood intervention programs within a universal early childhood service system and/or specialised response provisions. These services need to be based on core values and principles concerned with evidence based best practice pedagogy as identified in the early childhood generalist and early intervention research (Brennan et al., 2003; Bruder, 2001; Coleman et al., 2006; Cullen, 2004; Dunst & Bruder, 2002; Edwards et al., 1998; Fleer et al., 2006; Forster, 2007; McLoughlin & Stonehouse, 2006; Siraj-Blatchford, 2004; Shonkoff et al., 2000).

# 3.6 Summary

Over the past few decades, there have been changes in conceptualisations of disability, involving a shift from a deficit model to a social model. This recognises that environments can constrain the functioning and participation of children with disabilities as much as their impairments do. Our growing knowledge of child development also reveals the importance of children's social and physical environments for their ongoing learning and development.

Children with disabilities have the same general needs as children who are developing normally. Similarly, families of children with disabilities have the same general needs as families of other children, but also have additional support needs. These needs include

- emotional support from family, friends, and professionals
- information about their children's disability and about relevant services
- strength-building and empowerment strategies to help parents develop the capacity to meet the children's needs
- practical support to help families meet the additional demands and resources associated with having a child with a disability
- timely diagnosis, assessment, monitoring and feedback

In addition, this overview has indicated some of the ways in which early childhood interventions services can respond to these needs. These include:

- key worker model of support to simplify access to services
- ready access to early childhood and early childhood intervention services
- helping families establish sustainable family routines.

However, it is also apparent that families' experiences of services are not ideal - while professional assistance can be very helpful to families, it can also create problems for them when it is delivered in ways that make parents feel disempowered, when services do not consider the demands they are making on families, and when services are hard to access or poorly coordinated.

In the light of the above list of additional needs of children with developmental disabilities and their families, the next question is what interventions / supports are needed to address these issues? In the next section, we turn out attention to early childhood intervention services themselves to see what role they play in supporting children with developmental disabilities and their families.

# 4. EARLY CHILDHOOD INTERVENTION SERVICES

The field of early childhood intervention continues to evolve, reflecting developments within its own practices as well as related developments in other fields (Moore, 2008c). Recent reviews of early childhood intervention by Bruder (2010), Carpenter & Campbell (2008), Dunst (2000, 2004, 2007, 2011), Dunst & Trivette (2009) and Turnbull et al. (2007) have reflected upon these developments and suggested ways forward.

# 4.1 Definition and rationale

Early childhood intervention services have usually been defined in terms of services to children with disabilities and their families. For example, the definition given by Shonkoff and Meisels (2000) in the *Handbook of Early Childhood Intervention* (2<sup>nd</sup>. Ed.) is as follows:

Early childhood intervention consists of multidisciplinary services provided to children from birth to 5 years of age to promote child health and wellbeing, enhance emerging competencies, minimise developmental delays, remediate existing or emerging disabilities, prevent functional deterioration, and promote adaptive parenting and overall family functioning. These goals are accomplished by providing individualised developmental, educational, and therapeutic services for children in conjunction with mutually planned support for their families.

This emphasis on service provision as the essence of early childhood intervention has been challenged by Dunst (2000, 2004, 2007) who argues that there is little evidence that a service-based approach to early intervention is effective, and that it may even have negative effects. Dunst and Trivette (2009a) propose an alternative definition:

Early childhood intervention and family support are defined as the provision or mobilisation of supports and resources to families of young children from informal and formal social network members that either directly or indirectly influence and improve parent, family, and child behaviour and functioning. The experiences, opportunities, advice, guidance, and so forth afforded families by social network members are conceptualised broadly as different types of interventions contributing to improved functioning.

This definition differs from most other definitions by its inclusion of informal experiences and opportunities as 'interventions' contributing to improved functioning, and by its focus on parent and family capacity building as the principle means of supporting and strengthening child functioning (Dunst, 2004).

More specifically, early childhood intervention involves parents or other primary carers and practitioners providing young children who have developmental disabilities with experiences and opportunities that promote the children's acquisition and use of competencies that enable them to participate meaningfully with others and with their environment (Dunst, 2007).

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 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.

Dunst (2007, 2011) argues that the US early childhood intervention system is essentially a service-based system, and that these are being implemented on the faulty assumption that the services provided are de facto efficacious. He maintains that early intervention programs in the US generally do not use evidence-based or recommended practices, and that many infants and toddlers are not provided with the kinds of experiences and opportunities that are likely to have beneficial effects.

We will return to this debate after considering the rationale for early childhood intervention services.

There are at least four general reasons for the provision of early childhood intervention services for young children who have disabilities or developmental delays (Bailey et al., 1998; Moore, 2005): ethical or moral, developmental, economic, and empirical.

• **Ethical rationale.** The ethical rationale for early childhood intervention is concerned with societal and community obligations to meet and protect child and family rights to these services and practices. Larry Schweinhart, one of the chief researchers in the Perry Preschool Project early intervention longitudinal study, believes that the ethical rationale is important as the first principle:

'Every child needs a good early childhood education. That's an ethical principal that transcends what the data say' (Schweinhart, 2004).

Rights for all children and families can be enshrined in different conventions, legislation and regulations, but they require commitment to action if they are to be of any transformative use.

- Developmental rationale. The developmental rationale for early childhood intervention is based on the research evidence concerned with how young children develop, including early brain development and its vulnerability to neglect and young children's receptivity to learning (Gopnik, 2009; Lally, 2000; McCain & Mustard, 1999; Sameroff, 2009; Shonkoff, 2010; Shonkoff & Phillips, 2000; Shonkoff et al., 2009; Sroufe, 2009; Stiles, 2009; Worthman et al., 2010). Developmentally, the research confirms that early interventions are more effective than later efforts. For families, the earlier the interventions begin, the easier it will be for them to adapt to the challenges they face when their children are identified with a disability or developmental delay.
- Economic rationale. Economically, the research is convincing from several major longitudinal studies in the USA (Perry Preschool project; Chicago, Child and Parent Centres' project and the Abecedarian Project) and in the UK (EPPE study). These studies confirm that investments made in the early years of life, and especially in high quality early childhood services, are cost effective as they save the need for more costly expenditure on remediation or other interventions later in the child's life course (Cunha & Heckman, 2009, 2010; Cunha et al., 2010; Heckman, 2000; Kershaw et al., 2009; Perez-Johnson & Maynard, 2007; Schonkoff & Phillips, 2000; Schweinhart, 2004). The positive outcomes from the early interventions provided in these projects are broad and affect both the individual and their communities. While none of the listed projects have focused entirely on early intervention for children with disabilities or developmental delay and their families, it seems reasonable to argue that the same economic principles would apply (Barnett, 2000; Moore, 2005). Indeed, the empirical evidence supports this claim.
- Empirical rationale. The empirical rationale supports the importance and benefits of early childhood early intervention for children with a disability or developmental delay through the research evidence in early intervention. In summary, this evidence indicates that evidence-based best practices in early childhood interventions have short and long term positive effects on children and family functioning and adaptation (Odom & Wolery, 2003; Reynolds, 2002; Shonkoff & Phillips, 2000).

Any one of the reasons might be considered grounds enough for providing early childhood intervention services, but in combination they form a very powerful rationale, and serve as a strong foundation for policy and funding provisions. However, they do not tell us what form services should take. Besides having a general rationale for providing ECI services, we need a specific rationale to guide what form of service is provided.

Just such a rationale has been outlined by Moore (2001a), grounded in our understanding of how child develop. One of the key features of child development noted above is that children's ongoing learning depends upon the nature and quality of their environments. That being the case, we need to consider what the main environments for young children are. 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 notice about this list is that it does not include specialist services such as those provided by ECIS professionals. Children spend the majority of time with their families in everyday routines and activities (Bruder, 2001; Jung, 2003). While ECIS 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, ECIS 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 the 3% of their waking hours. As McWilliam (2010c) points out, the bulk of the child's learning occurs between home visits or other sessions with professionals, not during them. Regular caregivers' interactions with children are not affected by having more professionals providing more services: its maximal intervention the child needs, not maximal services (McWilliam, 2010c).

We are now in a position to articulate the rationale for early childhood intervention service provision. There are four key points:

- If children are shaped by their environments, then we need to ensure that these environments and all the experiences and relationships that make up those environments are as fully supportive as they can be of children's learning and development.
- If children develop through relationships with their parents and caregivers, then we need to ensure that those relationships are optimal
- If children's learning is cumulative and depends upon having repeated opportunities to practice skills, then we should ensure that they have as many such opportunities as possible
- If ECIS cannot provide the environments, experiences and learning opportunities that children need, then its job is to work with and through those that can provide them – families, community settings, and the early childhood programs

It should be noted that, from this perspective, the inclusion of children with disabilities in mainstream early childhood programs is not an add-on to ECIS, but a major form of intervention in its own right. Thus, mainstream early childhood

programs are not simply desirable settings for normalising or widening children's social experiences, but are major settings for learning and intervention. This reconceptualises inclusion as intervention and as mainstream early childhood programs and settings as essential learning environments for young children with developmental disabilities.

### Inclusion as intervention

Inclusion is the active participation of children with and without additional needs in the same early childhood programs and community settings (McLoughlin & Stonehouse, 2006). Inclusion is not just children with exceptional needs attending mainstream programs, but involves such children being meaningfully engaged in and participating in program activities.

This conceptualisation of inclusion is more radical than earlier ways of thinking about inclusion. For instance, Guralnick (2001) identified four different forms of inclusion:

- Full inclusion: Typically developing children and children with additional needs participate fully in a program or service that caters for all children
- The cluster model: A group of children with additional needs participate together in a program that operates alongside a mainstream program
- Reverse inclusion: A few typically developing children participate in a program that caters largely for children with additional needs
- Social inclusion: Children with additional needs are catered for in special settings and come together with typically developing children at times for social experiences

Of these, only the first of these corresponds to the definition given above. Others use the term inclusion in a much wider sense, and see it as both a right and a need for all children with a disability or developmental delay and their families (eg. Bailey et al., 1998; Fegan & Bowes, 2004). Inclusion in this wider sense is identified as a necessary component of being able to participate meaningfully in community life and is essential for child and family wellbeing (Fegan & Bowes, 2004).

The reason why inclusion is so critical is that children's participation in more developmentally advanced settings is essential if they are to learn the skills for successful and independent participation in those settings (Odom & Wolery, 2003). The skills cannot be taught effectively in other contexts and then transferred; skills for specific contexts are only learned by participating in those contexts.

What is the evidence regarding the inclusion of children with developmental disabilities in mainstream early childhood programs? Do they benefit from the

experience? Research on the effects of preschool inclusion for children with disabilities has been summarised by Odom et al. (2002, 2004) and the National Professional Development Centre on Inclusion (2007). The key findings are these:

- Across a range of disabilities, positive outcomes are reported for children with disabilities in inclusive settings. Children in inclusive programs generally do at least as well as children in specialised programs. For children with disabilities, these outcomes are reflected in more mature or positive behaviours occurring in the inclusive settings. Developmental and academic outcomes appear to be related to the type of curriculum employed.
- Positive outcomes are also experienced for typically developing children enrolled in inclusive settings. These outcomes are related to gaining a greater understanding of disability and greater sensitivity to individual differences among others. The parents of children without disabilities whose children participate in inclusive programs often report beneficial changes in their children's confidence, self-esteem, and understanding of diversity.
- Children with disabilities engage in social interaction with their peers less often than typically developing children and, as a group, appear to be at higher risk for peer rejection than their typically developing peers. A range of intervention techniques has been developed to foster positive interactions and relationships for children with disabilities.
- Family members generally express favorable attitudes toward inclusion of their children in inclusive programs, and positive attitudes increase over time. However, families also voice concerns about preschool inclusion, and about whether their child is receiving all the extra assistance they need.

What do we know about the features of programs and practices that are needed for effective inclusion, ie. for children with disabilities to benefit from the experience? Syntheses of the evidence (Bailey et al., 1998; Grace et al., 2008; Odom et al., 2002, 2004; National Professional Development Centre on Inclusion, 2007) indicate that key features are the following:

- High-quality early childhood programs form the necessary structural base for high-quality inclusive programs; thus, all children benefit when programs are of high quality and truly inclusive.
- Specialised instruction is an important component of inclusion. Attendance at community-based or general education settings is not enough: the individual needs of children with disabilities must be addressed directly and their engagement in learning and social activities purposely facilitated by staff, ideally through naturalistic, embedded interventions.
- Adequate support is necessary to make inclusive environments work. Support includes training, personnel, materials, planning time, and ongoing

consultation. Support can be delivered in different ways, and each person involved in inclusion may have unique needs.

- Collaboration is the cornerstone of effective inclusive programs. Collaboration among professionals within and across systems and programs is essential to inclusive programs.
- Collaboration with parents is also essential. This means including and empowering them as part of the decision-making team in the education of their children.
- Programs, not children, have to be 'ready for inclusion'. The most successful inclusive programs view inclusion as the starting point for all children.

These findings – about the potential benefits of inclusion and the key practices necessary for those benefits to be realised – strengthen the case that inclusion should be regarded as essential for the development and participation of children with developmental disabilities. Bailey et al. (1998) summarise the argument thus:

In our opinion, placement in inclusive settings should be a goal for all children with disabilities. The legal, moral, rational, and empirical arguments provide a consistent and compelling foundation which supports this position. However, we temper our recommendation with the caveat that inclusive settings also should be of high quality, able to address the special needs of children, and consistent with parent goals and priorities. (p. 36)

This position has recently been endorsed by the peak US bodies representing early childhood services for children with disabilities and mainstream early childhood services. In a joint position statement issued by Division for Early Childhood and the National Association for the Education of Young Children (DEC/NAEYC, 2009), early childhood inclusion is defined in the following terms:

Early childhood inclusion embodies the values, policies, and practices that support the right of every infant and young child and his or her family, regardless of ability, to participate in a broad range of activities and contexts as full members of families, communities, and society. The desired results of inclusive experiences for children with and without disabilities and their families include a sense of belonging and membership, positive social relationships and friendships, and development and learning to reach their full potential. The defining features of inclusion that can be used to identify high quality early childhood programs and services are access, participation, and supports.

However, in practice, achieving these goals consistently has been a challenge, as there are a number of barriers to be overcome.

#### **Barriers to inclusion**

Australian studies suggest that parents of children with developmental disabilities can face many barriers in ensuring that their children participate in mainstream early childhood services with appropriate supports (Grace et al., 2008; Llewellyn et al., 2002; McLoughlin & Stonehouse, 2006; Mohay & Reid, 2006). One such study (Mohay & Reid, 2006) found that it was not negative attitudes that limited the inclusion of children with a disability in long day care centres, but rather a lack of confidence about having the skills and resources to provide an appropriate program. A NSW study (Llewellyn et al., 2002) found three main types of barriers to the inclusion of children with disabilities in early childhood programs: securing funding, enrolling children with disabilities, and accessing specialist support services. Yet another Australian study, Grace et al. (2008) investigated the experiences of mothers of children with disabilities in ensuring the inclusion of their children into mainstream children's services. They concluded thus:

Few of the early childhood centres in this study were able to provide those elements of early childhood education identified ... as being essential to social inclusion. Most had insufficient resources to employ trained staff to facilitate positive social interactions and engagement through naturalistic, embedded interventions. Nor did they have the time to send existing staff for training on including children with disabilities. Inadequate staffing levels also meant that time was limited for collaborative teamwork with other agencies. The failure of many early childhood services to incorporate and empower parents as part of the decision-making team involved in the education of their children was not only due to a lack of time for such ideal practices but also due to the lack of centres' employing family-centred models.

Why is inclusion such a problem? Seeking to answer this question, McLoughlin and Stonehouse (2006) documented the current range of Australian State and Commonwealth programs involved in supporting the inclusion of children with additional needs and disabilities. They found that the extensive range of providers, funding mechanisms, programs and services for children with additional needs creates confusion and complexities for families, especially when there is limited collaboration and communication among providers. Different eligibility criteria, application processes and funding allocations result in parents having to 'cobble together' a collection of services to meet their child's needs. Grace et al. (2008) concur with this analysis. They suggest that ensuring the prerequisites for truly inclusive early childhood settings were frequently hampered or precluded by two major barriers: one was inadequate government funding levels and an unnecessarily complex application process; the other was that Australian early childhood centres are not obliged to enroll children with disabilities.

Parents have consistently identified barriers to social inclusion for themselves and their children in the research (Bach, 2002; Brown et al., 2001; Grace et al., 2008; Muir et al., 2008; McLoughlin & Stonehouse, 2003). (For a contemporary personal account of the challenges faced by parents of children with developmental disabilities in ensuring that their children attend regular preschools with appropriate support, see Day, 2010). Some of the barriers for parent's social inclusion relate to matters mentioned already, such as the intense and additional time and energy demands placed on parents when a child has a disability or developmental delay which can make it difficult for them to participate in social events that occur in a community. Research with families indicates that it is the social aspects of inclusion that are often most salient for them: 'having a friend for their child' is a common aspiration for parents (Batchelor & Taylor, 2005). One of the barriers to children with disabilities developing the social skills necessary for friendships is being 'velcroed' onto an integration aide (Cullen, 2004), which can happen when early childhood services see additional staffing as the prime way of supporting the child, rather than individualised programming and family involvement (Llewellyn et al., 2002).

# Strategies for promoting inclusion

Strategies for supporting the social inclusion of children with a disability or developmental delay have been identified by Batchelor and Taylor (2005) and Brown et al. (2008). Batchelor and Taylor's (2005) research in an Australian kindergarten found that planned social inclusion that focused on peer mediation and naturally included in daily routines has the potential to improve social inclusion of children with disabilities.

While social inclusion can be supported through child and family participation in a quality early childhood service or centre, it is important to ensure that it does not get overlooked in the focus that might be given to other aspects of early intervention such as working on children's skill development or supporting parents to use family routines and events as potential sites for their children's learning and development. McWilliam and Casey (2007) describe a strong, evidence-based approach to promoting engagement in preschoolers. It describes strategies to help them make the most of natural learning opportunities and encourage developmental goals, assess child functioning in daily routines to ensure progress, and integrate therapy into classroom routines so teachers and therapists can learn from each other. Other accounts of how to promote the participation of children with developmental problems in early childhood settings have been provided by Boschetti and Stonehouse (2007) and Grisham-Brown et al., 2005).

Parents' social inclusion can be supported through the combined efforts of professionals or practitioners and the services they represent. There are parent focused interventions such as parent to parent groups, parent education programs or programs developed for special groups of parents such as

adolescent parents, sole parents, parents from a particular ethnic group, or vulnerable parents (Tannous & Katz, 2008). While all of these programs or interventions can be helpful for improving parenting skills and overall wellbeing and confidence, there may need to be more targeted interventions focused on social inclusion in a community. These social inclusion strategies can be offered in parallel with or after a parent program is completed or included as part of every parent program objectives where possible. Noah's Ark's *A Framework that Addresses the Social Dimensions of Disability* (Centre for Community Child Health, 2003a) identifies several programs which target social inclusion for families. (See also the SA Government's website for further discussion on social inclusion - www.socialinclusion.sa.gov.au/files/RR SIIPFebSIndicators.pdf).

While the concept of inclusion is embedded in early childhood intervention and general early childhood education, care and wellbeing literature and discourse, it is not an unproblematic concept or a term that should become entrenched without debate. There is some concern that a focus on inclusion could mean that additional needs are overlooked or ignored. Statements by practitioners such as 'we treat everyone the same in this service' could mean that some children are marginalised because the program does not respond to individual differences and the need for differentiated responses or resources. A fully inclusive program is one that responds to the individual needs of all children, including those with additional health, behavioural, language and learning needs. To achieve this, early childhood programs need to be based upon principles of universal design for learning (Conn-Powers et al., 2006; Rose & Wasson, 2008) and use practices such as recognition and response (Coleman et al., 2006, 2009; FPG Child Development Institute, 2008; McCart et al., 2009) to provide the additional forms of help needed by individual children. (These are discussed more fully in Section 5.) What this implies is that realising the goal of inclusion as intervention cannot be achieved unilaterally by ECIS and integration support professionals but requires a matching shift by early childhood programs and professionals. Such a shift – to truly universal early childhood programs – is heralded in the national Early Years Learning Framework and its Victorian counterpart.

Another issue with using the term 'inclusion' is that it may suggest that some groups or individuals are positioned negatively, or need 'value adding' or 'normalising' in some pre-determined way order to become fully participating members of a group or the community (Dahlberg & Moss, 2005). When the rights of all people are recognised and responded to appropriately and the handicapping effects of additional needs are eliminated or reduced, then it could be argued that the term 'inclusion' has become a redundant idea. Perhaps the concept of inclusion is helpful at this stage in the development of a universal systems' approach in early childhood education, care and wellbeing, but remaining alert to and continuing to discuss its problematic nature is important.

# The role of ECIS providers

If inclusion is seen as a major *form* of early intervention rather than an add-on to ECIS, what exactly is the role that ECIS providers should play in working with families and with mainstream early childhood services? In the light of earlier discussions of the rationale or program logic for early childhood intervention and of the reconceptualisation of inclusion, we are in a position to clarify this role. Moore (2010a) has summarised the role thus:

In partnership with parents, early childhood and other professionals, the role of ECIS providers is:

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

Does this mean that early childhood interventionists never work directly with children? If we accept that the main role of ECI service providers is to ensure that the child's home and early childhood learning environments are optimal for the child, then we have to be able to explain how direct therapy with a child achieves this. If it does — and there are surely some circumstances in which this will be the case — then direct therapy will continue to play a role. Case-Smith and Holland (2009) 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 (a) to establish a relationship between the child and therapist that facilitates particular performance goals; (b) to offer, in addition to the teaching staff, support of the child's social—emotional growth; (c) to gauge how to adapt an activity to provide a 'just-right challenge' to a particular child; and (d) 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.

With this framework in mind, we will now examine what outcomes ECIS should be seeking.

# 4.2 Outcomes in early childhood intervention services

Just as the needs of children with developmental disabilities are essentially the same as those of all other children, so are the outcomes we want for them. Therefore, this discussion of outcomes begins with a brief consideration of outcomes for all children and why a focus on outcomes is important.

What outcomes do we want for all children? There is no real consensus on this, although there has been much more effort in recent years to identify outcomes that can be used to guide service delivery. Outcome statements are now central to current policy developments in Australia and in the States and Territories. The Victorian Government has developed the *Victorian Child and Adolescent Outcomes Framework*. This comprises 35 outcomes of children's health, learning, development, wellbeing and safety, and 150 indicators to measure progress towards the outcomes. Some of the outcomes relate to the child directly, and others relate to key factors that influence child wellbeing: the family, the community and services and supports.

It is inevitable in a pluralist society that there should be debate about the exact outcomes and indicators. For instance, according to Hamilton and Redmond (2010),

Recent Australian strategic policy documents emphasise the importance of the whole child, meaning, as the 2008 Melbourne Declaration puts it, that children and young people should be successful learners, confident and creative individuals, and active and informed citizens, and also that children's and young people's social, economic, ethnic or indigenous backgrounds should not be seen as determining their future place in society.

This whole child approach means that we should be concerned about the child's total well-being, including social and emotional well-being, material wellbeing, to physical health, to agency, and to the capacity to be both reflexive and critical. Hamilton and Redmond suggest that measures of overall quality of life would better reflect this whole child approach than the current reliance on indicators.

# Outcomes-based approaches for child and family services

The efforts to identify what outcomes we are seeking for children are based on a growing awareness of the values and importance of using an outcomes-based

approach to service delivery. *Outcomes-based approaches* 'start with the end in mind', that is, they begin by identifying the outcomes to be achieved and work backwards from there (Anderson, 2005; Friedman, 2000, 2005; Moore, 2007). This approach is also known as backward mapping (Dokecki & Heflinger, 1989; Elmore, 1979-1980, 1983; Fiorino, 1997).

The need for an outcomes-based approach arises partly from a prevailing tendency among human service providers to focus more on the product (ie. service) than the outcome, that is, they think that the reason the service exists is to provide support and intervention programs to children and parents. But that is to confuse the means with the ends: all our technical expertise and various forms of service are only a means to an end – to make some kind of change in the child and family. The question is what kind of change are we seeking? And exactly how does the services we provide achieve that change?

There have been a number of models developed to help service providers and systems adopt an outcomes-based approach (Centre for the Study of Social Policy, 2001; Chinman et al., 2004; Friedman, 2000, 2005). These various models all have certain features or steps in common. These have been incorporated into a model developed at the Centre for Community Child Health (2009) as part of its *Platforms Service Redevelopment Framework*. This builds upon work previously undertaken by Early Childhood Intervention Australia (Victorian Chapter)(2005).

### This model involves five phases:

- Vision planning (including identifying the desired outcomes and the corresponding objectives and indicators)
- Action planning (including identifying strategies based on evidence and program logic, and activities to implement them)
- Translation and implementation (including developing complementary action and evaluation plans)
- Evaluation (including process and impact evaluations)
- Analysis and review (including analysing the evaluations, reviewing and reporting)

Using this framework, all human services models of service should include the following components (Moore, 2010b):

- A statement of the *intended outcomes of the service*. These outcomes will be selected on the basis of values as well as evidence. All aspects of the service should be seen as contributing to the achievement of these outcomes.
- A listing of the *objectives and indicators* that are used to determine whether these outcomes have been achieved.

- Identification of the *strategies* used to achieve the outcomes. These should include strategies derived from evidence-based practice and practice-based evidence, as well as program logic models of how these strategies contribute to the outcomes.
- A description of the activities and services based on these strategies that are provided
- Procedures for evaluating service delivery whether what was planned was delivered and whether it was delivered in the way that was intended
- Procedures for evaluating the impact of services

Other features of importance include:

- A statement of the competencies needed by practitioners to deliver these services
- A systemic process for training practitioners in these competencies and for supporting their ongoing professional development throughout their careers

This framework is useful in evaluating models of service and will be used in a later section to assess the value of different ECIS models of service delivery.

#### **Outcomes for ECIS**

For early childhood intervention services to be effective, it is essential that there is agreement about what they are trying to achieve, what the desired outcomes are. However, shifts in early intervention philosophy and practice have been accompanied by changes in how we conceptualise what outcomes we are seeking for children and families (Moore, 1996, 2007; Bailey et al., 1998). The result is that there may no longer be a clear consensus in the early childhood intervention field as to what the desired outcomes are (Bailey et al., 1999; Harbin et al., 2005).

To address this uncertainty, efforts have been made to clarify what outcomes early childhood intervention services should be seeking, both in Australia (Early Childhood Intervention Australia - Victorian Chapter, 2005) and overseas (Dunst, 2000, 2004, 2007; Early Childhood Outcomes Centre, 2005; Parrish & Phillips, 2003).

Dunst (2007) argues that aims of early childhood intervention for 0-3 year olds are two-fold:

 to strengthen children's self-initiated and self-directed learning and development so as to promote their acquisition of functional behavioural competencies  to strengthen parents' confidence and competence in providing their children with the experiences and opportunities that will promote their children's learning and development.

Thus, early childhood intervention and family support practices are deemed effective only to the extent that children, parents, families and other caregivers become more capable and competent (Dunst, 2004). These include, but are not limited to, improved child development and interactive competence, parent well-being, parenting competence and confidence, and family quality of life. This is a parent-mediated, evidence-based approach: the role of early childhood intervention practitioners is to support and strengthen parent capacity to provide their children with the kinds of experiences and opportunities known to be most likely to support and strengthen child capacity *without* the need for ongoing professional intervention and guidance (Dunst, 2004, 2007).

In the US, the Federal government has funded the Early Childhood Outcomes Centre to promote the development and implementation of child and family outcome measures for infants, toddlers, and preschoolers with disabilities. The Early Childhood Outcomes Centre (2005) defines the long-term goals of early childhood intervention and early childhood special education in the following terms:

For children, the ultimate goal of this support is to enable young children to be active and successful participants during the early childhood years and in the future in a variety of settings – in their homes with their families, in child care, preschool or school programs, and in the community. For families, the ultimate goal is to enable families to provide care for their child and have the resources they need to participate in their own desired family and community activities.

Three key child outcomes and five key family outcomes have been identified (Bailey et al., 2006, 2008; Early Childhood Outcomes Centre, 2005). The child outcomes are:

- Children have positive social relationships
- Children acquire and use knowledge and skills
- Children take appropriate action to meet their needs

US states now are required to submit data annually to the US Department of Education on the progress of infants and toddlers in early intervention programs in three outcome areas: social-emotional skills, the acquisition and use of knowledge and skills, and the use of appropriate behaviour to meet needs (Hebbeler et al., 2008).

The five family outcomes are:

• Families understand their children's strengths, abilities and additional needs

- Families know their rights and advocate effectively for their children
- Families help their children develop and learn
- Families have support systems
- Families are able to gain access to desired services, programs, and activities in their community

Bailey et al. (2008) report that several other outcome areas were discussed but were not included in the final set of recommended outcomes. For example, quality of life was proposed as an important outcome of early intervention. Discussions during development of the instrument, however, concluded that it would be difficult to hold programs accountable for improving families' quality of life. Nevertheless, it was noted that quality of life should be the ultimate goal of early-intervention programs and that the five indicators could serve as partial indicators of meeting this goal.

The Early Childhood Outcomes Centre has developed the Family Outcomes Survey (Early Childhood Outcomes Centre, 2005; Bailey et al., 2006, 2008) to assess these outcomes. A large-scale trial with this instrument (Raspa, Bailey et al, 2010) has shown that it is psychometrically sound and that it measures two broad types of family outcomes: those related to the family interacting with the child (the first three of the five outcomes above) and those associated with the family and the community (the other two outcomes).

In Australia, Early Childhood Intervention Australia (Victorian Chapter)(2005) has developed a set of outcome statements to guide the work of early childhood intervention service providers. These included outcomes for children, families and communities, and distinguished between outcomes that related to gaining functional skills and competencies, and those that related to learning how to participate meaningfully in home and community activities.

	Functioning	Participating
Children	Children will gain functional, developmental and coping skills that are appropriate to their ability and circumstances.	Children will participate meaningfully in home and local community activities to the extent of their ability.
	Children will show confidence and enjoyment in their everyday life	Children will experience and enjoy family life and community activities that are preferred by the family.
Families	Families will be able to nurture and support their child according to their values and preferences.	Families will participate in social and community activities to the degree they choose.

	Families will be able to identify and address the needs of their child(ren) and family.	Families will feel supported by personal networks and local communities
	Families will be able to advocate for themselves and their family, to the degree they choose.	
Communities	Communities will have a range of service options and facilities to respond to emerging needs of families in supportive ways.  Communities will know how to, and be able to respond to the needs of all individuals and families.	Communities will value all members.  Communities will be inclusive, providing for diversity, access and quality services for all families.

In Victoria, the need for outcome statements for children with disabilities and developmental delays has been addressed by *Better Opportunities*, *Better Outcomes* (DEECD, 2010d). This framework supports the learning, development and inclusion of all children and young people with a disability or developmental delay and their families through a more holistic, life-cycle approach to the diverse and changing needs of children and young people with a disability or developmental delay and to the needs of their families.

Underpinning this document is a guiding vision and set of aspirations:

All Victorian children and young people with a disability or developmental delay:

- actively participate, enjoy and learn, along with their peers, in care and education settings and prepare for an active adulthood
- belong to supportive and inclusive communities
- are cared for effectively by families and carers who choose, and benefit from, the services and supports they need.

The framework also includes a statement of outcomes that now guide the work of ECI services in Victoria. These are based on relevant Council of Australian Governments (COAG) National Partnership agreements, including the National Disability Agreement, National Education Agreement, Investing in the Early Years – A National Early Childhood Development Strategy and the National Quality Agenda for Early Childhood Education and Care.

There are six outcomes in all, three relating to children, two to their families, and one for communities:

- Children and young people with a disability or developmental delay develop the skills and capabilities to achieve meaningful civic, social and economic participation
- Children and young people with a disability or developmental delay enjoy optimal health, wellbeing and quality of life
- Children and young people with a disability or developmental delay are engaged in, and benefit from, educational opportunities, achieving improved knowledge and skills
- Empowered families and carers access quality services that support the workforce and community participation choices of families
- Families and carers are well supported and are confident in their abilities to support their children's learning and development and capacity to live independently
- Inclusive communities benefit from the contribution that children and young people with a disability or developmental delay make and will make into the future

Performance indicators are being developed for each of these outcomes, drawing on the measures and data collected through the *Victorian Child and Adolescent Monitoring System* (VCAMS).

The other key outcomes document is the *Victorian Early Years Learning and Development Framework: 0-8 Years* (DEECD, 2009a). This identifies five Early Years Learning and Development Outcomes for all children:

- Children have a strong sense of identity
- Children are connected with and contribute to their world
- Children have a strong sense of wellbeing
- Children are confident and involved learners
- Children are effective communicators.

These are meant to apply to all children, including those with developmental disabilities and delays. The challenge for the ECI service sector is to embed the outcomes for children with developmental disabilities and delays within this wider set of outcomes for all children. Preliminary efforts to do this suggest that this can be done and that doing so serves to broaden the perspective of ECIS practitioners about the scope of outcomes that they should be seeking for the children they serve.

### 4.2 Service frameworks

What do we mean by a service framework or model? Guralnick (2005) argues that community-based early childhood intervention programs 'must articulate a

clear organisational structure, carefully outlining its components and interrelationships, as well as presenting a set of principles that together readily translate into a functioning and coherent system of early intervention practices' (p. xiv).

Has this challenge been met? Turnbull and her colleagues (2007) suggest not. They maintain that there is a gap in current policy and practice related to families: the absence of a clear conceptualisation of *what* supports and services should be offered in early intervention programs. They argue that, in implementing family-centred practices, early childhood intervention services have focused primarily on *how* families and professionals should interact. The field has not sufficiently addressed what supports and services should be offered to families to enhance the likelihood of positive outcomes for the families themselves and for their children with disabilities.

- The how of service delivery includes the key features of family-centred practice, such as the way that professionals honour parents' choices, involve multiple family members, build on family strengths, establish partnerships, and collaborate with families in individualised and flexible ways.
- The what of service delivery includes the specific types of family supports and services that are provided, such as respite care, provision of information (eg. community resources, government benefits, legal rights, information about the nature of the disability), and provision of emotional support (eg. counseling, parent-to-parent support, participation in support groups).

Turnbull and her colleagues suggest that the field has not yet developed a conceptual framework for the types of supports and services the ECI professionals should be competent to offer and that ECI programs should have the resources to provide.

Is this a fair claim? Dunst (2009) argues otherwise, maintaining that advances in knowledge have made possible the development of early childhood intervention models and frameworks that explicitly focus on features and elements of practices that are likely to produce optimal positive benefits. Models that have been developed include

- The developmental systems model (Guralnick, 1997, 2001, 2005)
- The integrated framework model (Dunst, 2000, 2004; Dunst & Trivette, 2009)
- The support-based home visiting model (McWilliam, 2010c; McWilliam & Scott, 2001)
- The unified theory of practice model (Odom & Wolery, 2003)
- The UK Early Support Model

In considering these different models, it should be noted that there are some major differences between the Australian service systems and those we are about to examine. The most important of these is that early childhood

intervention in the US (and Canada) refers to services for children 0 to 3 years of age, whereas the Australian system caters for children 0 to 6 years. In the US, the 3-6 year old age group is catered for by early childhood special education services, which are mainly centre- and classroom-based. The UK system resembles the Australian in serving children 0-6 years, but, as we shall see, has a quite different emphasis.

# ■ *The developmental systems model* (Guralnick, 1997, 2001, 2005)

Perhaps the most widely recognised overall model of this kind in the early childhood intervention field is the developmental systems approach proposed by Guralnick (1997, 2001, 2005). In this model, children's developmental outcomes are seen as a product of their immediate experiences in the family which in turn are shaped by family characteristics and potential stressors on the family. The immediate experiences in the family comprise three sets of parent-child transactions which are known to shape children's development:

- the quality of parent-child interactions the desirable qualities being 'responding contingently, establishing reciprocity, providing warm and nonintrusive interactions, appropriately structuring and scaffolding the environment, being discourse-based, and ensuring developmentally sensitive patterns of caregiver-child interactions' (Guralnick, 1998, pp. 323-4)
- experiences with the physical and social environment as orchestrated by the family, primarily the parents – major dimensions include 'the variety and developmental appropriateness of toys and materials provided, the general stimulation level of the environment, and the frequency and nature of the contacts with other adults and children that occur through parentbased friendship and family networks or alternative care arrangements' (ibid. p. 324)
- ensuring the general health of and establishing a safe environment for the child – 'eg., obtaining immunisation, providing adequate nutrition, protecting child from violence' (ibid. p. 324)

These patterns of family interaction are themselves the product of various family characteristics, including

- personal characteristics of the parents such as parental attitudes and beliefs, maternal mental health status, and coping styles
- family characteristics not related to the child's disability status such as existing supports and resources, quality of the marital relationship, financial resources, and the child's temperament

Another major set of influences on family interaction patterns are potential stressors specifically affecting families of children with developmental disabilities. Guralnick identifies four such stressors:

- the need for information about their children's health and development
- the interpersonal and family distress that can result from having a child with a disability
- additional resource needs resulting from having a child with a disability
- threats to the parents' confidence in their ability to meet their child's needs

Guralnick concludes that ECI services should be seeking to address these four potential sources of stress. He identifies three program components that should feature in all ECI programs:

- resource support, including awareness of and access to co-ordinated services, as well as supplemental supports (financial assistance, respite care etc.)
- social supports, including parent-to-parent groups, family counseling, and mobilising family and community networks
- information and services, including formal intervention programs (home or centre based), individual therapies and educational programs, and personal support and guidance

The developmental systems model provides an approach to inclusion and early intervention which acknowledges both the structural and process components required for a state-wide system of services (Guralnick, 2005). This model focuses on the immediate processes within family contexts, by drawing the parent's and practitioner's attention to the influence of parent or family relationships, interactions, characteristics and stressors on the child's development and learning (Guralnick, 2005; Moore, 2005; Muir et al., 2008).

Guralnick's model is informed by Bronfenbrenner's (1979, 1995) ecological systems theory. This theory has been developed further by theorists as research improves the knowledge base concerned with family functioning, social support networks, and the social and cultural aspects of learning and development (Bowes & Hayes, 2004; Guralnick, 2005; Rogoff, 2003). A systems approach to early childhood intervention recognises the complex, interweaving and connectedness across and within the different contexts where families, children, professionals and practitioners participate either directly or indirectly (Bowes & Hayes, 2004; Guralnick, 2001; 2005; Centre for Community Child Health, 2003a).

It also recognises that the most salient features of the social environment for families are not the formal early childhood and early childhood intervention services, but the personal support networks and community environments in which families live. Ensuring that families have positive social support networks should be seen as one of the key tasks of professional services. In the case of families of young children with developmental disabilities, this can

take the form of parent-to-parent programs (Santelli et al., 2001), such as the Commonwealth Department of Family and Community Services and Indigenous Affairs *MyTime* program, that provide parents with opportunities to meet and build links with other parents of children with developmental disabilities.

Ecological systems theory also informs one of the key features of family-centred practice – that families should be helped to utilise family- and community-based resources in preference to scarce professional resources.

Eco-cultural systems acknowledge that children are active agents or participants in different communities or contexts within the system including home or an early childhood service. Children are intense observers of the everyday patterns and types of interactions and events which occur within their family or community contexts (Fleer et al., 2006; Rogoff, 2003; Rogoff et al., 2003). As children actively participate in these interactions and events. with the support of more experienced people (e.g. parents or siblings), they learn the socially and culturally sanctioned values and practices of their family or community (Anning & Edwards, 2006; Rogoff, 2003; Rogoff et al., 2003; Woodhead, 2005). Children are not merely influenced by their environments and participation in interactions or events with others, they also influence other people's behaviours and responses to them (Rogoff, 2003; Rogoff et al., 2003; OECD, 2006). Rix et al.'s (2008) study of parental perspectives on the early years learning of their children with Down syndrome provides evidence of how these children, like all children, actively influenced their parent's response to them. The children's refusal or resistance to participate in parentplanned intervention experiences and their obvious enjoyment of activities where they could exercise personal control over the play, gave the parents clues as to what types of intervention experiences might be most appropriate to engage their child's sustained interest. The parent's comments about their child's inquisitiveness, strong will, determination, strong mind, or stubbornness, were not made in a negative sense, rather they reflected an understanding that these dispositions and agencies could be harnessed for improving their child's motivation for learning (Dunst, 2007).

The evidence base for the practices underlying the developmental systems model is discussed in Guralnick (2005), a book edited by Guralnick in which he invited various early childhood intervention researchers and experts to review the evidence regarding each component of the model.

A model that is similar to Guralnick's model has been developed by Goelman et al. (2005) for use in the Canadian context. This is not an alternative to the developmental systems model, but an example of how it can be implemented in ways that meet the needs of specific communities.

■ Integrated family systems framework model (Dunst, 2000, 2005, 2007a; Dunst & Trivette, 2009)

The integrated family systems framework proposed by Carl Dunst and colleagues includes four major components (children's learning opportunities, parenting supports, family/community supports, and capacity-building help-giving practices) and three intersecting components (everyday activity settings, caregiver interactional behaviour, and participatory parenting opportunities). Each major and intersecting component includes practices that research indicates matter most in terms of strengthening child, parent, and family functioning (e.g., Dunst, 2007a; Dunst et al, 2007).

The major operational or practice elements of the framework are:

- Child learning opportunities providing development-enhancing learning opportunities for the child
- Parenting / caregiver supports providing parenting / caregiving supports
  that reinforce existing parenting abilities, provide opportunities to acquire
  new parenting knowledge and skills, and strengthen parenting confidence
  and competence
- Family and community supports ensuring that parents have the support and resources necessary for them to have the time and both physical and psychological energy to engage in child-rearing responsibilities and parenting activities
- Family-centred helpgiving the active engagement of parents and other family members in obtaining desired resources and achieving familyidentified goals
- Activity settings everyday activity settings serve as the sources of children's natural learning opportunities in the context of family and community life
- Parent/child interactions using interactional and instructional practices that are most likely to have development-enhancing consequences
- Participatory parenting opportunities having positive support from personal network members

The focus of intervention is practitioners' use of capacity-building help-giving practices to ensure parents have the necessary supports and resources to provide their children development-enhancing learning opportunities in everyday activity settings (natural environments) where the parents' interactive behaviour with their children in those settings both supports and strengthens child and parent competence and confidence.

Every element of this model is grounded in research evidence (Dunst & Trivette, 2009a). The research includes

- the help-giving practices associated with parent capacity-building consequences (e.g. Trivette & Dunst, 2007)
- the caregiver interactional behaviour associated with child competence (e.g. Trivette, 2007)
- the kinds of social supports associated with positive parent and family functioning (e.g. Dunst et al., 1997)
- **Support-based home visiting model** (McWilliam, 2010c; McWilliam & Scott, 2001)

Robin McWilliam and colleagues (McWilliam, 2010c; McWilliam & Scott, 2001) have described a support-based home visiting model for working with children with additional needs who are below the age of three years. This model de-emphasises professional *services* and emphasises the *support* that professionals can provide. The model is essentially an organisational and practice one, and differs from models of social support that describe how a host of people (including early interventionists) and other resources can help families.

The focus of this service is on the family quality of life rather than just child competence. The aim 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.

The framework is similar to Guralnick's early intervention program components, which are labeled *resource supports* (service coordination, financial assistance, respite), *information and services* (formal program, parent-professional relationships, therapies), and *social supports* (parent groups, counseling, mobilising informal networks). McWilliam and Scott regroup and relabel these components to fit the support framework, as follows:

- Informational support. This includes information about
  - the disability or condition of their child
  - services and resources
  - child development (i.e. what comes next, what other children this age do
  - intervention strategies (i.e. what they can do with their child)
- Material support. This is an expansion of informational support since it
  includes finding resources to meet basic needs, such as programs for
  monetary assistance, adapting materials for everyday living, obtaining
  needed equipment, and establishing financial support. Providing support

for families to meet basic needs contributes to overall well being and ability of the family to focus on their other priorities, such as child-level interventions, and community inclusion opportunities.

Emotional support. This is provided through responsiveness to family
questions and concerns, and a sense of positiveness about the child and
parents, sensitivity, orientation to the family as a whole, competence in
providing information about community, and about development. Early
interventionists provide emotional support to families by helping a family
build social networks, facilitating parent groups, and engaging in helpgiving
practices that promote family empowerment. Emotional support has been
found to reduce stress, promote well-being and positive parent-child
interactions in families.

Specific practices to implement a support approach can be undertaken during intake, assessment, and service delivery. These include:

- Understanding the family ecology (Jung, 2010). Intake is one of the first contacts a program or service provider has with a family. From this point, families will develop expectations based on their interactions with professionals. Service providers can take this opportunity to establish a relationship with the family and learn about their experiences and resources. A meaningful and relevant activity is the development of an ecomap. Done correctly, this activity sets the stage for trusting, friendly relationships and a view of early intervention as a family-centred, not just child-centred, endeavour.
- Routines-Based Assessment (McWilliam, 2010a, 2010b). This provides families with a framework for recalling their concerns is routines-based assessment, which is friendly to families and results in functional goals (or outcomes).
- *Transdisciplinary teamwork.* This involves one primary service provider who integrates all domains of intervention.
- Home visiting practices (McWilliam, 2010c). In this model, home visiting focuses on family routines as the context for providing the three types of support.

### ■ *Unified theory approach* (Odom & Wolery, 2003)

Odom & Wolery (2003) approached the issue of developing a service model by examining the research evidence. They proposed a unified theory of early childhood intervention practice that includes eight tenets, three to five practices for each tenet, and an accumulated body of research evidence for the practices. The tenets of the evidence-based practices include

- families and homes are primary nurturing contexts
- strengthening relationships is an essential feature of early childhood 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 is necessary for successful and independent participation in those settings
- early childhood 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 contexts in which they are embedded

The description of the practices for each tenet is based on a wealth of evidence from many different kinds of studies.

### ■ UK model

In the UK, there has been a strong emphasis on lead professional / key worker model and provision of integrated services, but much less attention has been paid to what actual services are offered and by whom.

The *Early Support Programme* (<a href="http://www.earlysupport.org.uk/">http://www.earlysupport.org.uk/</a>) is the central government mechanism for achieving better co-ordinated, family-focused services for young disabled children and their families across England. It facilitates the achievement of objectives set by broader initiatives to integrate services, in partnership with families who use services and the many agencies that provide services for young children. The program has been developed specifically for children under the age of three. However, in announcing its intention to roll out the program across the country, the Department has indicated that the principles underlying Early Support are applicable to all children under five.

Early Support implements *Together from the Start*, practical guidance for professionals working with disabled children, which was published jointly by the Department for Education and Skills and the Department of Health in May 2003. The guidance recognises that where children have additional needs and disabilities, it is important that these are identified at an early stage and that identification leads directly to effective early intervention and multiagency support for children and families.

This program was thought to be needed because, despite the best efforts of many practitioners working at operational level, research into the needs of families of disabled children carried out at different times, in different areas of the country and on different populations, has delivered very consistent messages. Families have reported that they find it difficult to:

- find out about the services that are available to help them
- make sense of the role of different agencies and different professionals
- get professionals to understand their situation and needs in the context of the whole family
- · have their own knowledge of their child recognised
- negotiate delays and bureaucracy.

# Early Support promotes:

- better joint assessment and planning processes for individual children and their families
- better co-ordination of service provision to families where many different agencies are involved
- better information for families
- the introduction and development of lead professional or key worker services to improve the continuity and co-ordination of support available to families
- better exchange of information about children and families between agencies and at points of transition
- joint review of multi-agency service provision and joint planning for service improvement at strategic level
- the development of family-held, standard material to monitor children's development which can be shared across agencies

None of this makes very clear *what* services are provided, only that they are provided in an integrated fashion. The most prominent ECIS model appears to be the Portage model.

• The Portage model. This is a home-visiting educational service for preschool children with additional support needs and their families. The first such scheme was developed in Portage, Wisconsin, USA in the early 1970s to meet the needs of the young children living in rural communities. Since its introduction in the UK, the success of the approach has lead to an increasing number of services being developed nationally. There are 150 services registered with the National Portage Association (www.portage.org.uk). They offer parents regular, usually weekly, opportunities throughout the child's early years to be fully involved with decisions on their child's development.

Portage services work in partnership with parents in their own homes and offer a flexible and individual program that takes into account each family's unique circumstances. The aim of Portage is to support the development of young children's play, communication and relationships and to encourage full participation in day to day life within the family and beyond

the home. Portage services are committed to securing inclusion in the wider community for all children and families in their own right. Support offered through Portage is based on the principle that parents are the key figures in the care and development of their child and Portage aims to help parents to be confident in this role whatever their child's needs may be.

Portage services have been operating in this country for over 25 years. They have been evaluated at local and national level and found to be valued by parents and other professionals and to offer high quality teaching.

 Another more recent model is the *Team Around the Child* model (Limbrick, 2001, 2009, 2010). This involves the identification of a team of manageable size involving the parents plus a handful of people with the most regular and practical involvement whose task, at regular meetings, is to create successive action plans for early childhood intervention. Again, this is more about service coordination than about what is provided.

# Comparing the different service models

On the basis of the outcomes-based framework outlined earlier, the principle components of human services models of service were identified. This framework can be used to evaluate the different service models just described. Rather than use all the components, the evaluation will focus on the following key components:

- Whether the model was based on a clear statement of the intended outcomes of the service
- Whether the strategies to achieve these outcomes were based on evidencebased practice and practice-based evidence, as well as program logic models

Using these two criteria, we will briefly examine each of the models.

- Guralnick's developmental systems model was devised as a way of identifying the stressors on families and hence the type and frequency of support needed. While it does this successfully, it does back this up with a comprehensive program logic or set of evidence-based practices.
- Dunst 's *integrated framework model* is clear about the outcomes intended, and offers the most coherent program logic and evidence-based strategies. Every element of the model is based upon rigorous research.
- McWilliam's support-based home-visiting model includes a number of highly useful and evidence-based practices and techniques, but does not integrate these into a coherent theoretical framework as well as the two previous models.

- Odom and Wolery's unified theory of practice model is strong on identifying evidence-based principles and strategies but does not clearly articulate outcomes and objectives, and therefore does not show how the various strategies produce desired outcomes.
- The UK early support model is very service-oriented and does not articulate clear child and family outcomes, develop the underlying program logic, or identify evidence-based strategies.

It should be noted that even the most comprehensive of these models – the developmental system theory and the integrated framework model – do not describe how the actual services should be provided, nor do they claim to do so. As Guralnick (2005, p. xv) is at pains to point out, although his model contains both a framework and specific guidelines, these constitute guidelines only and must be translated into systems-based practices by community-based services.

Nevertheless, these frameworks, individually and collectively, provide a strong basis for the development of a comprehensive evidence-based model of service delivery for the ECIS sector, both at a state and federal level. The development of such a service framework could contribute greatly to the promotion of uniformly high-quality ECI service delivery across Victoria.

# 4.4 Evidence-based / practice-based intervention strategies

There is a growing recognition of the importance of using intervention strategies that are based on evidence and on program logic models (Buysse & Wesley, 2006; Moore 2007).

The importance of *program logic* or theories of change have been highlighted by many, including Anderson (2005), Hamilton & Bronte-Tinkew (2007), Shonkoff & Phillips (2000), and Ziviani et al. (2011). One of the key features of effective programs is that they are based on clear, scientifically-validated theoretical frameworks and methodologies which articulate how the services that are delivered achieve the desired outcomes (Moore, 2005; Shonkoff and Phillips, 2000). Thus, Shonkoff and Phillips (2000) argue that

All successful interventions are guided by a theoretical model that specifies the relation between their stated goals and the strategies employed to achieve them. ... Sometimes these frameworks are articulated explicitly; other times, they are implicit but not clearly formulated. (p. 340).

### **Evidence-based practice**

The importance of *evidence-based practice* has also been widely recognised, initially in medicine (eg. Cutspec, 2004; Sackett et al., 1997), but subsequently more generally. As promoted by the major international bodies such as the Cochrane Collaboration (<a href="www.cochrane.org">www.cochrane.org</a>) and the Campbell Collaboration (<a href="www.campbell.gse.upenn.edu">www.cochrane.org</a>) and the Campbell Collaboration (<a href="www.campbell.gse.upenn.edu">www.campbell.gse.upenn.edu</a>), the 'gold standard' for determining the efficacy of an intervention has been the randomised control trial, and rigorous review protocols for conducting systematic reviews of the research literature and collating the results of such trials have been developed. This has, in turn, led to the compiling of lists of proven evidence-based practices, such as those on the *Promising Practices Network* (<a href="http://www.promisingpractices.net">http://www.promisingpractices.net</a>). (A local example is the *Catalogue of Evidence-based Interventions* developed for Best Start programs).

However, a number of problems with this reliance on such a narrow definition of evidence have emerged (see critiques by Moore, 2010c; Patton, 2010; Pawson, 2006; Petr & Walker, 2009; Petticrew & Roberts, 2003). As a result, there have been moves to redefine evidence-based practice in areas such as medicine, psychology and early childhood intervention. In medicine, the progressive broadening of the concept of evidence-based practice in medicine can be seen by comparing these two definitions from David Sackett (one of the champions of this approach in medicine) and colleagues:

Evidence-based practice is the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients (Sackett et al., 1997)

Evidence-based medicine is the integration of best research evidence with clinical expertise and patient values (Sackett et al., 2000)

The first definition refers only to 'current best evidence' (which is the how evidence-based practice has traditionally been conceptualised), whereas the second definition adds two additional sources of information: clinical expertise and patient values.

In psychology, there has been a similar expansion of the definition of evidence-based practice in psychology. The latest formulation by the American Psychological Association (APA Presidential Task Force on Evidence-Based Practice, 2006) defines evidence-based practice as 'the integration of the best available research with clinical expertise in the context of patient characteristics, culture, and preferences'. In the early childhood intervention field, the same three elements appear in the model developed by Buysse and Wesley (2006). They define evidence-based practice as 'a decision-making process that integrates the best available research evidence with family and professional wisdom and

values'. In other words, it involves a balance of scientific proof, family and professional wisdom, and family and professional values.

#### Practice-based evidence

Of the three elements of evidence-based practice identified above – empirically supported interventions, clinical expertise or practice wisdom, and client or family values, preferences and circumstances – there are several different ways of conceptualising the second of these elements. Sometimes referred to as *practice-based evidence*, this body of knowledge can include individual clinical expertise, collective practice wisdom, practice-based syntheses, and concurrent gathering of evidence during practice (Moore, 2010c).

- Individual clinical expertise. Individual clinical expertise means the ability of
  individual practitioners to use their clinical skills and accumulated experience
  to rapidly identify each patient's unique health status and diagnosis, the
  individual risks and benefits of potential interventions, and their personal
  values and expectations.
- Collective practice wisdom. This can take the form of efforts to collate best practice statements based on the collective wisdom and knowledge of acknowledged experts in a particular field. In the early childhood intervention field, the most notable example has been the DEC Recommended Practices in Early Intervention / Early Childhood Special Education (Hemmeter et al., 2001; Sandall et al., 2000, 2004).
- Practice-based syntheses. An alternative definition practice-based evidence
  and of assessing evidence-based practice has been developed by Carl Dunst
  and colleagues (Dunst et al., 2002; Dunst, 2009). They define evidencebased practices as

Practices that are informed by research, in which the characteristics and consequences of environmental variables are empirically established and the relationship directly informs what a practitioner can do to produce a desired outcome.

According to this perspective, a practice is evidence-based when the findings from different studies of the same practice replicate and show that the same practice characteristics are related to the same outcomes. This involves identifying the different characteristics of a planned or naturally occurring practice (intervention or experience) and then relating the presence of these characteristics to the outcomes in different studies. As many characteristics of a practice as possible are examined, with an emphasis on the characteristics that stand out as being most important. This may be accomplished, for example, by comparing and contrasting the influences of variations in how

practices were implemented on patterns of outcomes to identify the conditions under which the practices have optimal positive consequences (Dunst, 2009).

Dunst and colleagues have conducted a number of practice-based syntheses (see <a href="http://researchtopractice.info/productBridges.php">http://researchtopractice.info/productBridges.php</a> for the full list). Examples of practices studied in this way include:

- Response-contingent learning opportunities (Dunst, 2003)
- Influence of caregiver responsiveness (Trivette, 2003)
- Effectiveness of pivotal training (Masiello, 2003)
- Interventions promoting parental sensitivity to child behaviour (Dunst & Kassow, 2007)
- Characteristics of parental sensitivity related to secure infant attachment (Kassow & Dunst, 2007).
- Influences of contingent touch on infant behaviour (Masiello, 2006)

This practice-based research synthesis approach may help resolve a long-standing tension within early childhood intervention services regarding evidence-based practice. On the one hand, evidence-based practice (in the sense of empirically supported treatments) requires that one maintain fidelity to the original manualised programs or treatment protocols and not vary them at all. On the other hand, family-centred practice requires that one adapt programs and practices to suit the particular needs and circumstances of the child and parent. To complicate matters, there is evidence that family-centred practice is an essential feature of effective service provision.

The practice-based synthesis approach gets around this problem by identifying intervention practices that are directly applicable in a wide number of situations. Rather than identifying *effective programs* (with all the attendant problems of program fidelity and widespread implementation), it identifies *universal features of effective practice*, and does so in a rigorous fashion. These features are compatible with the tailored approaches required in family-centred practice.

Concurrent gathering of evidence during practice. The final form that
practice-based evidence may take is the process of constantly monitoring the
effects of the service being provided (through observation, testing and
feedback from those receiving the service), and using this evidence to modify
the intervention to maximise its effectiveness.

### The process of decision-making

All of these definitions of evidence-based practice involve the same three elements. This poses problems for practitioners in selecting strategies that are backed by evidence. They can no longer rely solely on compilations of research-based 'proven' practices, but must also take account of clinical knowledge and family values. How are these to be balanced and integrated and balanced. What

is needed is a decision-making process that enables professionals and parents to weigh up the different elements in selecting the most effective strategy that suits their needs and circumstances.

Buysse and Wesley (2006) recommend a five-step process for evidence-based practice decision-making for the early childhood field:

- 1. Pose the question
- 2. Find the best available research evidence
- 3. Appraise the evidence quality and relevance
- 4. Integrate research with values and wisdom
- Evaluate

Another approach to decision making for early childhood interventionists has been proposed by Moore (2010c). This uses an outcomes-based approach. In making decisions about intervention strategies, we need to begin by deciding what outcomes are being sought. Particular programs may have been shown to be efficacious using the highest standards but not be preferred because they do not produce the outcomes that we want for children and families. As our ideas about what ECI is trying to achieve evolve, some 'proven' strategies or interventions may no longer be the best option because they do not achieve the ends we now have in mind.

Accordingly, the Buysse and Wesley model needs to be expanded to take fuller account of the importance of basing decisions on outcomes, the varieties of evidence to be consulted, and the need to take account of the practical issues involved in implementing the intervention. The following six-step process of evidence-informed decision-making is proposed:

- 1. Decide the outcome with the family
- 2. Identify how you will know when the outcome has been achieved
- 3. Identify the most effective known strategy for achieving the outcome:
  - review efficacy studies to establish what has (and has not) been tested and what has been shown to be effective
  - where there are gaps in the evidence, review practice-based evidence for what has been shown to be effective
  - review what is known about how particular interventions are understood to 'work'
- 4. Select the strategies that have the best evidence and/or program logic
- 5. Consult with family to identify which strategy is most able to be implemented in their particular circumstances

6. Support the family as they implement the strategy and help them monitor its effects

The discussion so far has focused on understanding what evidence-based practice and practice-based evidence involve, and what process we might use in deciding which strategies to use. We now turn to a consideration of what is known about the particular strategies that are known to be effective in early childhood and early childhood intervention services. (Note that effective *strategies* are different from effective *programs*: the former have to be interpreted and adapted to context, whereas the latter have to be faithfully applied regardless of context.)

# Effective intervention strategies

Effective strategies have two aspects: what is delivered and how it is delivered. For services to be fully effective, both aspects have to be involved: *how* programs are delivered is as important as *what* is delivered (Moore, 2005). This distinction between process and structural properties is used in discussions of quality in early childhood education and care services (Phillipsen et al., 1997; Podmore, 2004; Woodhead, 1998). The process or interpersonal aspects of service delivery are concerned with participation, relationships and interactions and the ways in which all children and families experience their every day participation in the contexts of family, community or early childhood services. The structural aspects of service delivery are those matters which are derived from or are to be found in organisational and systemic structures.

# Effective practices in early childhood services

In the general early childhood field, research evidence regarding effective services have been synthesised by Brooks-Gunn et al. (2003), Centre for Community Child Health (2007a), Groark et al. (2006) and Waldfogel (2006), among others. Key features of effective community-based services have been identified by the Centre for Community Child Health (2007a) – these include ten process or interpersonal properties and eleven structural properties. The ten *key interpersonal features* of effective early childhood and family support services are as follows:

- services are based upon the needs and priorities of families and communities
- services are individualised and responsive to particular family needs and circumstances
- services start where families are at developmentally
- services recognise that relationships are just as important for achieving success as program structure and curriculum
- services seek to empower families and communities
- services build on existing strengths of families and communities, strengthening their existing competencies

- services seek to build partnerships with parents and communities
- services are sensitive and responsive to family and community cultural, ethnic, and socio-economic diversity
- services see families in the context of the community and the wider society, and seek to strengthen community links and utilise community resources to meet their needs
- services provide high quality services

In early childhood services, the importance of process or interpersonal aspects of service delivery are highlighted in key curriculum documents such as New Zealand's early childhood curriculum document, *Te Whariki He Whaariki Matauranga: Early Childhood Curriculum* (1996) and the NSW early childhood curriculum framework, *The Practice of Relationships* (2002). The concept of relationships as 'pedagogy' (Malaguzzi, 1993; Rinaldi, 2006) shifts the notion of relationships in early childhood from a 'warm backdrop' surrounding the main events that occur in an early childhood program, to being central to all of its activities and experiences.

Process matters can be difficult to mandate, assess or evaluate as they may be taken for granted or unexamined practices which are highly dependent on the contexts where they are enacted. Finding ways to understand how children and families experience each day in a children's service has generally not been given sufficient attention as a research question in early childhood services. Process matters also depend on whose perspective on quality is being assessed – child, parent, practitioners or management ( Fleer & Kennedy, 2006, Dahlberg et al., 1999).

In the early childhood intervention field, there have been some studies of how children and families experiences services (eg. Moore & Larkin, 2006). There are also many questionnaires and tools that have been developed to measure different aspects of service delivery (Dempsey & Keen, 2008), including measures of family-centred practice (from both service deliverer and service recipient perspectives), help-giving practices, enablement and empowerment practices, and partnership practices. However, it is unclear how widely or regularly these process measures are used.

In addition to these key interpersonal features, there are a number of *key structural features* of effective early childhood services. Structural aspects of service delivery are generally more readily mandated, assessed or evaluated through systems such as regulations. For early childhood services, the core structural properties that have been identified include group size (number of children in a class), staff-child ratio, and caregiver qualifications (years of education, child-related training, and years of experience)(Buysse et al., 1998; Centre for Community Child Health, 2007a; Cleveland et al., 2006; Early Childhood Learning Knowledge Centre, 2006; Phillipsen et al., 1997; Podmore, 2004). Smaller group sizes and favourable staff-child ratios allow each child to

receive individual attention and foster strong relationships with caregivers (Early Childhood Learning Knowledge Centre, 2006; Graves, 2006; Melhuish, 2003; Work and Family Policy Roundtable, 2006).

Since the curriculum is only as good as the people who deliver it (Duffy, 2006), having well-trained staff and ongoing staff development and support is essential (Bennett, 2007; Best Start Expert Panel on Early Learning, 2006; Duffy, 2006; Early Childhood Learning Knowledge Centre, 2006; Elliott, 2006; Melhuish, 2003; OECD, 2001; Saracho & Spodek, 2007; Work and Family Policy Roundtable, 2006). Specialised training contributes to quality interactions and rich child-centred contexts (Elliott, 2006). Children make better progress when early childhood practitioners are professionally qualified and possess sound, sensitive pedagogic approaches and knowledge. In the case of early childhood teachers, the more highly qualified they are the more progress children make subsequently (Montie et al., 2006, 2007).

Another key structural feature is staff continuity (David, 2003), which is particularly important for very young children (Elliott, 2006). Young children need stability in their relationships with caregivers and teachers, so staff rosters should be arranged with this in mind, In addition, to reduce staff turnover, staff need fair working conditions and remuneration rates that are sufficiently generous to recruit and retain a qualified and committed workforce (Work and Family Policy Roundtable, 2006).

It should be noted that all of these structural features are necessary but not sufficient conditions for high quality services – they should be understood as means to an end (the end being the delivery of services according to the key principles above). As Pianta (2007) notes, it is the teacher's implementation of a curriculum, through both social and instructional interactions with children, that produces effects on student learning. Structural indicators, such as the curriculum being used, teacher credentials, and other program factors, are only proxies for the instructional and social interactions children have with teachers in classrooms. Thus, it is not teacher qualifications per se that affect outcomes but the ability of the staff member to create a better care and learning environment that makes the difference (Sammons et al., 2003).

As identified by the Centre for Community Child Health (2007a), other structural properties of effective services are that they

- adopt an ecological approach that addresses the multiple influences on child and family functioning
- are part of a comprehensive integrated service system that is able to address all the factors known to put children and families at risk
- have a clearly defined purpose and goals that are broadly agreed upon by all stakeholders
- are based on clear theoretical frameworks that show how the services that are delivered achieve the desired

- base services on proven methods of intervention
- focus on outcomes rather than services
- are structured and packaged so as to be transferable and translatable to other settings
- are staffed by people who are trained and supported to provide high quality, responsive services
- maintain positive organisational climates
- encourage shared learning and help staff to become reflective practitioners
- regularly evaluate and monitor their services to maintain quality and to guide improvement

# Effective practices in early childhood intervention services

All of the above process and structural properties of effective services apply to early childhood interventions services. In addition, there are a range of effective strategies and practices that have been developed.

Shonkoff and Phillips (2000) have argued that there has now accumulated 'sufficient knowledge to build an intellectually rigorous, common theory of change for the field' (p. 340). Similarly, Odom and Wolery (2003) argue that there now exists as a strong, evidence-based set of practices that service providers and caregivers use to promote the development and well-being of infants and young children with disabilities and their families. Features of effective early childhood intervention services have been identified by Moore (2005), and established and emerging trends in early childhood intervention services have been summarised by Moore (2008d). Law (2000) outlines a process whereby direct service providers can identify and introduce evidence-based practices, while McClusky and Cusick (2002) describe strategies that program managers can use to introduce evidence-based practices in work settings.

Many effective early childhood intervention strategies have been developed. Moore (2007) gives the following selection of strategies, divided between the *what* and the *how* of service delivery.

# Effective early childhood intervention strategies

	What is delivered	How it is delivered
CHILD	<ul> <li>Assessment of child functioning and identification of child needs</li> <li>Direct therapy and teaching</li> <li>Inclusion in mainstream early learning and development programs</li> <li>Natural learning opportunities</li> </ul>	<ul> <li>Responsive engagement and care practices</li> <li>Child-centred practice</li> </ul>

FAMILY	<ul> <li>Emotional support to parents</li> <li>Information about child's health and development</li> <li>Information about and access to relevant resources</li> <li>Access to parent-to-parent support</li> <li>Skills and empowerment</li> <li>Quality of life</li> </ul>	<ul> <li>Responsive engagement and partnership</li> <li>Family-centred practice</li> <li>Strength-building</li> </ul>
COMMUNITY	<ul> <li>Access to community facilities and services</li> <li>Child- and family-friendly urban environment</li> </ul>	<ul> <li>Community engagement and partnership</li> <li>Community strength-building</li> </ul>
SERVICE SYSTEM	<ul> <li>Integrated services and key worker models</li> <li>Tiered system of services based on universal system</li> </ul>	<ul> <li>Interagency collaborative practices</li> <li>Transdisciplinary teamwork</li> <li>Leadership style</li> <li>Consultation and coaching</li> </ul>

A number of specific evidence-based strategies that have been identified. Many of these apply to children with a range of disabilities, while some are specific to particular disabilities. A disability-specific analysis of evidence-based strategies is beyond the scope of this literature review, so only the following general strategies are listed below. These are all based on a caregiver-mediated approach to early childhood intervention (Dunst, 2007a; Dunst & Trivette, 2009).

### Interactions with children

Children's behaviour only changes through the direct experiences provided by their social and physical environments. In terms of the social experiences, the strategies that are known to be effective in promoting children's learning and development include the following:

• Response-contingent child learning (Dunst, 2007b). Response-contingent child learning refers to environmental arrangements by which a child's production of behaviour produces or elicits a reinforcing or interesting consequence that increases the rate, frequency, or strength of behavioural responding. Research shows that children with disabilities are capable of response-contingent learning and that these kinds of learning opportunities constitute a useful early intervention practices for these children. In almost every study of children with disabilities, rates of behaviour responding increased, sometimes three- or fourfold, once the children were reinforced for their efforts. There are, however, important differences in the way that children with disabilities learn. Whereas infants without disability typically demonstrate response-contingent learning in a few minutes, children with

disabilities may take considerably longer. The more profoundly delayed child is, the longer it takes the child to learn the relationship between his or her behaviour and its consequences.

- Participatory child learning opportunities (Dunst, 2011). While many factors influence child learning, active child involvement in participatory child learning opportunities is now known to be an important contributor to infant and toddler development. Findings from a research synthesis of the operant learning of young children with and without disabilities indicated that young children demonstrate a sense of mastery after 'coming to understand' that they produced the observed environmental consequences of their behaviour (Dunst, 2007b). There is evidence that many of the practices (services) used by US early intervention practitioners do not actively involve infants and toddlers in interactions with their social and non-social environment but rather primarily elicit behaviour from the children in response to adult demands or requests, or engage the children in passive actions or movements. There is evidence that the use of such non-contingent stimulation as an intervention practice is not effective if the goal is to promote children's competencies (Dunst, Raab et al., 2007). Strategies for promoting children's participation in activities in natural settings have been described by Campbell (2004).
- Interest-based child learning (Dunst et al., 2010; Raab, 2005; Dunst & Raab, 2006; Rix et al., 2008). One factor that functions as a developmentinstigating characteristic of learning opportunities is children's interests. These interests may be personal (the child's preferences and likes) or situational (those aspects of the social and non-social environment that attract child attention, curiosity, and engagement in interactions with people and objects). Research indicates that both kinds of interests have positive effects on child behaviour and development (Raab & Dunst, 2007). Experiences and opportunities that are interest-based are more likely to engage children in prolonged interactions with people and objects and provide contexts for practicing existing capabilities and learning new behaviour. Results of recent studies show that the children who participated in interest-based learning activities demonstrate more positive and less negative social--emotional behaviour and make more developmental progress compared to children whose learning opportunities were less interest-based. Available evidence suggests that many, if not most, Part C early intervention practices do not use or incorporate children's interests into intervention activities.
- Parent responsiveness to child behaviour (Dunst, 2007; Landry et al., 2006; McCollum & Hemmeter, 1996; Mahoney et al., 1998; Mahoney & MacDonald, 2007; Mahoney & Perales, 2003, 2005; Mahoney et al., 2006; Trivette, 2003; Warren & Brady, 2007). Parents' sensitivity and responsiveness to their infant or toddler's behaviour during parent-child interactions is a potent determinant of child development. Encouraging and supporting parents' use of responsive interactional styles with children with

disabilities has been an important early intervention practice for many years. Parent responsiveness includes parental response quality, timing, appropriateness, affect, and comforting.

There is evidence that the degree of parental sensitivity, responsiveness and emotional availability are predictive of outcomes in children with intellectual and developmental disabilities (Biringen et al., 2005; Koren-Karie et al., 2002; Venuti et al., 2008; Warren & Brady, 2007). The effectiveness of the parents behaviour is maximised when the parent is attuned to the child's signals and intent to communicate, when the parent promptly and appropriately responds to the child's behaviour, and when parent-child in interactions are synchronous and mutually reinforcing. In studies of children with disabilities, parents' responsiveness to the child's behaviour shows very much the same kind of relationship with the outcomes found in studies of children without disabilities (Dunst, 2007).

Kelly et al. (2008) have developed *Promoting First Relationship*, a relationship-focused approach that is designed to promote trust and security in infancy, and healthy development of self (mastery motivation and confidence) in toddlerhood. Initial results using this approach are promising. Other strategies and programs have been summarised by Moore (2009b).

• Everyday natural learning opportunities (Bruder & Dunst, 1999, 2006; Childress, 2004; Dunst & Bruder, 2002; Hanft & Pilkington, 2000; Noonan & McCormick, 2005). The traditional clinical approach (in which children were 'treated' by specialists in clinical settings) limits the opportunities the child has to practise the skills they need to develop and cannot guarantee that the child will transfer those skills to everyday settings. Accordingly, this form of service is being replaced by a natural learning environments approach in which specialists seek to identify and utilise natural learning opportunities that occur in the course of children's everyday home and community routines. These everyday activities invite or inhibit child learning, depending on the characteristics of the setting and the behaviour of the people in the settings. Everyday activities are natural learning environments in which contextually meaningful and functional behaviour is learned, further increasing children's participation in family and community life.

Infants and toddlers with disabilities on average tend to participate in somewhat fewer everyday activities compared with their typically developing peers. These differences are due less to their disabilities and more to their parents' beliefs about the value of everyday learning opportunities. Research shows that learning opportunities that either provided a context for interest expression or had interest-evoking features were associated with increased positive and increased negative child functioning. Moreover, the benefits were greatest in situations in which interest-based learning occurred in the context of everyday activities, in which the pattern of relationships between the

characteristics of the activities and benefits to the child with very much the same for children with and without disabilities (Dunst, 2007).

Dunst and colleagues (Dunst, 2006; Dunst & Swanson, 2006; Dunst et al., 2010) describe an approach to early childhood intervention called *Contextually Mediated Practices*. This is a promotional approach to early childhood intervention that uses everyday activities as sources of child learning opportunities and child interests as the basis for promoting child participation in those activities. This is accomplished by parents both providing their children different kinds of interest-based everyday learning opportunities and using responsive, supportive, and encouraging interactional behaviours that strengthen both child and parent competence and confidence as part of child involvement in everyday activities. Another activity-based approach has been developed by Humphry and Wakeford (2008).

Use of natural learning environments (Bruder & Dunst, 1999; Childress, 2004; Dunst & Bruder, 2002; Hanft & Pilkington, 2000; Noonan & McCormick, 2005). The traditional clinical approach (in which children were 'treated' by specialists in clinical settings) limits the opportunities the child has to practice the skills they need to develop and cannot guarantee that the child will transfer those skills to everyday settings. Thus, Hanft and Pilkington (2000) argue that:

No infant or toddler needs physical, occupational, or speech therapy twice per week in order to grow and develop. What young children need is exposure to communication, mobility, play, gradual independence in activities of daily living, and nurturing interaction with family members, everyday, in their usual places and situations. Therapists, using their therapeutic expertise as the means to this end, can help young children and family members achieve their desired outcomes. (pp. 11-12)

Accordingly, the traditional clinical form of service is being replaced by an natural learning environments approach that seeks to ensure that children have multiple opportunities to practice the functional skills they need in their everyday home and community environments.

### **Interactions with parents**

As we have seen, a central aim of early childhood intervention services is to promote the ability of families to provide their children with experiences and environments that will promote the children's learning and development. The strategies that are known to be effective in doing this are listed below. As Dunst and Trivette (2009) note, the *manner* in which support is provided, offered, or procured influences whether the support has positive, neutral or negative consequences. Providing social support to parents in response to an indicated need for help is associated with positive consequences, whereas providing social

support in the absence of an indicated need for help has negative consequences (Affleck et al., 1989).

- Relationships between parents and professionals. The relationship between parents and professionals is the key to effective practice (Berlin et al., 1998; Davis et al., 2002). On the basis of a detailed analysis of what makes early childhood interventions work, Berlin et al. (1998) conclude that
  - ... the most critical dimension of early interventions is the relationship between the program and the participants. The benefits of program services will not be fully realised unless the participant is genuinely engaged (p. 12)

Research into the efficacy of early childhood intervention has rarely included the nature of the relationship between parents and professionals as a contributing variable. However, there strong theoretical grounds and much indirect evidence to suggest that the *manner* in which services are delivered is as important as *what* is delivered. How services are delivered is a function of the kind of relationship that services build with parents, and the qualities of the service provider. Davis et al. (2002) suggest that the key qualities are respect, genuineness, humility, empathy, personal integrity, and quiet enthusiasm.

• Family-centred practice (Blue-Banning et a., 2004; Dunst, 1997; Moore, 1996; Moore & Larkin, 2006; Rosenbaum et al., 1998; Trivette & Dunst, 2007; Turnbull et al., 2000). As in many other forms of human service, early intervention has seen a shift away from a service delivery model in which the professionals controlled the process of diagnosis and treatment to one which seeks to base service on needs and priorities identified by parents, building upon existing family competencies and mobilising local resources. This family-centred approach is based on a partnership between parents and professionals with the parents making the final decision about priorities and intervention strategies, and represents a profound shift in the manner in which early intervention services are delivered.

Based on a synthesis of the best statements of family-centred principles and practice (Moore & Larkin, 2006), the core principles, practices and skills are as follows:

### **Principles**

 Services recognise that all families are unique, and provide support in ways that are respectful and non-judgmental of particular family styles, values and abilities.

- Services are sensitive and responsive to family cultural, ethnic, and socioeconomic diversity.
- Services recognise that parents know their children best and want the best for them.
- Services accept that parents have the ultimate responsibility for the care
  of their children and for all decisions about the child.
- Services understand that children's needs are best met when families are supported in making informed decisions about the child and family, and in developing competencies to meet their needs.
- Services recognise that children, families and service providers themselves all benefit most when services are based on true collaborative partnerships between families and professionals.
- The way in which services are delivered is as important as what is delivered.
- Children's needs are most likely to be met when the needs of all family members and of the family as a whole are also met.

### **Practices**

- Families and family members are treated with dignity and respect at all times.
- Services are based on the needs and priorities of families.
- Service providers seek to engage parents in collaborative partnerships based on mutual trust and respect.
- Service providers acknowledge and respect the family's expert knowledge
  of the child and the family circumstances as complementing their own
  professional expertise.
- Service providers take account of the needs of all individual family members as well as the needs of the family as a whole.
- The information that families need to make informed choices is shared in a complete and unbiased manner.
- Service providers offer families choices about the goals and nature of the services, and support and respect the choices that families make.
- Services are provided in a flexible fashion according to the evolving needs and circumstances of particular families.
- Family needs are met through a broad range of informal, community, and formal supports and resources, rather than through formal resources alone.

- Where possible, families are helped to find ways of meeting their own needs using the existing strengths and competencies of the family and family members.
- Families are helped to develop new strengths and competencies to meet the needs of their children and the family as a whole.
- Families are helped to identify and mobilise sources of support in their family and social networks and local communities.
- Service providers help families establish and maintain strong social support networks according to need.
- Services form strong links with other mainstream and specialist child and family services to ensure that all family needs are addressed in an integrated fashion.

### **Skills**

- Service providers need well-developed listening and communication skills
- Service providers need skills to establish and maintain good collaborative relationships with families.
- Service providers need skills in helping parents determine their priorities and clarify their goals.
- Service providers need skills in recognising, acknowledging and helping families build upon their strengths and competencies.
- Service providers need skills in identifying and mobilising social support networks and community resources.
- Service providers need skills in establishing and maintaining good collaborative relationships with other mainstream and specialist child and family services.

The evidence for the effectiveness of family-centred practice has been summarised by Dempsey & Keen (2008), Dunst et al. (2007, 2008), Moore & Larkin (2006), Trivette & Dunst (2007), Trivette et al. (2010), and Rosenbaum et al. (1998).

Capacity-building help-giving practices (Dunst, 2007a; Dunst & Trivette, 2009). Practitioner help-giving practices can potentially influence parents competence in performing parenting tasks, their confidence in carrying out parenting responsibilities, and their enjoyment in interacting with their children. Studies of the characteristics of effective help-giving practices has identified two clusters of help-giving that have capacity-building influences: relational help-giving and participatory help-giving (Trivette & Dunst, 2007). Relational help-giving includes practices typically associated with good

clinical practice (e.g., active listening, compassion, empathy, respect) and help-giver positive beliefs about family member strengths and capabilities. Participatory help-giving includes practices that are individualised, flexible, and responsive to family concerns and priorities, and which involve informed family choices and involvement in achieving desired goals and outcomes.

Participatory help giving involves practices that promote parent decision-making and action based on choices necessary to obtain desired resources or goals. Parent-practitioner collaboration involves practices in which partners work together to plan courses of action and to decide what will be the foci of intervention. In terms of promoting parenting competence, confidence or enjoyment, the evidence shows that collaboration has no discernible direct or indirect effects, relational help giving has small direct effects and somewhat larger indirect effects, and participatory help giving has both large direct and indirect effects. These findings were much the same for parents of children with or without disabilities (Dunst, 2007a).

How do family-centred practice and capacity-building practices achieve their effects? Meta-analyses of multiple studies have shown that family-centred helpgiving has the strongest effect on the most proximal variables, namely parental satisfaction with service received, parental self-efficacy beliefs, and, to a lesser extent, how helpful the parents judged the supports and resources provided by the helpgiver and their programs (Dunst et al., 2007, 2008). Outcomes measures that are more distal to family-centred helpgiving (parental ratings of child behaviour and functioning, personal/ family well-being, and parenting behaviour) were also affected by family-centred helpgiving, but not nearly as strongly. The results nonetheless indicate that the ways in which helpgivers interact and treat families influences to some degree judgments of their own behaviour, that of their family, and their children's behaviour. Relational helping practices are more closely linked to satisfaction measures, whereas participatory helping practices are more closely related to self-efficacy beliefs and parental perceptions of child behaviour and their own parenting.

Thus, family-centred practices produce direct beneficial effects for families but indirect beneficial effects for child development. This is because family-centred practices have empowerment type effects (e.g., strengthened efficacy beliefs), and parents who feel empowered about their parenting capabilities are more likely to provide their children development-enhancing learning opportunities. However, as Dunst et al. (2007) note,

There is no reason to believe or expect that family-centred practices would be directly related to child development outcomes. Child focused or parent/child-focused interventions are what is done and family-centred practices are how the interventions are implemented. The latter is expected to influence the ways in which the former is carried out.

The most recent analyses by Dunst and colleagues (Trivette et al., 2010) show how this process works. Family-centred help-giving practices have a direct impact on parental self-efficacy beliefs, which in turn influence parent well-being. The combination of more positive self-efficacy beliefs and well-being leads to improved parent--child interactions which then shape the child's development. In other words, the impact on child development is indirect – positive help-giving had direct impacts on parental self-efficacy beliefs and well-being, which in turn led to direct impacts on child behaviour and functioning.

Family-centred practices are only one of a number of factors that would be expected to contribute to improved child, parent, and family behaviour and functioning. In particular, there is a third element of effective help-giving – technical competence – that is essential for help-giving to be fully effective in promoting change in children's development and functioning.

- Technical competence (Trivette & Dunst, 2007). This is a key component of an expanded model of help-giving proposed by Trivette and Dunst (2007). This has three components, each with two elements:
  - Technical quality includes the knowledge, skills, and competence one possesses as a professional and the expression of this expertise as part of practicing one's craft
  - Relational helpgiving includes both help giver interpersonal skills with help receivers, and help giver attitudes about help receivers' capability to become more competent
  - Participatory helpgiving includes both help receiver choice and action and help giver responsiveness and flexibility

What is the relationship between technical competence and the other two characteristics? A thorough review of the evidence regarding interventions relevant to the prevention of mental health problems of infants and toddlers (Barnes, 2003; Barnes & Freude-Lagevardi, 2003) throws some light on this question. This review concludes that, to be optimally effective, programs must address simultaneously

- the *representational level*, i.e. the psychological needs of the parents (especially their sense of mastery and competence)
- the *behavioural level*, i.e. child behaviours as well as parental behaviours that influence maternal, foetal and infant development
- the *situational stresses and social supports* that can either interfere with or promote their adaptation to pregnancy, birth, and early care of the child

Barnes (2003) and Barnes & Freude-Lagevardi (2003) conclude that there appears to be a number of necessary, but not sufficient, factors associated with enhanced early intervention outcomes. They can be divided into primary

(threshold) factors that function in an all-or-nothing manner and secondary factors (fine-tuning)(see model in Barnes & Freude-Lagevardi, 2003).

### Primary factors:

- Shared decision-making between parent and therapist/intervenor
- Quality of relationship between the parent and the intervenor
- Non-stigmatising presentation of intervention
- Cultural awareness/sensitivity
- Flexible settings/hours
- · Crisis help prior to other intervention aims

## Secondary factors:

- Choice of theoretical model
- Choice of timing of intervention
- Choice of location to offer intervention—home, clinic, community location
- Choice of intervenor—professional, paraprofessional

For example, if a reasonably satisfying therapeutic relationship cannot be established between intervenor and client, then the duration or intensity of an intervention program may be of little consequence. The same applies if the intervention model fails to match the parent's needs; if the parent is not involved in the decision-making or disagrees with any prescribed program goals or outcomes.

If the intervention is experienced as stigmatising or labeling, or if the family's cultural background is ignored, then participation is unlikely to be maintained. If the parent is so overwhelmed by urgent and basic needs such as housing or food that this crisis prevents any focus/engagement with the content of the intervention then their capacity for engagement will be limited, even if they are assisted by strategies such as transport. It appears that these primary factors are predominantly factors of participant perceptions and beliefs about the importance or potential benefits of the intervention and if these are not addressed then it will be difficult to achieve change in behaviour.

A telling illustration of the importance of combining technical, relational and participatory skills comes from a study by Hebbeler and Gerlach-Downie (2002). This took the form of an in-depth analysis of a program that provided monthly home visits to mothers over the first 3 years of the child's life. The study looked at the content of the home visits and the nature of the interaction between the home visitor and the mother in order to understand precisely how the program improved developmental outcomes for children or, alternatively, to explain why it did not. In fact, the program was not very effective: there were small and inconsistent effects of participation in the home visiting program on parent knowledge, attitude and behaviour but no overall gains in child development or health. This is despite the fact that the parents were overwhelmingly positive

about the program and spoke highly of their relationships with the home visitors. Analyses of the home visitors' theories of change (ie. how they understood the program produced results) showed that they saw their prime responsibility as being the provision of social support, and, although they recognised the importance of parent-child relationships, they did little to model or teach the parents better ways of interacting with the children. Even when they did so, the parents did not recognise what they were doing and thought the home visitor was trying to teach the child something. Many parents did not see the importance of duplicating the types of home visitor-child interactions and activities they observed.

The key lesson from this study is that, if the goal is to improve outcomes for children, it is not sufficient to provide good relational support to the parents – one must also give the parents actual skills and strategies that will have a direct effect on their children's functioning and participation. And to do this, professionals need both technical skills and participatory skills in addition to relational skills.

## Interactions with other professionals

The reconceptualisation of early childhood intervention described in this paper emphasises the importance of children's everyday learning environments and of working with and through those who provide those environments. In the previous section, we examined what is involved in working with families in home environments. This section looks at what is involved in working with other professionals who are key providers of early learning environments for children, particularly staff in early childhood programs.

The key skills required for this work are those of building relationships and partnerships with other professionals, sharing specialist knowledge and skills with those professionals, and working in transdisciplinary teams.

- Building positive relationships and partnerships with other specialist and mainstream agencies (Brunelli & Schneider, 2004; Pilkington & Malinowski, 2002). Partnerships with other specialist services are necessary to ensure that families receive all the supports they need in an integrated fashion. Partnerships with mainstream services are needed to ensure that they are able to meet the needs of children with developmental disabilities in an inclusive fashion. According to Brunelli and Schneider (2004), 'Research, clinical experience, and common sense strongly suggest that relationship-based team building benefits early intervention professionals and families in many ways' (p. 49).
- Sharing knowledge and skills with other professionals. The role of ECI and allied staff is to ensure that the relational and learning environments provided by other professionals (especially in settings such as early childhood programs) promote children's participation and development. This is

essentially a process of knowledge transfer (Jacobson et al., 2005). To share their expertise with other professionals effectively, ECI and allied staff need well-developed consultation (Buysse & Wesley, 2004) and coaching skills (Hanft et al., 2004).

The difficulties of this task should not be underestimated. Johnston and Brinamen (2005) describe the challenges facing consultants to child care settings:

When one enters a child care program, one crosses the threshold into an established community environment of child care providers, parents, and children. The consultant is an outsider who hopes to effect changes, but the potential for change is dependent upon the wishes, challenges, and abilities of all the participants. This is a mutually constructed endeavor that requires the consultant's flexibility and understanding as she joins with the providers. Accepting that the practices of child care serve not only the children but also the adults can be challenging, especially when a consultant is faced with substandard care or practices that conflict with her own ideals of developmentally appropriate care for children. However, change in a system occurs only when we understand the underlying causes and meaning of behaviour of all involved. This consultative stance, this way of thinking and being, can be difficult to embrace and sustain when working with many caregivers, many parents, and many children with varying needs and points of view.

Buysse and Wesley (2004) present a framework for consultation by early childhood interventionists in mainstream early childhood settings. In this model of consultation, the process is viewed as three interrelated tasks - problem solving, social influence, and professional support - that are accomplished within a collegial consultative relationship. They outline an 8-stage model that shows practitioners how to help educators, parents, and early childhood professionals work together to address concerns and identify goals. Core consultancy skills have been identified by Buysse and Welsey (2004) and Johnston and Brinamen (2005).

Hanft et al. (2004) describe a coaching model for use by ECI and allied professionals in supporting those who work directly with young children in natural settings. They show professionals how to help colleagues acquire new knowledge and skills, and how to support families and other caregivers in taking an active role in promoting a child's development and participation in home and community activities. They outline a five-step model — initiation, observation, action, reflection, and evaluation.

Perry and Kaufmann (2009) describe how to integrate early childhood mental health consultation services in early care and education settings. They define mental health consultation as

... a systematic approach to building the capacity of an early childhood professional to promote young children's social-emotional and behavioural development. In early childhood mental health consultation, a mental health professional partners with an early childhood educator and models strategies that promote healthy social-emotional development, prevent the development of problematic behaviours and reduce the occurrence of challenging behaviours.

According to Perry and Kaufmann, there is an emerging evidence base that demonstrates the range of outcomes that can result from the provision of early childhood mental health consultation. The provision of such services has been linked to decreased expulsion rates, reductions in child challenging behaviour, improvements in child social behaviour, increases in teachers' sense of efficacy, decreases in teaching stress, reductions in staff turnover, and increases in the overall quality of the program.

• Transdisciplinary teamwork (Briggs, 1997; Drennan et al., 2005; Pilkington & Malinowski, 2002; Woodruff & Shelton, 2006). Working in a transdisciplinary way is both a necessary economy required of us by social and economic changes, and a desirable streamlining of support to families. Learning to work in a transdisciplinary way is a developmental accomplishment for early childhood interventionists that takes support, training and time. Ways of promoting transdisciplianry teamwork have been described by Blasco (2001), Briggs (1997), Drennan et al. (2005) and Martin (2004).

It should be evident that this list of key functions and skills for working with other professionals parallels those needed for working with parents. The elements of effective help-giving discussed in the previous section – technical competence, relational practices and participatory practices – are just as relevant for working with other professionals. Relationship and partnerships are the medium through which knowledge and skills can be transferred and collaborative solutions developed.

From a training perspective, it is worth noting that ECI professionals are not as well trained in the consultancy role as allied professionals such as PSFOs and ISFs.

## **Effective intervention programs**

The bulk of the preceding section has focused on what is known about effective intervention *strategies* as distinct from effective intervention *programs*. There is no scope in this paper to review all the evidence for specific programs, but many such reviews exist. Recent systematic reviews of effective programs for specific disabilities include Mesibov & Shea (2010), National Autism Centre (2009).

Odom et al. (2010), Spreckley & Boyd (2009), Wallace & Rogers (2010) and Ziviani et al. (2010).

Such systematic reviews are not without their problems. One is that the kind of interventions that characterise much ECI work do not lend themselves easily to randomised control studies, the accepted 'gold standard' for establishing the efficacy of an intervention. As a result, there are few ECIS studies that meet this standard. This was the problem that emerged in two recent attempts to identify effective ECI using systematic review principles (Lee & Miller, 2009; McConachie & Diggle, 2007). Both reviews found too few studies that met the highest standards and therefore could not come to any useful conclusions. (This is not to say that ECI services are not effective, only that there is no evidence of the conventional kind to prove that they are.)

# 4.5 Workforce competencies and skills

As noted earlier, one of the key features of effective early childhood intervention services is that they are staffed by people who are trained and supported to provide high quality, responsive services. Those who work in early childhood intervention services come from a variety of disciplines, and have all been trained in their discipline-specific knowledge and skills. The extent to which their initial training equips them to work with young children with developmental disabilities and their families varies, although it is clear that no specialist discipline trains practitioners in all the skills they need to work effectively in early childhood intervention services.

So, what knowledge and skills do early childhood interventionists need to deliver effective services? A UK study by Greco et al. (2007) tells us something about the views of parents on this subject. On the basis of interviews with parents of disabled children who are users of key worker schemes in England and Wales, they identified the following characteristics of a good key worker:

## Knowledge

- Knowledgeable, informed and knows where to find the information necessary about local services
- Knows what it is like to have a child with a disability

### Skills

- Organised
- Able to chair a meeting and speak on parents' behalf at meetings
- Able to liaise between different services, agencies
- Able to communicate information at different levels to families and to professionals
- Is good with the disabled child

### **Professional characteristics**

- Includes the whole family
- Available at the other end of a phone
- Treats all that is said as confidential
- Is respected by other professionals
- Contacts the family regularly
- Is persistent
- Treats the family like experts on their child

### **Personal characteristics**

- Friendly, approachable
- · Compassionate, caring, enthusiastic
- Has tact, diplomacy
- Listens and is not judgmental
- Is respectful of the family

In a review of the training needs of those who work with young children and their families, the Centre for Community Child Health (2003b) identified a core set of knowledge and skills that all such workers need. In a subsequent review of the training needs of early childhood intervention practitioners, the Centre for Community Child Health (2007b) identified the following core knowledge and skills needed by those working with young children with developmental disabilities and their families:

### Core knowledge and skills in early childhood intervention

Key elements of effective relationship-building	Specific knowledge and skill areas
Technical knowledge and skills	Knowledge of early childhood development
	<ul> <li>Skills in identifying and assessing young children with developmental disabilities</li> </ul>
	<ul> <li>Skills in working with young children with developmental disabilities</li> </ul>
	Cultural competency skills
	Inclusion support skills
	Skills in using natural learning opportunities
	Skills in outcomes-based service delivery and evaluation
Attitudes and help- giving skills and practices	<ul><li>Helping / counselling skills</li><li>Consultancy and coaching skills</li></ul>

	Teamwork and collaboration skills
Empowerment skills and practices	Family-centred practice skills

All early childhood intervention practitioners will have some of these skills by virtue of their original specialist training, but few will have all the skills. At present, there is no systemic induction or on-going training program to ensure that early childhood intervention practitioners gain all the skills they need to be fully effective.

For instance, training in the key interpersonal skills needed - relationship skills, family-centred practice, and strength-based capacity-building skills – is available through courses run by peak bodies and training institutions, but only a minority of early childhood intervention practitioners have been trained in these skills. However, we know that to implement a complex relationship-based approach such as family-centred approach requires training in the ethics and practices of this approach and value a commitment to its philosophy (Bruder, 2000; Grace et al., 2008; Mohay & Reid, 2006; Moore, 2001). The principles and the concept of family-centred practice, like most theoretical frameworks in early childhood, can be seen as problematic (Baird & Peterson, 1997; Dunst et al., 2007; Mahoney & Wheeden, 1997; Woodhead, 2005), and it can take many years of experience and support to know how to resolve the challenges that arise.

Inevitably, there tends to be a gap between the rhetoric of family-centred practice and the reality of service delivery (Bruder, 2000; Moore & Larkin, 2006). For example, parents particularly value respectful and supportive care from practitioners, and being treated as equals, but the evidence suggests that, although practitioners generally do provide services that are respectful and supportive, they are less consistent in treating parents as equals and involving them in all decisions (Moore & Larkin, 2006). Parents also want practitioners to use empowerment approaches that build on family strengths. In practice, the evidence suggests that practitioners tend to see themselves as the major agents of change, rather than as supporters whose primary responsibilities include helping parents develop the skills to become the major change agents (Moore & Larkin, 2006).

Another analysis of ECI practitioner competencies comes from a recent Department of Education and Early Childhood Development (DEECD) and Early Childhood Intervention Association Victorian Chapter (ECIA - VC) project. DEECD funded ECIA (VC) to develop a statement of competencies for ECI practitioners that would underpin high quality service provision for young children with a disability or developmental delay and their families and link with professional development opportunities for the ECI workforce.

The resulting report (Hollo, 2009) identified six core competencies. Capable ECI practitioners should be able to

- engage others
- develop their own capabilities
- deliver services

### in order to:

- develop the abilities of children
- strengthen participation of families
- optimise community inclusion.

There are three levels to these competencies presented here. Each of six competencies contains a number of elements, which are defined by a handful of observable behaviours as follows.

Competency	Competency Elements
1.Develop abilities of children with disabilities	1.1 Apply knowledge of typical childhood development to recognise characteristic developmental achievements.
	1.2 Apply knowledge of atypical childhood development and awareness of its many causes.
	1.3 Apply knowledge of environmental influences on a child and recommend appropriate interventions.
	1.4 Foster relationships with the child to support their learning, development and skills.
2. Strengthen family participation in a child's development	2.1 Recognise features of family systems.
	2.2 Enable families to develop their strengths.
	2.3 Work in partnership with families to ensure their needs are addressed.
	2.4 Create conditions which enable a family to advocate for their child to the degree they choose
3. Optimise community inclusion for children with disabilities	3.1 Promote inclusive environments
	3.2 Within a child's community, encourage the capacity of individuals who can support inclusion.
4. Deliver service	4.1 Assess a child's ability to participate confidently at home and in a local community
	4.2 Design service based on objectives agreed by carers / family

	4.3 Deliver and evaluate specific interventions
	4.4 Work effectively within own service
	4.5 Collaborate with other practitioners
	4.6 Empower and enable others while managing realistic expectations
	4.7 Frame and solve problems collaboratively
	4.8 Articulate how one's consultancy facilitates improved outcomes for a child, family and community.
5. Engage others	5.1 Engage others
6. Develop own capabilities	6.1 Actively seek feedback
	6.2 Reflect on own and team-members' practice
	6.3 Develop professional skills
	6.4 Apply learning to achieve better outcomes

A recent analysis of the nature and significance of relationships in the lives of children with developmental disabilities (Moore, 2009b) has thrown further light on the fifth of these competencies. The evidence indicates 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. 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. To achieve this, early childhood interventionists need well-developed skills in engaging and building partnerships with parents, as well as knowledge of the strategies and programs to help families build positive relationships with their children and promote their children's development. In addition, interventionists also need skills to engage and respond to these children, and how to build on these to promote children's learning and development.

### Training practitioners in workforce competencies

The development of effective ways of training ECI practitioners has been a focus of attention for many years (eg. Bricker & Widerstrom, 1996; Winton et al., 1997). Despite this, Buysse et al. (2008) maintain that there is little scientific research to indicate exactly what approaches to professional development are most likely to enhance practices, or even an agreed definition of the term professional development. The US National Professional Development Centre on Inclusion (2008) offers the following definition of professional development for the early childhood sector:

Professional development is facilitated teaching and learning experiences that are transactional and designed to support the acquisition of professional knowledge, skills, and dispositions as well as the application of this knowledge in practice. The key components of professional development include: (a) the characteristics and contexts of the learners (i.e., the "who" of professional development, including the characteristics and contexts of the learners and the children and families they serve); (b) content (i.e., the "what" of professional development; what professionals should know and be able to do; generally defined by professional competencies, standards, and credentials); and (c) the organisation and facilitation of learning experiences (i.e., the "how" of professional development; the approaches, models, or methods used to support self-directed, experientially-oriented learning that is highly relevant to practice).

The quality of the early childhood workforce is a critical factor and may be of overriding importance in determining whether early education and intervention is of high or poor quality (Buysse & Hollingsworth, 2009; Buysse et al., 2009). Along with a safe and well-equipped early learning environment, it is the characteristics and behaviours of the practitioners themselves that likely contribute most to the quality of the program and its effectiveness for young children and their families. Professional development to help practitioners acquire knowledge or improve teaching and intervention practices should reflect this vital connection between the quality of the program and the quality of the early childhood workforce.

Recognising the gap between evidence and current practice, several leaders in the field have considered ways in which this gap can be reduced (eg. Buysse et al., 2008, 2009; Dunst & Trivette, 2009b; Odom, 2009). Drawing on a classification used by *Wired* magazine to describe current trends, Odom (2009) classifies strategies for promoting the adoption of evidence-based practices according to whether they are 'expired' (no longer at the forefront of the most active thinking about the issue), 'tired' (still active and important but are not the visionary next steps) or 'wired' (most contemporary and advanced thinking):

- Expired practices: Practices based only on professional opinion or on narrative reviews of the literature
- Tired practices: Meta-analyses, the What Works Clearinghouse, quantitative reviews of studies
- Wired practices: Practice-based review of evidence, implementation science, enlightened professional development and aggregation of results

An evidence-based approach to professional development has been developed by Dunst and Trivette (2009b). Based on the findings from a series of research syntheses and meta-analyses of adult learning methods and strategies, this approach, called PALS (Participatory Adult Learning Strategy), places major emphasis on both active learner involvement in all aspects of training opportunities and instructor/trainer-guided learner experiences. Most professional in-service training falls along a continuum from one-time didactic workshops to informal discovery or experiential learning. The PALS approach occupies a middle ground where trainers structure learning opportunities for learners in which learners are actively involved and take responsibility for learning and mastering targeted knowledge and practice. The use of PALS practices has been found to be associated with improved learner knowledge, use, and mastery of different types of intervention practices.

In addition to direct training, practitioners need ongoing professional support to consolidate and further develop their skills and values. Strategies for doing this include apprenticeship and mentoring models (Applequist et al., 2010; Gallacher, 1997; Gilkerson, 2004) and building communities of practice (Turnbull et al., 2009).

# 4.6 Summary

The field of early childhood intervention continues to evolve, reflecting developments within its own practices as well as related developments in other fields. One of the most important aspects of this evolution concerns the shift in how we conceptualise the fundamental aims of ECI services. Reviewing the rationale for ECI in the light of developmental research findings leads us to conclude that the aim of ECI 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 a major setting for early childhood intervention, not just as a desirable addition, and the task of ECI services is the same as in the home: to work with and through the early childhood staff to ensure that the early childhood environment provides them 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.

This section has also explored a number of other key aspects of ECI practice. The importance of adopting an outcomes-based approach has been highlighted – focusing on the outcomes to be achieved and the strategies known to achieve these, rather than on the services. Various outcome statements for children with disabilities as well as children in general have been reviewed. This outcomes-based focus was used in reviewing some of the major ECIS models that have been developed. Evolving ideas about evidence-based practice and practice-

based evidence has been explored, and a range of effective interventions and practices identified. Key skills for working with children and parents – including the core features of effective help-giving (technical skills, relational skills and participatory and strength-building skills) – were summarised. Finally, ways of training practitioners in these skills were considered.

In the next section, we turn our attention to the ECIS system itself and explore a number of challenges that it faces. A series of ideas are canvassed as possibilities for transforming early intervention services in Victoria through focusing on the common aspirations and needs of all children and families while maintaining a commitment to meet the additional needs of children with a disability or developmental delay and their families.

# 5. EARLY CHILDHOOD INTERVENTION SERVICE SYSTEMS

# 5.1 Current early childhood intervention service systems

The existing ECI services and service systems in Australia have both strengths and weaknesses. Some of the weaknesses reflect the haphazard way in which the services were developed, and the way that ideas and practices have changed faster than the service system. From a historical perspective, differentiating ECI as a separate set of services was important in establishing the identity of the sector and in gaining independent funding. However, there has been a growing realisation that such a system can make it harder to achieve the outcomes we now consider to be desirable (Johnston, 2006, Moore, 2008b).

One of the main problems is that early childhood intervention services can be difficult to get into and equally difficult to get out of. Getting into the early childhood intervention system can be problematic because of the eligibility requirements – some children have to wait until they get 'worse' relative to normally developing children before they meet the specified eligibility criteria, while for others there can be a protracted period in limbo while they search for a diagnosis that will make them eligible. Once in the system, it can be difficult to be accepted back into the mainstream service system: there is still a residual assumption among mainstream service providers that only specialists can meet the needs of children with developmental disabilities, and this assumption acts as a barrier to services becoming truly inclusive. (Moore, 2008b)

Another problem is that the current early childhood intervention system lacks many of the key features one would expect to find in fully mature service system (such as the school sector). As identified by Moore (2008c), the missing features include:

- A service framework / model that describes what children and families receive and what principles, practices and procedures are followed
- A professional development framework that covers pre-service skills, knowledge and values, induction procedures for new staff, and a in-service professional development program (incorporating supervision and mentoring)
- A career structure with sufficient depth to attract and retain capable staff
- Remuneration levels and staff working conditions to match other comparable service sectors

- A quality assurance system to monitor service delivery
- An outcomes-based funding framework
- An appropriate unit cost funding level to cover the provision of all of the above
- Sufficient overall funding to eliminate waiting lists and enable all identified children to have prompt access to early childhood intervention services.

Despite the weaknesses identified above, it should be acknowledged that the current early childhood intervention system has many strengths (Johnson, 2006; Moore, 2008c). These include:

- Its services are highly valued by parents
- It has a well-developed philosophy and practice model for working with parents (family-centred practice)
- It has some well-developed procedures (such as Family Service and Support Plans) for applying this philosophy
- There is a strong rationale for the provision of specialist support for children with developmental disabilities and their families early in life
- It has a body of experienced and well-trained practitioners
- It has collaborative skills and knowledge of transdisciplinary approaches to working with families and other professionals
- It has an sound understanding of child development and what constitutes atypical development
- It has a commitment to evidence-based practice and practice-based evidence
- It has begun work on an outcomes-based framework for service planning and delivery

In seeking to reform ECI services in Victoria, it is critical that these qualities and characteristics are not jeopardised in any way but are seen as strengths that the system needs to preserve and build on.

# 5.2 Challenges for early childhood intervention service systems

In this section, a number of challenges facing early childhood service systems will be discussed.

# Early identification

There is considerable evidence of the importance of early identification and prompt involvement in early intervention services. As a result, much effort has

been devoted to improving early identification, eg. in detecting hearing loss (universal neonatal hearing screening)(McPhillips, 2010; Wolff et al., 2010) and autism spectrum disorders (Boyd et al., 2010).

Despite these efforts, many challenges remain (Rydz et al., 2005), and there is evidence that many children are not being identified early. For instance, Goelman (2008) cites Canadian survey data (Cosette, 2002) that shows that 14.6% of persons 15 and older had a disability compared with 4.0% of children aged 5 to 14 years and 1.6% of those from birth to 4 years. This 1.6% in the youngest age group falls far short of the 5% to 10% thought to be a more accurate representation of the prevalence of disability in early childhood. This major underrepresentation is largely due to the definitions and categories of disability used in the survey, inadequate screening programs, and the difficulty in accurately identifying infants, toddlers, and preschoolers with developmental delays and/or developmental disabilities (Goelman et al., 2005). As a result, there are large numbers of young, unidentified at-risk children who are missing out on the opportunity to benefit from early intervention programs that can positively impact their developmental trajectories.

Even when these efforts to detect developmental problems early are successful, they create problems for services, both in terms of increasing numbers of children needing support, and in terms of knowing how to intervene effectively with younger children. For instance, as Wallace and Rogers (2010) point out, the age of early recognition of autism spectrum disorders is fast approaching 12 months and research groups are working hard to identify risk signs even earlier, for the express purpose of enabling treatment to begin as soon as possible in order to reduce or reverse signs and symptoms of autism. However, while there is considerable progress being made in early detection of autism spectrum disorders, there is currently a scarcity of empirically validated treatments for infants and toddlers under age 3 years with ASD, and a scarcity of treatment studies for those under 18 months. Proven intervention strategies that have been developed for preschoolers do not fit the lifestyle or learning patterns of infants and toddlers in the first and second years of life (Rogers & Vismara, 2008).

Goelman (2008) describes a study that explored the use of three complementary community-based approaches to the early identification of young children at risk for developmental delays / disorders – longitudinal follow-up of infants admitted to neonatal intensive care units, targeted screening for children with neuromotor delays, and universal screening early identification programs. These three approaches represent points along a continuum and can all be used as part of a comprehensive integrated framework for the surveillance, screening, and early identification of young children. Goelman describes such a framework, involving early, regular, and universal screening assessments of young children's abilities. Parents have a critical role to play in identifying and articulating their concerns about their children's development in different domains and at different stages of

development. The aim of the program is to facilitate the early identification of developmental concerns followed up by more detailed diagnostic assessments. For such a system of developmental surveillance to be effective, there needs to be a process for monitoring and facilitating the flow of information between parents and professionals and across disciplinary boundaries.

In the US, states are required to develop and implement comprehensive 'child find' systems that promote referrals for evaluation and assessment to determine child eligibility for early intervention or preschool special education. Dunst et al. (2004) and Dunst and Trivette (2004) have developed a framework for studying and categorising child find, referral, early identification, and eligibility determination practices.

### Point of access

Harbin (2005) has summarised the arguments for an integrated point of access to the ECI system. Describing the situation in the US, Harbin reports that there are four interrelated system problems for children with developmental disabilities in gaining access to early childhood intervention services: lack of early identification, lack of easy access, lack of timely access to services for some children and families, and lack of *full access*. To address these problems, Harbin suggests establishing an integrated and coordinated point of access or intake team. Once a concern about a child's development has been identified, families need to be referred, or refer themselves to a specific place that can begin the process of examining this concern. The mission of the point of access would be to help diverse children and families gain access to a broad array of specialised and natural resources to adequately meet their individual needs. The point of access would be run as an interagency collaborative, overseen by an interagency group that includes several family representatives. Harbin also envisages the point of access developing and integrated interagency data system that would require families to provide demographic and background information once only.

Harbin notes that the families' experiences with the point of access lay the foundation for their future expectations about their role and participation in subsequent stages in the process. Once children and families are referred to, or refer themselves to, the integrated point of access, one of the most important tasks is to develop a positive and trusting relationship with the families. The organisational structure, climate and activities therefore need to be family friendly, family-centred, and culturally sensitive. This requires a paradigm shift away from a bureaucratic and de-personalised approach, traditionally referred to as 'intake' to an empowering and empathetic 'welcoming' of children and families in a caring manner in more natural contexts.

## 'Soft' entry points

Research indicates that families of children with the highest need for services often are less likely to use them. For vulnerable and marginalised families who do not readily seek out or make use of services, 'soft' entry points to the service system are needed. These are non-targeted and non-stigmatising services such as toy libraries or playgroups that provide a welcoming and non-threatening setting and that allow staff to build relationships with families as a basis for engaging them in services. An Australian example is the SDN Family Resource Centre (SDN Children's Services, 2009) that made use of a toy library as a foundation, adding layers of support as needs emerged. An overseas model is the CUIDAR Early Intervention Parent Training Program for Preschoolers at Risk for Behavioural Disorders (Lakes et al., 2009) in California. This seeks to engage families, especially ethnic families, who make little use of services. It does so by providing prevention and early intervention services prior to diagnosis. This service before diagnosis approach allows parents to self-refer and obtain services without labeling their children with a diagnosis, which may be particularly important to parents of preschool children, and to families from diverse cultural backgrounds.

# Waiting lists

Waiting lists are a recurring problem in ECIS systems. As already indicated, it is clear that early identification and prompt access to ECI services are important for successful outcomes. Leaving families on waiting lists for long periods of time carries with it many risks.

One solution is to provide brief interventions for those on waiting lists. This has been shown to be effective with children with autism – Coolican et al. (2010) showed that three short sessions devoted to teaching parents of newly diagnosed children with autism the use of pivotal response treatment was sufficient to produce significant changes in the children's communication skills. Other economical ways of supporting families of newly diagnosed children need to be explored or developed, and procedures for ensuring that no family is left without some form of support devised.

### Children served

Which children should ECIS serve? The traditional criteria involve identified disabilities and developmental delays. However, there are arguments that, from the perspective of the early childhood service system as a whole, these criteria should be reviewed. Thus, Carpenter and Campbell (2008) argue that

Early childhood intervention services can no longer focus solely upon children with traditionally recognised disabilities (eg, visual or hearing impairment, Down syndrome), but also must offer support to families of children with special educational needs in emerging categories associated with factors such as low birth weight, a wide range of genetic abnormalities, and prenatal abuse (eg, those born with substance or alcohol addictions). Some of these children may have obvious disabilities, whereas others may have characteristics that predispose them to developing special needs ....Early childhood intervention services should include preventive interventions to attempt to preempt or at least lessen the impact of emerging difficulties ...

There are some initiatives and parenting programs already in place to address the needs of these children and their families. Whether these add up to a comprehensive systemic strategy to meet the needs of all such children is a question to be considered. From an ECIS perspective, the issue raised by Carpenter and Campbell is whether ECI services can or should play a role as part of a preventative systemic approach to responding to emerging developmental concerns in children and supporting universal services in meeting the needs of all children effectively. Under current ECIS funding and service arrangements, that would not be possible, even if services had any free time to devote to this task. If ECIS are to undertake an expanded role of this kind, revised criteria and targeted funding would be needed.

## Eligibility determination

Determining eligibility for service can be a protracted business that is distressing for families and delays access to services unnecessarily. An undue reliance of formal methods of assessment contributes to these delays. Alternatives that have been proposed include *presumptive eligibility* and *clinical judgment*.

- Presumptive eligibility (Dunst, 2011). Many different kinds of children's programs use a procedure called presumptive eligibility for expediting enrollment of young children in health care, human services, and other programs. Presumptive eligibility is a process that uses existing information at the time of referral or application, rather than a lengthy evaluation process, to determine eligibility. Brown and Brown (1993) recommended use of the procedure to facilitate the eligibility determination of infants and toddlers who have identified conditions or disabilities that are covered by Federal and State early intervention legislation. If presumptive eligibility was used to expedite enrollment of infants and toddlers in early intervention, then assessment practices could focus on intervention planning, where the experiences and opportunities used to promote child learning and development, were a main focus of the assessment process.
- Clinical judgment. According to Bagnato et al. (2008), traditional testing for detecting developmental delay fails to match the incidence rates of young children who need early intervention. An alternative approach is to use clinical judgment, but there has been little research and uniform methodologies for

clinical judgment to support this approach. On the basis of a broad research synthesis, they concluded that it is possible to structure and quantify observations and resultant clinical judgments so that reliable, valid, and useful evaluations for early detection can occur for children with developmental delays and disabilities. They identified five practice characteristics of clinical judgment that must be implemented to ensure reliable, valid, and practical use of clinical informed opinion in the field:

- Constructing operational definitions of observed/judged attributes.
- Using structured rating formats and field-validated measures to record informed opinions.
- Gathering data from multiple sources (settings, individuals, occasions, and methods).
- Establishing consensus decision-making processes.
- Providing training to facilitate reliable ratings.

Bagnato et al. also identified five judgment-based instruments and formats that possess these practice characteristics, and that have also been shown to have high reliabilities and validities in studies of young children with diverse disabilities.

A parent-completed tool that has been widely used for developmental screening is the Ages and Stages Questionnaires (Squires & Bricker, 2009). This has been widely used for developmental screening (Pizur-Barnekow et al., 2010). Although not designed for the purpose, it has also been used as a tool for eligibility determination. Bricker et al. (2010) discuss the precautions that should be taken when doing so.

### Approaches to assessment

A number of problems have been identified with traditional approaches to assessment (Hebbeler et al., 2008). These include:

- They are usually deficit-based need to shift to strength-based approaches (Dunst, 2011) - the assessment of infants and toddlers focus almost entirely on what children cannot do where interventions in turn target behaviour children are not capable of doing
- They are usually administered in clinical settings need to shift to ecological assessments (assessments of behaviour in the child's real-life settings)(Dunst 2011)
- They rely on norm-referenced tools needs to shift to authentic assessment (Bagnato, 2005, 2007)

There are numerous reasons why standardised tests are not considered to be good measures of what young children know and can do. For young children with disabilities, standardised testing poses additional challenges. Few standardised assessment tools provide detailed guidelines for appropriate accommodations

during testing to effectively measure capabilities among the broad range of children who have additional needs. Even among the tools that do provide some guidance about administering the test with accommodations, the psychometric properties and the norms for the tests have not been based on samples using these alternative administration approaches; this limitation substantially weakens the test's usefulness for examining functioning in children with additional needs. Alternatives include ecological assessments, authentic assessments, and strength-based assessments:

• Ecological assessment. According to Dunst (2008), the term human ecology refers to the relations between developing persons and their social and non-social environment, and how person and environmental characteristics, both independently and in combination, influence child behaviour and development. The purpose of this paper is to describe an ecological framework for assessing infant and toddler behaviour and development. The proposed approach expands the typical purposes and functions of assessment to include the identification of factors accounting for variation in child behaviour and functioning. The author describes a framework for conducting an ecological assessment of infant and toddler behaviour and development as part of a child's involvement in early childhood intervention.

Ecological approaches to assessment differ from more traditional approaches to assessment in three ways (Dunst, 2011):

- First, the focus of ecological assessment is functional and adaptive behaviour that permits a child to interact with his or her social and nonsocial environment in intentional, meaningful, and efficacious ways. In contrast, traditional approaches to assessment typically focus on the extent to which a child can produce behaviour included on some type of developmental scale or instrument.
- Second, ecological approaches to assessment appraise child behaviour in the context of typically occurring, everyday activities such as meal time, bed time, play, parent--child story book reading, etc. In contrast, traditional approaches to assessment typically are conducted in settings unfamiliar to a child or under conditions that are incongruent with behaviour setting expectations (e.g., administering a developmental test to a child in his or her home while seated in a high chair).
- Third, ecological approaches to assessment emphasise the identification of those factors and variables that influence child participation in everyday activities and variations in child behaviour in those activities. In contrast, traditional approaches to assessment almost entirely ignore the factors influencing variations in child behaviour and focus almost entirely on what a child can and cannot do.

The Dunst (2008) ecological framework for assessing infant and toddler behaviour involves gathering information about six variables:

- the settings that are the contexts for child learning
- the characteristics of the settings and the materials available in the settings
- the child characteristics that encourage participation and display of competence
- the interactional behaviour adults use to support, encourage, and reinforce child competence
- the parent characteristics that shape and influence positive caregiving behaviour
- the extrafamily factors that shape and influence parenting confidence and competence.
- Authentic assessment (Bagnato, 2005, 2007). According to Bagnato (2005), early childhood intervention requires assessment procedures that are designed and field-validated specifically for young children with disabilities, capture real-life competencies in everyday routines, help plan individual programs, and document incremental improvements in developmental competencies. Conventional tests and testing, which have dominated measurement in the field, fail to meet early intervention purposes and published professional recommended practice standards. Fundamental changes in assessment for early intervention are needed to produce practices that are authentic, universal, and useful. Due to the advocacy of parents and professionals working together, early childhood measurement is morphing into authentic assessment, the optimal alternative to conventional testing in early intervention.

Bagnato (2007) provides recommendations for authentic developmental assessment of children from infancy to age 6, including those with developmental delays and disabilities. He describes principles and strategies for collecting information about children's everyday activities in the home, preschool, and community, which provides a valid basis for intervention planning and progress monitoring. He emphasises the importance of enlisting parents as partners with practitioners and teachers in observation and teambased decision making.

Macy et al. (2005) argue that traditional standardised, norm-referenced assessments have at least two drawbacks: (a) test items and activities often do not reflect children's functional repertoires; and (b) outcomes are difficult to link directly to goal development, intervention, and evaluation. They describe an alternative assessment approach that reflects children's functional repertoires in familiar environments (i.e., authentic), and directly connects outcomes to programmatic efforts (i.e., linked). They report a study investigating the validity and reliability of an authentic and linked alternative assessment. Results suggest the potential for using alternative assessment for determining eligibility for early intervention services.

Comparisons of authentic assessment procedures with conventional, highly standardised, norm-referenced testing procedures in determining eligibility for service show that parents were generally more satisfied with the former (Macy et al., 2010). Authentic developmental assessments allowed parents to play an active and significant role in the early intervention system from the beginning, and promote their meaningful engagement in early childhood intervention services.

• Strengths-based assessment practices (Dunst, 2011). Traditional approaches focus almost entirely on what children cannot do where interventions in turn target behaviour children are not capable of doing. An alternative assessment practice focuses on the existing and emerging behaviour children "can do" and provides children opportunities to use those behaviours in ways strengthening existing competence and providing opportunities to learn new skills. Strengths include a person's interests, preferences, likes, and so forth, and their abilities, competence, and skills, and so forth. A number of strengths-based child assessment tools have been developed for this purpose (eg. Dunst et al., 2004). Strengths-based assessment practices not only differ from more traditional assessments by focusing on what children can do but also by focusing on the kinds of activities (experiences, opportunities, etc.) that are the contexts for interest and competence expression.

Other aspects of best practice in assessment include interdisciplinary assessment (Guralnick, 2000) and parental involvement (Centre for Community Child Health, 2008b; Head & Abbeduto, 2007).

### Program fidelity

The benefits of providing early intervention services (including multidisciplinary therapy and family support) for children with disabilities and their families are widely acknowledged. For intervention to be successful, both the intervention itself and the implementation process must be effective (Guldbrandsson, 2008). As Fixsen et al. (2005, 2009) note, ineffective programs can be implemented well and effective programs can be implemented poorly. Many effective programs fail to deliver positive findings as a result of flawed or incomplete implementation. Desirable outcomes are achieved only when effective programs are implemented well.

A recent Australian study illustrates the gap that often occurs between between policy and practice. Ziviani et al. (2011) used program logic to analyse the extent to which three Queensland ECI services adhered to or modified the goals outlined in the Queensland Government's Disability Services early intervention initiative for children with physical disabilities. These goals were broadly aimed at enhancing families' capacities to promote their children's development, through education about strategies to enhance developmental attainments and support in

implementing therapy programs at home. Improved participation of children and families in home and community settings was targeted through the provision of therapy services for children (which aimed to improve their functional abilities) and information and support for families regarding strategies for community engagement. The three service providers differed considerably with respect to their service delivery approaches. Engaging early intervention staff in program logic exercises provided a rich way of understanding the manner in which services were being delivered by different organisations for children with physical disabilities and their families. While each of the agencies provided services and identified outcomes that were congruent with the broad Disability Services goals, staff were able to interpret the broad policy goals in light of their particular organisational context, hence there were both similarities and differences in the means by which they sought to achieve the goals of the initiative.

One of the ongoing debates in human services concerns whether new interventions should be implemented with maximum fidelity or whether adaptation (reinvention) should be permitted or encouraged to suit local needs and preferences. As Durlak & DuPre (2008) observe, some interventions are more conducive to fidelity because they are highly structured and have accompanying detailed manuals or lesson plans, but many interventions do not have these features. Research reviewed by Durlak and DuPre suggests that fidelity and adaptation frequently co-occur and each can be important to outcomes. That is, providers often replicate some parts of programs but modify others. Several studies indicate that higher levels of fidelity are significantly related to program outcomes, but fidelity levels never reach 100%, so there is still room for adaptation to have an effect, and there is some evidence that adaptations made by providers can improve program outcomes.

## Use of evidence-based practice and practice-based evidence

Developing effective interventions is only the first step toward improving the outcomes for children and parents. The next step is to ensure that practitioners know and use these interventions. Durlak and DuPre (2008) outline the challenges this involves:

Transferring effective programs into real world settings and maintaining them there is a complicated, long-term process that requires dealing effectively with the successive, complex phases of program diffusion. These phases include how well information about a program's existence and value is supplied to communities (dissemination), whether a local organisation or group decides to try the new program (adoption), how well the program is conducted during a trial period (implementation), and whether the program is maintained over time (sustainability). Moreover, if many people are to benefit, diffusion must be successful in multiple communities, and at each stage of the process, from dissemination through sustainability.

Unfortunately, research indicates that the diffusion of effective interventions typically yields diminishing returns as the process enfolds. For many reasons, information about effective interventions does not adequately reach many communities. When it does, only some in the community become motivated to try something new. Many innovations encounter implementation problems that diminish a program's impact. Finally, only a relatively few interventions are sustained over time, regardless of their success achieved during a demonstration period.

Some aspects of ECI best practice – such as family-centred practice – have proven difficult to implement consistently (eg. Boavida et al., 2010; Dunst & Trivette, 2005). For instance, Dunst and Trivette (2005) studied a particular program over a 14-year period to establish the extent to which staff were able to maintain consistently high levels of family-centred practice. They found that levels varied over the time span, and that adherence was difficult to attain and maintain. They concluded that constant vigilance and attention to the principles are necessary conditions to achieve adherence, and that programs must regularly collect adherence data so as not to be lulled into a belief that adherence has been achieved when this was not the case. Ways of improving practices have been discussed by Reiman et al. (2010).

Other studies have shown that recommended practices in a number of other aspects of ECI service delivery were not always being implemented. For instance, a US survey of programs for young children with autism spectrum disorder (Downs & Downs, 2010) found that the practices used by such programs are in many ways inconsistent with the recommended practices identified in the literature. Strategies for bridging the gap between research evidence and practice have been discussed by Dingfelder and Mandell (2010).

### Intensity of service

One of the recurring questions in early childhood intervention concerns the intensity of service. What level of service is sufficient to achieve good outcomes? Do more intensive interventions produce better outcomes? Before looking at the evidence, it is important to keep in mind what outcomes are desired. If we accept the argument outlined earlier that the main aim of early childhood intervention services should be to ensure that children's main caregivers are able to provide them with optimal social and learning environments, then we will prefer strategies that promote the ability of caregivers to do this over strategies that try to change the child directly. And if we accept the evidence that promoting family adaptation and establishing sustainable family routines are the keys to families meeting their children's needs effectively, then we will prefer strategies that support rather than disrupt such routines.

With these points in mind, we return to the question of levels of intensity. As it happens, there is relatively little research that compares different levels of

intensity, but some recent studies suggest that more is not necessarily better (Coolican et al., 2010; Reichow & Wolery, 2009; Wallace & Rodgers, 2010). A review by Reichow and Wolery (2009) of early intensive behavioural interventions (EIBI) for young children with autism found that the more intensive the intervention, the better the results. However, that does not mean the less intensive forms of other interventions might be just as or even more effective. As Reichow and Wolerv note, there have been no comparisons between EIBI and other widely recognised treatment programs, and without such comparisons, it is not possible to determine if EIBI is more or less effective than other treatment options. Evidence that more is not always better comes from a review by Wallace and Rogers (2010) of interventions with children who have other disabilities. They note that the mean corrected effect sizes reported in the Reichow and Wolery review are moderate, similar to those achieved by intervention studies for other infants with delays. For the children in the studies cited by Reichow and Wolery, interventions were carried out for 30–40 hours per week, in 1:1 ratios, mostly at home but a few in special group settings, using discrete trial teaching. While these studies are delivering more intensive intervention than most of the other studies cited in the review by Wallace and Rogers, the outcomes were no different.

Another relevant study by Coolican et al. (2010) involved parents of newly diagnosed children with autism. This found that three separate 2-hour training sessions over two consecutive weeks on the use of pivotal response treatment produced just as much improvement in the children's communication skills as a comparable study involving 20 hours of group parent training. More research of this kind is needed. (In the early childhood field, there has been a recent example of such research: the EPPE study showed that, for 4-year olds in preschool programs, half-time attendance was just as beneficial as full-time attendance.) What do we know about the actual levels of service being provided? US studies, summarised by Raspa et al. (2010), show that children receiving early childhood intervention services receive an average of one hour of service per week typically from one of five types of service providers (speech therapist, occupational therapist, physiotherapist, special educator, and service coordinator) and services predominately are provided in the home. The National Early Intervention Longitudinal Study (NEILS), which was initiated in the late 1990s and is the only nationally representative study of early intervention services in the US, found that the median amount of scheduled service per week was 1.5 hours although 13% of families were scheduled to receive less than 30 minutes per week and another 9% were scheduled to receive more than 6 hours per week (Hebbeler et al., 2007).

This variation in service levels raises the question of how to match child and family needs to service levels. Based on a review of different types of early intervention, Statham and Smith (2010) concluded that the common thread linking apparently disparate findings is that intervention should match level of need: 'light touch' interventions are unlikely to be effective for 'heavy end'

problems, nor intensive programs targeted at specific difficulties for those without such problems. Similarly, Moran and colleagues (2004) draw similar conclusions about duration and intensity needing to be matched to level of need, rather than 'more' necessarily being better. From their comprehensive review of evaluations of English-language parent support programs, they conclude that longer, more intensive programs are more appropriate for parents experiencing severe difficulties; while shorter, low-level interventions are more effective with parents experiencing less serious problems.

Despite these preliminary studies, much work remains to disentangle the complexities of the service system. As Raspa et al. (2010) point out,

Little evidence exists that bridges the gap between the theoretical frameworks of organising the service system and the manner in which services are actually delivered.

### Funding levels

As Hebbeler et al. (2009) note, the early childhood intervention community has not traditionally concerned itself with questions about cost, but in this time of increasing need and limited resources, this is no longer tenable. ECIS systems need data on expenditures in order to allocate resources for early intervention both equitably and effectively.

So what level of funding should ECI services receive and how should they be distributed? There is very little published data that addresses these questions. One exception is the study by Hebbeler et al. (2009) that used data from the National Early Intervention Longitudinal Study (NEILS) to determine expenditures for 0-3 year old children and their families receiving early childhood intervention services. The NEILS was a national study conducted in the late 1990s, and the costs cited below have been adjusted to 2009 equivalents. The study found that the national average monthly expenditure for children with developmental delays was \$US948 (equivalent to an annual expenditure of \$US11, 376) and for children with diagnosed disabilities was \$US1103 (or \$US13, 236 annually). There were considerable variations in the level of service provided. Expenditures varied as a function of children's health with the highest average monthly expenditure for children in poor or fair health.

Given the variety of disabilities and the varying levels of delays of children served by early intervention, we would expect variations in services across children and families. Some of this difference may reflect variation in child and family need for service, which possibly is 'good' variation because it demonstrates responsiveness to child and family characteristics. Other sources of variation may be due to the state's approach to service delivery or the availability of providers and have nothing to do with the child or family. Even when the variation in service packages reflects child and family characteristics, it is likely that some

approaches are more cost-effective than others, that is, produce equal or better outcomes at less cost. Services should not simply be responsive to child and family characteristics; they also should reflect the most cost-effective way of delivering services. It is important to emphasise that cost-effectiveness is not equivalent to the least expensive service; it refers to the least expensive way to produce good outcomes and so it is entirely consistent with best or recommended practice.

An Australian review of early intervention services for children with autism spectrum disorders (Roberts & Prior, 2006) found no studies on the cost benefits associated with treatment programs in terms of funding, treatment times, short-term outcomes and benefits over time. However, they were able to gather information regarding the aims of the intervention or treatment program, the target population, treatment times, associated costs, and how the treatment was being funded. This showed that there were wide variations in the form of service provided, the actual costs of programs, and source of funding. The most expensive forms of service were the intensive behavioural programs. These involved up to 25-30 hours of programming a week and cost families as much as \$30,000-\$40,000 dollars a year.

# Funding models

A related issue in early childhood intervention services concerns models of funding. How should funds be distributed or allocated? Should all families receive the same allocation?

The current funding model for ECI services in Victoria is a per capita allocation (currently \$6277, rising to \$7205 in 2011-2012) to the service agency in which the child is enrolled. 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). Here, the funding is allocated to families rather than services. This funding is aimed at providing increased access to early intervention for children aged zero to six with an autism spectrum disorder. 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. Each eligible child receives \$12,000 that can be used until the child's seventh birthday to a maximum of \$6,000 per financial year. Up to 35 per cent of the funding may be used to purchase resources, to a maximum of \$2,100 per financial year, or \$4,200 in total. Resources must have been assessed by an Early Intervention Panel Provider as

being integral to the child's therapy. The majority of the money is for parents to purchase services from approved providers.

This approach has recently been extended through the *Better Start – Early Intervention for Children with Disability* initiative, which, from July 2011, will provide similar levels of funding for children diagnosed with a sight or hearing impairment, Down syndrome, cerebral palsy or Fragile X syndrome.

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. This is clearly inequitable: there is no justification, evidence-based or otherwise, for funding particular groups of children with disabilities and not others.
- The funding is category-based, that is, dependent upon children being classified as falling into a particular disability category. This is problematic for two reasons. First, there are no absolute cut-off points to use: autism spectrum disorders, like all other disabilities, fall on a continuum, and determining eligibility is always going to be a contentious issue. Second, there are many commonalities between the various forms of disability, both in terms of the children's needs and the intervention strategies that work for them. At the very least, it is unhelpful to provide separate funding streams based on disability categories.
- The funding is based on a service-oriented conceptualisation of early childhood intervention, rather than an outcomes-based model. Many of the services being provided by approved service providers under this scheme are therapy-based interventions that seek to change the children through direct therapy, rather than family-based interventions seeking to strengthen the capacity of the families to meet the child's needs. Families naturally tend to assume that direct therapy from a trained professional is better than anything they can provide (or learn to provide) themselves.
- The funding is independent of the current ECIS system and adds an unwelcome layer of complexity to an already complicated system. Although some of the existing ECIS agencies have been registered on the list of approved providers for the program, many have not. (This may be because they felt they were already fully stretched and lacked the additional capacity to provide more services.) The gap has been filled by the arrival of a range of private service providers who are not linked in with the existing service system and whose understanding of ECIS philosophy and best practices is uncertain.
- Each family receives the same allocation of funding regardless of need. This appears to be equitable but ignores differences in child and family needs.

These can vary greatly, as can the supports and services families need. Some families will need less than the allocation while others will need much more. From an outcomes-based perspective, what we should be aiming at is equity in *outcomes* rather than equity of service provision or funding: each family should receive the support they need to achieve their particular goals.

 There are not enough trained and skilled practitioners to meet the demand for service. The introduction of such a large injection of money in one hit has stretched the capacity of the ECIS system to provide enough appropriately trained and experienced practitioners to the limit. This risks children and parents having to make use of practitioners with very limited experience and poorly developed skills.

The proposed National Insurance Scheme may run into some of the same problems, since it too is based on allocating funding to people with disabilities and their families. The notion of allocating funding to individual families to control arises from work on what is variously called self-directed care, self-directed support or consumer-directed care. As described by Leadbeater et al. (2008), this is a transformational approach to public services that involves allocating people budgets so they can shape, with the advice of professionals and peers, the support they need. This participative approach delivers personalised, lasting solutions to people's needs at lower cost than traditional, inflexible and top-down approaches, allowing the service users to devise better solutions. The key advocacy group for this approach in the UK, *In Control* (<a href="https://www.in-control.org.uk">www.in-control.org.uk</a>), now has an Australian counterpart - *In Control* (<a href="https://www.partnerships.org.au">https://www.partnerships.org.au</a>

There is some evidence that, with adults at least, this approach has benefits. In a report funded by FaHCSIA, Fisher et al. (2010) examined the effectiveness of individual funding of disability support for adults, defined as a portable package of funds allocated for a particular person that facilitates control over how they purchase their disability support needs. All people using individual funding said it had improved control, choice, independence and self-determination in their lives. Most people experienced personal wellbeing, as well as physical and mental health, at levels similar to both the Australian population norm and the Victorian norm of people with intellectual disabilities. They attributed these positive results to the better control they have over the way they organise their disability support. People with disabilities and their families commented on how changing to individual funding had improved the wellbeing of family members because they could share the responsibilities. However, these positive results may not reflect the experience of adults with intellectual disabilities in low functioning, vulnerable and disadvantaged families.

Can this approach work with families of young children? There have not been any studies addressing this issue. One of the questions is whether families are capable of making informed decisions regarding the best strategies for their child. It could be argued that the approach works with adults with disabilities because

they have had plenty of experience about what their needs are and how these can best be met. Families of young children with disabilities are just beginning on this journey and are likely to need more support while they accumulate the knowledge and experience they need to understand the complexities of the options available. Unless (or until) they gain that knowledge and experience, they are likely to think that 'more is better' and that 'experts should do it for us', and are likely to put pressure on governments to provide such support. (To be fair to the *Helping Children with Autism* scheme, it does not expect parents to make these decisions on their own, but provides access to Autism Advisors to help them.) On the other hand, family-centred practice supports parental decision-making and building parental competencies (including the ability to make informed decisions about their family needs), so would support the idea of families controlling funds. Overall, an approach that provides more support early and that builds progressively to giving people with disabilities and their families control over funds would be worth trialing.

## Service system fragmentation

The current ECIS system in Victoria is fragmented in a number of ways:

- Services are provided by a mixture of government and non-government ECIS teams and agencies, with some local government also providing services
- Services are mostly provided by dedicated ECIS agencies, but some are provided by agencies that have a wider brief (eg. Community Child Health, Preschool Field Officers)
- Some agencies are stand-alone ECI services, while others are linked with other support programs (such as Preschool Field Officers, Inclusion Support Agencies, Kindergarten Inclusion Support services, and Family Support Packages) or integrated programs (child and family centres or hubs)
- ECI services vary greatly in size, from large agencies (such as Noah's Ark) with many staff and the resources to support them, to small agencies with limited resources
- Some services cater for specific disabilities while others cater for a range of disabilities
- Most non-government service providers are from not-for-profit agencies, but there appears to be an increasing number of private practitioners and agencies providing services
- The actual service provided varies considerably between agencies, depending upon their auspice, philosophy and knowledge of contemporary evidence and best practice
- The actual practices also vary, with some services using a more medical model, while others use a more family-centred and family-focused approach

- The locus of service provision varies greatly, with some being almost totally home-based, some totally centre-based, and some school- based (Special Developmental School programs)
- Most work done by ECIS agencies and teams is family-focused, while
  inclusion support to early childhood programs is provided through separately
  run and funded services (eg. Kindergarten Inclusion Support
  services)(although ECIS does provide some support to mainstream services
  in the form of specific inclusion support related to the particular child)
- Service coordination practices vary greatly, with some services using a key worker model, some providing case management separately to service delivery through a family service coordinator, and some having no formal coordination method, providing services through multiple individual practitioners each with different goals
- The bulk of funding for ECIS provision comes from the State government, but the Federal government funds other related initiatives, and some agencies augment their funding through fees, fund-raising, charitable and corporate funds
- There are limited mechanisms for the state and federal governments to coordinate their funding initiatives or their policies
- Although there are mechanisms for the state and federal governments to coordinate their funding initiatives or their policies (through COAG and through DEECD-DEEWR State liaison meetings), these are rarely used and little meaningful coordination occurs.

There is no direct evidence that such a fragmented system produces poorer results, nor could one conceive of an ethically responsible randomised control trial would test the question. However, there are a number of reasons for thinking that this degree of fragmentation is undesirable.

- Where more than one agency or service is involved, families are likely to find themselves in situations in which they receive competing demands on their time or contradictory advice about intervention strategies.
- Where more than one service option is available, parents are likely to find it
  difficult to judge the respective merits of the options. (For instance, is a
  school-based program better for the child than a combination of home-based
  and inclusion support in a mainstream early childhood program?)
- Where for-profit services are involved, it is more difficult to ensure that they
  are providing services that are consistent with Government policies and
  philosophies, or with current ECI best practice.
- Where home-based and community-based (inclusion support) services are funded and delivered separately, it makes it difficult to develop coherent plans and implement strategies consistently across the different environments that children experience.

It is highly likely that the combined effect of all of these factors compromises the effectiveness of services and increases stresses upon families. Reducing the level of fragmentation must be a priority.

## Accountability issues

There are growing demands for accountability from all forms of human services (Hebbeler et al., 2008). All agencies and programs, including those serving young children with disabilities, are increasingly being asked to demonstrate that their services are producing the intended effects. Policymakers and funders are raising legitimate questions about which programs are effective as they struggle with how to allocate scarce resources.

Hebbeler et al. (2009) suggest that, to ensure that the dollars being expended for early intervention services are well spent, policy makers and administrators need to know which services are achieving which outcomes for which children and families at what cost. Thus, four types of linked information are needed if early intervention services are to be administered effectively: data on the characteristics of who is served, what they receive, the costs of providing that set of services, and the outcomes achieved. Only when all four kinds of information are available will those charged with overseeing program implementation be able to make overall and within-program funding decisions based on evidence rather than the way things have always been done or which program model has the strongest advocates.

Hebbeler et al argue that the critical policy question about early intervention needs to move from 'Is early intervention effective?' to 'Who achieves what outcomes as a result of what services provided at what cost?' Obtaining and linking data on the four elements of early intervention as it is being delivered in states (ie, the population served, the services received, the cost of the services, and the associated outcomes) are essential to informed decision making at both the state and federal levels. We cannot afford, nor is it fair to children and families, to continue to provide high-cost services to some families and low-cost services to others without evidence that any particular constellation of services is more or less effective than any other.

#### Gaps between professional and lay knowledge and understanding

Inevitably, many of the ideas discussed in this review – about how children learn and how children with developmental disabilities can best be helped – will be at odds with the understanding that parents and others have about these issues. Recent surveys of US parents' views about child development (Lerner & Ciervo, 2010) and Australian community views about child abuse (Tucci et al., 2010) show that there can be a considerable gap between professional views and those of the general public on these matters. In introducing changes to services

and systems based on the ideas identified in this review, one of the challenges to be faced is how to communicate these ideas in such a way that families and other service providers grasp them and understand the logic of the proposed changes.

## Building community awareness and acceptance of disability

Community-level outcomes for ECIS have been identified by Early Childhood Intervention Australia (Victorian Chapter)(2005) and also appear in *Better Opportunities, Better Outcomes* (DEECD, 2010d). In the latter document, one of the six outcomes that are meant to guide the work of ECI services in Victoria is that 'Inclusive communities benefit from the contribution that children and young people with a disability or developmental delay make and will make into the future.'

Achieving these outcomes involves building community awareness and the acceptance of disability. Negative community attitudes can contribute to family stress. A recent small scale study of parents of young children with disabilities conducted by Noah's Ark (Ochiltree & Forster, 2010) found that they had varied experiences of community acceptance, inclusiveness or rejection. Some had experienced criticism, especially when their child had no physical signs of their disability, and these mothers felt that they were viewed as bad parents. It was not only strangers who were insensitive or critical, but sometimes people within the extended family circle, often grandparents. This was a painful experience for these mothers who love their children dearly, who have done their best to accommodate their additional needs and to support their learning in ways that go beyond what most parents experience in family life and parenting. Being seen as a poor mother in the eyes of the community is not only a painful experience but it made mothers angry and frustrated. Other parents felt more accepted, but many of the mothers expressed the need for more information to be made available to the public so that other people can understand conditions, such as autism spectrum disorders and developmental delay, which are not immediately apparent. The mothers did not want pity either, although it is preferable to criticism, what they want was understanding, respect and community education.

Promoting such understanding and respect is a challenge. There is little research that shows how this can be done effectively. However, there a number of strategies that could be explored, including communication of key messages about early childhood issues in general and inclusion / diversity in particular to the general public, building community skills building and confidence in interacting with people with disabilities, community leadership development etc.

## 5.3 Reconceptualising ECIS: towards a unified system

The previous sections of this review presented an overview of the education, care and wellbeing needs of all children and families and the additional needs for children with disabilities or developmental delay and their families if they are to achieve positive developmental outcomes and genuine inclusion in their communities. Much has been written in Australia and internationally confirming the importance of these matters by researchers and in numerous reports, directions' papers, policy briefs and other documents prepared for or by governments, agencies and service providers (Bach, 2002; Gascoigne, 2006; Guralnick, 2005; Premier's Children's Advisory Committee, 2004; McLoughlin & Stonehouse, 2006; Centre for Community Child Health, 2003a; Shonkoff & Meisels, 2000).

Connecting evidence-based best practice in early childhood education, care and health services with evidence-based best practice in early childhood intervention remains an elusive goal and ongoing challenge in Australia and Victoria. While there are examples of this type of connecting, a systems-wide universal approach has not yet been achieved despite the rhetoric and compelling evidence arguing for the overall benefits for individuals and communities and as a right for all children and their families (McLoughlin & Stonehouse, 2006; Noah's Ark, 2006).

In Victoria, there are many parents of children who have additional needs who would like them to gain access to early childhood services such as child care or preschool, but they find structural and process barriers to this access. It is unethical and economically inefficient to have these children and families excluded from services, or gaining limited, conditional access, or gaining access only in the year prior to the child's school entry. Ensuring that all children and families can gain access to high quality children's services is an important issue which challenges countries globally. In countries such as the United Kingdom, the solution to these ethical, economic and empirical issues is believed to be found in a commitment to an approach focused on the child and family, and where every child and family can access the full range of high quality services from birth to school age and beyond (Every Child Matters, <a href="https://www.everychildmatters.gov.uk">www.everychildmatters.gov.uk</a>).

In Victoria, this continuum of access options for children birth to eight years could include the Maternal and Child Health Nurse service, playgroups, supported plagroups, childcare, family day care, preschool, primary school and out-of-school hours care. While the majority of children's education, care and health needs can be met within high quality mainstream services, those children with additional needs should be able to access additional services or interventions within the mainstream services (via secondary and tertiary tiers or levels of support), through participation in locally-based, specialist intervention services, or

through home-based interventions with the support of consultants or key workers.

Early childhood services and early childhood intervention services in Victoria could be deemed to be at a crossroad - a time when significant reforms are being planned or undertaken at national and state levels which will have an impact on future and current service provision and practices. The question is whether these reforms will result in the transformations that are needed to ensure meaningful participation for children with developmental delays within a universal systems approach? The recommendations outlined in the final part of this review identify how the reforms could support such a transformation.

Central to the philosophy underpinning the benefits of a universal systems approach is the recognition that the particular histories, cultures and practices associated with different sectors and service types (including the staff who work in these sectors or services) can act as barriers to reforms or transformations in early childhood education, care and health provision. Focusing on the needs of every child and family shifts the balance of the discussion from being focused entirely on the particulars of each sector (eg. public and private) and service (eg. childcare and preschool; mainstream and specialist) to a more holistic and universal understanding of what needs to be provided for all children and families, wherever the context or whatever the choices a family makes. The features of evidence-based best practice discussed earlier are elements that need to be provided within the context of *all* children's services (Gascoigne, 2006; 2008; McLoughlin & Stonehouse, 2006).

A universal approach to services for all young children and their families has been identified as an effective way to ensure genuine participation, amelioration of disadvantage and improved developmental, learning and health outcomes for all children (Allen Consulting Group, 2009; Centre for Community Child Health, 2006; Gascoigne, 2006; Moore, 2001, 2009c; O'Donnell et al., 2008; Perez-Johnson & Maynard, 2007; Siraj-Blatchford et al., 2008). A universal systems approach will help to ensure:

- · continuity of investment in all children and families
- commitment to all children and families
- whole of children's services sector reform
- the breaking down of service, professional or practitioner and research 'silos'
- equity in service provision and access to services
- better response to families who have increasingly complex needs
- earlier identification and recognition of children and families' additional needs and prevention, treatment or intervention strategies developed in response
- most interventions are offered in a less stigmatising environment
- trans-disciplinary staff teams are available to support all children and families
- reduction of social isolation experienced by some families and children

## 5.4 The features of a universal approach

A universal systems approach to education, care and health services for all children and families does not mean a 'one size fits all' model. There will be shared principles, goals and desired outcomes from adopting a universal approach, but communities and services need to be able to respond to their unique contexts and particular child and family circumstances. Universal high quality early childhood services are 'ready' for all children and their families (Brennan et al., 2003; Centre for Community Child Health, 2008c; McLoughlin & Stonehouse, 2006; Centre for Community Child Health, 2003a).

Key features of such a system have been identified as:

- High quality expected and provided in every service
- A connected, integrated or joined up system of all the services that children and families might need to access for their education, care and health needs
- A tiered system of universal, secondary and tertiary services able to meet the additional needs of individual children and families
- Services that are accessible and affordable for every child and family
- The service and not the child or family make adaptations as part of an inclusive philosophy, program and environment
- Every child and family experience a strong sense of being drawn into and welcome in the service
- All children's education, care and wellbeing needs met in the mainstream services, with additional secondary or tertiary services when deemed necessary, provided within the mainstream service where possible
- More comprehensive service delivery and more timely access to services
- Trans-disciplinary approach with different professionals learning from and with each other with ongoing opportunities for the transfer of knowledge, skills and practices
- Respect and acknowledgement of cultural and linguistic diversity

### Tiered early intervening strategies

An integrated tiered system - sometimes referred to as a public health model (Bromfield & Holzer, 2008; Jordan & Sketchley, 2009; O'Donnell et al., 2008 Scott, 2006), and called *progressive universalism* in the UK (Feinstein et al., 2008; Statham & Smith, 2010) - differs in approach from the current system in a number of important ways. It can respond to emerging problems and conditions, rather than waiting until problems become so entrenched and severe that they are finally eligible for service. It focuses on targeting problems as they emerge through the secondary and tertiary layers, rather than people as risk categories, thus avoiding unnecessary stigmatising. It aims to drive expertise down to universal and secondary services, strengthening their capacity to deliver

prevention and early intervention strategies. It would have outreach bases colocated with universal services to facilitate collaboration and consultant support.

Specialist services such as ECIS are usually funded on the basis of eligibility criteria and are precluded from providing any support until the criteria are met. This is contrary to the fundamental premise of early intervention – that it is better to provide support as early as possible rather than waiting until the problems are entrenched and more difficult to remediate. To overcome this anomaly, new strategies for addressing emerging problems are being developed. These involve the use of a tiered set of 'early intervening' strategies of increasing intensity that are designed to respond strategically to the child's learning or developmental needs and to prevent the problem worsening. Known as Response to Intervention, these strategies have been widely adapted in schools in the US (Glover & Vaughn, 2010; Jimerson et al., 2007).

The approach has been adapted for early childhood settings where it is sometimes known as Recognition and Response (Coleman et al., 2006; Coleman et al., 2009; FPG Child Development Institute, 2008) or Multi-Tiered System of Support (McCart et al., 2009). Accounts of how the essential components of this approach — universal screening and progress-monitoring with research-based, tiered interventions — can be applied in preschool settings has been provided by Coleman et al. (2009) and the FPG Child Development Institute (2008). According to Coleman et al., the essential components of the approach are high quality classroom instruction, tiered instruction and intervention, ongoing student assessment/progress monitoring, and family involvement.

Several hierarchical or tiered service models have been developed:

- A 'building blocks' model to promote the inclusion of young children with disabilities in early childhood programs (Sandall & Schwartz, 2002)
- A 'teaching pyramid' model to promote social emotional development and prevent the development of challenging behaviour (Fox et al., 2003, 2009; Hemmeter et al., 2006).
- Another 'pyramid model' involving recommended practices to help early care and education programs support the social—emotional competence of young children and address challenging behaviour (Hunter & Hemmeter, 2009)
- A hierarchical intervention system for promoting positive peer relationships in young children with disabilities (Brown et al., 2001)
- A three-tier model of intervention for parents of young children with developmental disabilities to reduce negative parent--child interactions and behaviour problems (McIntyre, & Phaneuf, 2007)

There is an emerging body of empirical evidence that this an effective method for identifying children at risk for learning difficulties and for providing specialised interventions, either to ameliorate or to prevent the occurrence of learning disabilities (Coleman et al., 2006). Tiered early intervening strategies have been shown to be effective in promoting early literacy development (Gettinger & Stoiber, 2007) and in supporting social competencies and preventing challenging behaviour (Fox et al., 2003; Hemmeter et al., 2006).

The only report of an attempt to implement this approach in a more systemic fashion comes from McCart et al. (2009). They tested the feasibility of delivering a family-based multi-tiered system of support to families of preschoolers through a family support agency. Parents from an Early Head Start agency were offered training to better prepare them to parent more effectively. Three levels (primary, secondary and tertiary) of training and support were employed to match family need with intervention intensity. The results indicate participants were satisfied with the service delivery and may have experienced reduced levels of stress as a result of their participation. This suggests that systems of support in which parents progress through a series of increasingly intensive interventions depending on their need appears a potentially promising framework for delivering services to families.

The challenges of attempting to transform a system with distinct organisational differences, inconsistencies in quality and outcomes, and often kept apart by professional silos and the different status of these professionals, into a connected, universal systems approach, should not be underestimated. For families with children who have a disability or developmental delay, these organisational differences may be even more evident if they are using multiple services for their children's education, care and health needs.

# 5.5 Features of effective integrated services and service systems

Many governments and jurisdictions have looked at ways of integrating services more effectively. These include initiatives in

- the United Kingdom (Anning, 2005; French, 2007; Hawker, 2006; Percy-Smith, 2005; Siraj-Blatchford, 2007; Tunstill et al., 2006; Worsley (2007)
- the United States (Halfon et al., 2004; Lepler et al., 2006; Waddell et al., 2001)
- Canada (Corter et al., 2006)
- Australia (Centre for Community Child Health, 2008d, 2009a; Fine et al., 2005; Moore & Skinner, 2010; State Services Authority, 2007; Valentine et al., 2007).

A recent review of these initiatives (Centre for Community Child Health, 2008d, 2009a) found that there was much more evidence on the process of integrating services than on the outcomes of such arrangements. These process studies have produced consistent findings on the conditions that promote or hinder multiagency collaboration. For instance, in Victoria, the State Services Authority (2007) had provided an overview of current approaches to joined up government in Victoria. This report focused on a number of case studies, and did not evaluate the outcomes of individual joined up projects, but did identify the key enablers which support the successful delivery of joined up projects.

## Principles underpinning a universal systems approach to services and practices

As in any system, model or approach, the universal systems approach to service provision and the practices within those services is based on commitments to core principles including:

- meaningful participation or engagement
- respect and response to diversity and difference
- valuing community connectedness
- ethical practices
- acceptance of every child and family
- importance of having a sense of belonging
- democratic governance
- valuing of partnerships and alliances within and beyond the service
- relationships focused
- commitment to on going quality improvement through evidence based practices
- practitioners are valued and have employment conditions which support job pride and satisfaction, retention, ongoing professional learning and career progression

## Features of universal, high quality services

Literature from both the early childhood intervention and generalist early childhood research has identified key features of universal, high quality services for children and families (Centre for Community Child Health, 2007a; Fleer & Kennedy, 2006; Podmore, 2004; Centre for Community Child Health, 2003a; Siraj-Blatchford et al., 2008; Sylva et al., 2004).

- A significant proportion of tertiary qualified staff in every service who can provide management and or pedagogical leadership
- Support for all staff to undertake further study or to upgrade qualifications
- Support for rigorous professional and trans-professional learning and development

- Child-staff ratios in accordance with world's best standards and research evidence
- Group size in accordance with world's best standards and research evidence
- Additional staff appointment/s (depending on service size) dedicated to inclusion support for children and families and to work with staff
- An early learning framework based on a coherent account of evidence based best practice which can respond to child, family and community contexts
- Environments and resources to support every child's holistic development, learning and wellbeing
- Pedagogy, environments and resources which reflect and respond to the cultural, linguistic and social contexts of the community
- All children have opportunities to play and to work with others (adults and peers) in sustained engagement in meaningful learning experiences
- Strong professional alliances or networks with other community services or agencies

A universal service systems approach can be provided in a range of connected or joined-up service types. While there can be a range of service types, in a universal systems approach there are commitments, incentives and supports for connecting with or joining up services so that the system is more coherent and there is more consistency in overall service provision. The range of service types to be found in a universal system approach could include

- Integrated Child and Family Service
- Hubs a range of services in close proximity and/or combined with integrated services in the one location
- Stand alone services (MCHN, child care, preschool or specialist EI services)
- Family day care
- Co-located and integrated with schools (Childcare, Early Learning Centres or preschool, OSHC)

Each hub or integrated service may share some common provisions such as MCHN, childcare and preschool. Additional services should be determined according to community contexts, and may include:

- Early intervention specialists
- Parent or family support programs
- Speech therapy
- Adult education or job skill programs
- Adult literacy programs
- Psychology or counselling services
- Health services such as a midwifery, medical, dental, or dietary services
- Financial support services
- Bilingual services
- Family Day Care offices

- Consultation rooms for visiting professionals(psychologists, doctors, nurses)
- Rooms available for community groups to hire/use during and after working hours
- Outreach services
- Community Development and Community Liaison workers
- Neighbourhood Watch

It is important to recognise that, while integrated services have the potential to provide a more comprehensive access to services for children and families, they are one service type in a universal systems approach. Integrated services may also need to connect or join up with other services in their community or region as it is not possible for every integrated service to have the full range of services to meet all children and families' needs. One of the identified additional needs of families who have children with a disability or developmental delay is that they are time stressed due to the number of regular appointments they have in order to support their child's needs. Muir et al.'s (2008) study of resilience in families of young children with disabilities found that some children in the study were receiving regular treatments or interventions from up to ten different professionals or services. Integrated services may be able to reduce the time stress for these families by having consultation rooms for visiting medical or health professionals for example as well as providing early intervention programs within the mainstream child care and preschool services.

However, as a recent review by the Centre for Community Child Health (2008d) concluded, there is no single model that has become accepted as the best model for a children's centre. What models do exist are not well enough documented to be 'transportable', ie. applied in other sites. Most Australian examples of children's centres are newly established or still in the development stage.

### Challenges for connected, integrated or joined-up services

The benefits of having a universal systems approach may be evident, however, the challenges to transforming from separate, fragmented services to connected or joined-up provision are considerable. The research suggests that some of the challenges include:

- Transdisciplinary provision different training, beliefs, practices, and knowledge of the professions or practitioners can make it difficult to develop a transdisciplinary team approach in and across service provision
- As a relatively new model of service and practice provision there are limited reference points for leadership, staff and management
- Establishment costs to support connections or integration
- Rethinking different professional cultures and images of the child and family (health, welfare, holistic, needy, strengths based, competent)

Building integrated services or developing connected services does not mean that professional collaboration will happen as a matter of course. In every country, region or city where this type of connected service system has been established, considerable effort and leadership has been required to shift from siloed support to a shared vision and collaborative practices approach (Brennan et al., 2003; Buysse & Wesley, 2005; Centre for Community Child Health, 2006; Moss & Petrie, 2004). A UK example of a successful effort to develop an interagency service delivery approach for school-age children with autistic spectrum disorders and attention deficit hyperactivity disorders has been described by Rowlandson and Smith (2009).

#### 5.6 Issues for consideration

## The need for leadership

The kinds of changes foreshadowed in this paper will not eventuate without strong commitments on a number of fronts. At present, there is no pressure from the early childhood sector (or from the general public) to create a universal early childhood service system that supports the meaningful participation of *all* children and families, including children with a disability or developmental delay. Nor is there anyone with a mandate to promote such a system. In the circumstances, the State government will need to be proactive and promote the proposed reforms. Each of these reforms is a critical structural element which will impact on the process elements within a high quality universal systems approach to children's services (Bruder, 2005; Guralnick, 2005; Moore, 2005; Sylva et al., 2004.) An example of using the revised State Government regulations to support a universal systems approach to high quality in children's services would be to limit group sizes and improve the ratios of staff to children as part of the regulatory framework in Victoria. Both these structural aspects of quality have direct links with staff capacity to form close relationships with every child and family and to have the time for sustained engagement with children every day which are core features of high quality education and care (Siraj-Blatchford et al. 2008; Sylva et al. 2004).

#### The Children's Trust model

The Children's Trust model developed in England (Every Child Matters, 2004) is worth considering as a way of providing a structural platform for an integrated universal service system. Based on local government regions and existing networks, Children's Trusts have been established to plan and take responsibility for managing or allocating state and local funding and resources for a universal children's services' system approach. Unless Victoria develops some type of over-arching structure to support coordination and planning, it is likely that current fragmented, disconnected and uneven quality service provision will remain. The building of hubs or integrated children's services means that there will be some areas with examples of connected and integrated provision, but

these examples do not mean that there is a universal systems approach to services and practices for all children and families in Victoria.

The UK Children's Trusts' model includes the following features:

- A Director or Commissioner of Children's Services
- Outcomes-led vision informed by the views of children and their families and budgets aligned with those desirable outcomes
- An unified inspection system for all children's services
- A commitment to meet the goals of the Government's radical agenda for reform of early childhood services which has a strong inclusion focus
- Integrated frontline delivery professionals working collaboratively to meet the needs of children and not constrained by organisational boundaries
- A focus on multi-agency service delivery including health services
- Multi-agencies share information, develop assessment frameworks, plan together on pooling or aligning of budgets and resources to meet outcomes and intervention strategies
- Inter-agency governance-setting clear frameworks for strategic planning, resource allocation, child protection, and accountability
- Long term goal is to have Children's Centres or Extended Schools at the heart of every community (Every Child Matters www.everychildmatters.gov.uk/aims/childrenstrusts

Victoria has some of the features of the UK Children's Trusts in place, including:

- Local governments coordinate and contribute funds directly or 'in kind' to some of the services provided for children and families (especially MCHN services, preschool and child care services)
- Local governments have Municipal Early Years Plans to set goals and to plan collaboratively for current and future provisions for young children and their families, and for engaging vulnerable families
- Local governments have Child and Family Services' Coordinators and staff teams supporting these services
- Inspection of early childhood services is undertaken in local government regions by DEECD staff
- School education is administrated and managed at a regional level and at a local level through School Councils
- Schools have or are building children's services on site or co-located and many have OSHC services
- Integrated or hub children's services are operating or are being built in local government areas in Victoria
- Community health services operate in many local government municiplaities
- The role out of the AEDI will provide a database of information which will help to provide information to support community or regional responses for prevention and early intervention

Developing a Children's Trust-type model would mean combining current services, supports and planning into a more coherent and whole-of-community responsive system. The Children's Trust would require a governance board which could be comprised of representatives from Children's services, schools, community associations, service clubs, local businesses, parents, and welfare organisations. Statutory authority would be required by the Children's Trust so that it could change the structural and organisational barriers which sometimes prevent professionals from responding effectively to emerging and identified early intervention needs. Under the UK model, schools are included as partners in the Children's Trusts. Adopting a similar approach in Victoria would help to support the integration of school education with early childhood education, care and wellbeing at the local or regional level.

## The key worker role and transdisciplinary practice

An issue repeatedly highlighted in the literature is the need for effective care coordination for families of children with additional care needs (Drennan et al., 2005; Sloper, 1999). The more health or development problems a child has, the more services they receive and the more service locations they have to access. Under these circumstances, services are less family-centred. What parents want is a single point of contact with services and an effective, trusted person to support them to get what they need (Drennan et al., 2005). This has led to the development of *key worker* models of service delivery (Davies, 2007; Drennan et al., 2005; Greco et al., 2004; Liabo et al., 2001; Mukherjee et al., 1999).

Key workers can help children and families in the following practical ways:

- Having a key worker can assist families who may have to cope with many different professionals who sometimes offer conflicting or confusing advice
- Key workers can help to prevent children and families 'falling through the cracks' because they don't meet particular eligibility criteria for access to services or because the family is unaware of available services
- Key workers can help to ensure that children and families receive more consistent types of interventions or support from other professionals and that interventions are appropriate and provided at the right time
- Key workers can provide advice to practitioners about the appropriateness of the interventions being offered
- Key workers can liaise with and on behalf of the child and family with practitioners and professionals
- Key workers can help to ensure that practitioners receive referral information and adequate assessments and support for how to work in partnership with other professionals
- Key workers can help families to understand the different roles and responsibilities of all the professionals who work with their child and the limitations within each of these interventions

In the UK, funding has been provided for lead professionals or key workers. The key worker plays a central role in ensuring that all children with additional needs have child and family-centred support systems available through gaining access to a range of services. The key worker is expected to undertake additional training or qualifications in order to be employed in this important and challenging role. The key worker's role is focused on:

- building trusting relationships with child and family over time
- advocating for and with the child and family
- providing information and support to empower the family to make informed choices for and with their child
- using assessment outcomes to plan with the family a 'solution focused package' of support
- identifying additional support services that could support the child and family and works to secure family agreement to use these services
- acting as a liaison person between the child and family and both the mainstream and targeted services they access
- ensuring that the child's progress is documented and monitored, taking into account the social, cultural and life chances' contexts for each child and family and their satisfaction with the services they receive
- recommending further interventions if necessary after this contextualised assessment and monitoring
- continued support for the child and family until the initial lead professional believes a new lead professional affiliated with a service or school should take 'over the baton'.

UK research on what makes key workers effective (Sloper et al., 2006) has shown that better outcomes for families were achieved when

- key workers carried out more aspects of the key worker role (provision of emotional support, information about services and the child's condition, advice, identifying and addressing needs of all family members, speaking on behalf of the family when dealing with services, co-ordinating care, and improving access to services and provision of support in a crisis)
- families had appropriate amounts of contact with key workers,
- there was regular training, had supervision and peer support for key workers
- there was a dedicated service manager and a clear job description for key workers.

The key worker role requires and builds upon *transdisciplinary practice* (Drennan et al., 2005; Harbin et al., 2000; King et al., 2009; McWilliam, 2000; Martin, 2004; Pilkington & Malinowski, 2002; Rapport et al., 2004; Stayton & Bruder, 1999; Woodruff & Shelton, 2006). In transdisciplinary teamwork, several professionals provide an integrated service to the child and family, with one

professional acting as the key worker (Liabo et al., 2001). The main reason for adopting this approach is that there is good evidence that parents prefer and do better with a single case worker (Bruder, 2000; Sloper, 1999; Sloper et al., 2006); according to Bruder (2000), transdisciplinary teamwork is 'absolutely necessary for effective intervention'. Other benefits include service efficiency, cost-effectiveness of services, less intrusion on the family, less confusion to parents, more coherent intervention plans and holistic service delivery, and the facilitation of professional development that enhances therapists' knowledge and skills (King et al., 2009).

The quality of relationships within teams contributes to the ability of team members to work supportively with parents and families (Pilkington & Malinowski, 2002). Ways of building supportive collegiate relationships have been identified by Brunnelli & Schneider (2004), Drennan et al. (2005), and Rapport et al. (2004).

#### Workforce reform

Practitioners working in children's services base their practices and decision-making on their values, beliefs and understandings concerned with their professional roles, children, families, community, teaching and learning. These values, beliefs and understandings are derived from life and professional experiences and usually reflect the history and philosophies of their particular early childhood specialisations. These understandings may become part of 'taken for granted' practices that are very important to the practitioner, but may not be understood well by outsiders such as parents or other professionals. Early intervention specialists also have values, beliefs and understandings which, depending on their initial education and training, may align with or could be quite different from the practices of their mainstream early childhood colleagues. Outsiders such as parents may struggle to understand these specialist practices and discourses. These differences have meant that professional groups sometimes work in what have been called 'professional silos' as they draw upon different research knowledge and experiences for their practice decisions.

One hallmark of a high quality universal systems approach to children's services and practices is that practitioners with different discipline knowledge, skills and practices will work collaboratively with each other and in partnership with all children and families. A further structural matter for ensuring high quality in children's services is that all staff have appropriate qualifications, education, training, access to ongoing professional learning and development and time for reflection and professional networking (Cullen, 2004; Klein & Gilkerson, 2000; Moore, 2008e; Shonkoff & Phillips, 2000).

The State government has included workforce reform as part of its overall strategies for improving quality in children's services. In addition to those reforms, consideration should be given to further workforce reforms to ensure

that all children's needs are met, including the additional needs of children with disabilities or developmental delay and their families.

Workforce reforms will need to be reflected in changes to training courses and requirements. Such changes will need to be negotiated with relevant training institutes, universities, and registration and course accreditation authorities. Possible changes for consideration include the following:

- Ensure that all pre-service courses have specific units or studies in early intervention, monitoring, and family-centred practice as part of core content knowledge
- Review and reform Recognition for Prior Learning (RPL) and credit points as part of the process of developing flexible pathways for upgrading diploma qualified staff to a degree. There needs to be a balance in RPL mechanisms between rigor and recognition for non-traditional pathways to professional competence such as demonstrated high level skills in management, service coordination or inclusion support practitioner experience
- Support for the development of new qualifications in early intervention and inclusive practices which could be undertaken at 4<sup>th</sup>, 5<sup>th</sup> or 6<sup>th</sup> year/s of studyfrom Bachelor to Masters levels
- Support the continued development of flexibly delivered courses and pathways programs for staff needing to gain or upgrade qualifications while they are working
- Recommend that training institutes need to include trans-discipline studies in pre- and post-service courses where possible and appropriate (e.g. child health or family-community studies)
- Require pre-service courses to include one placement (practicum) in a community or family context or with a professional from another discipline but related field
- Establish a Registration system for all qualified early childhood practitioners which provides for provisional registration for all graduates as well as career progression based on the need for continuous professional learning and demonstrated competence

Additional reforms as part of the Government's workforce reform and revised regulations could include:

- Significant improvement in the number of degree level staff required for all centre based children's services as part of a long term (e.g. over ten years) process of reform of the work force. For example, one degree trained staff member for every group in centre based services
- Support for the development of a culture in professional learning and development that has rigorous content and the opportunity to gain credit points towards further study

- Continue to provide financial support such as scholarships for practitioners disadvantaged by low income, remote or rural residence, immigrant or refugee status and to broaden the demographic profile of the children's services workforce
- Working with the Commonwealth government to find ways to link up-skilling and upgrading of qualifications for practitioners with the professional development funded under the Professional Support Coordination (PSC) Scheme

Many practitioners working in the field of early childhood participate in numerous professional learning workshops, seminars, forums and conferences. Very few of these experiences are linked to more formal study or qualifications through the granting of credit points for example. This seems economically and professionally inefficient. Developing a culture of professional learning recommended above, would help to address these inefficiencies by supporting the up-skilling of the children's service's workforce using existing professional learning opportunities.

## Exemplars of best practice in inclusion and connected services

Ways of identifying, sustaining and disseminating best practice in early childhood intervention and inclusion within a universal systems approach need to be explored. A well-funded program such as New Zealand's *Early Childhood Education Centres of Innovation* model can support the identification, sustainability and dissemination processes of a wide range of services by:

- presenting 'living examples' for practitioners, professionals and services to reflect on and learn from
- helping to generate 'local' data to improve the professional knowledge base for future policy and planning
- helping to break down the false dichotomy or divide between research, theory and practice by supporting an action research type model
- improving the collaboration between the 'traditional' research field (academics) and the field of practice
- helping raise the status, professional knowledge and skills of staff as they
  have paid time release for their action research, and learn from and share
  their findings within and beyond the service
- supporting the dissemination of the innovation or best practice through publications, conferences, resource development or workshops.

Under the New Zealand model, funds are available to support a three year action research cycle which is initiated by a service and supported by 'traditional' researchers such university academics who joins the project by invitation to provide research expertise such as how to design an action research project or how to publish results in an academic journal. Maori language programs, Family

Day Care Schemes and child care centres are some of the service types which have secured funding under this scheme (<a href="www.minedu.govt.nz">www.minedu.govt.nz</a>). Increasing the Australian knowledge base in early childhood intervention has been identified as an important goal in order to base current and future practices on a more theoretically firm footing (Dempsey & Keen, 2008). Funding to support the type of action research model being undertaken in NZ and in the UK (Anning & Edwards, 2006) would be an effective way to improve the early childhood intervention knowledge base in Australia.

Another model that has proven to be effective in promoting integrated service delivery is Victoria's Primary Care Partnership (PCP) strategy. There have been several evaluations of this strategy (Australian Institute for Primary Care, 2003, 2005; KPMG, 2005) as well as other studies (eg. Walker et al., 2007). The evaluation of PCP activities conducted by the Australian Institute for Primary Care (2005) found that, in the first five years of its operation, the PCP Strategy had brought about significant integration within the primary health care system and this has resulted in improved coordination of services and more positive experiences for consumers with the health system. Research completed by KPMG (2005) looked at the impact of Service Coordination on five community health services and three local government providers. It found that when successfully implemented, service coordination delivers benefits to agencies, practitioners and consumers.

## Supporting best practice pedagogy in early childhood education

The development of national and state Early Years Learning Frameworks (EYLF) and the Transition to School project being undertaken in Victoria are critical elements in helping to ensure that all those who educate and care for young children are guided by contemporary research and theories in combination with the practical wisdom and experience of the field. Meeting the education, care and wellbeing needs of all children and their families requires highly skilled practitioners and for some children with additional needs such as a disability or developmental delay, support from trans-professional skills and collaboration might be essential. All the practitioners who work with young children need to be educated and skilled in how to teach young children as individuals and as communities of learners (Anning et al., 2004; Fleer et al., 2006; Siraj-Blatchford et al., 2008; Sylva et al., 2004).

Working collaboratively with families to support them as the prime educators is an essential element of early childhood education and care. This is an important professional undertaking and particularly when working with families who have children with a disability or developmental delay.

Dunst (2007) argues that the current focus on services for early childhood intervention in the USA has not delivered the expected outcomes for children and families. He contends that a 'set of practices' rather than service provision should be the focus for early intervention. He identifies four of the practices that he

believes should be essential for family-mediated and evidence-based early childhood interventions.

If early childhood interventions are to be provided as frontline and embedded practices in mainstream services, then all staff need to have professional knowledge and skills in the types of practices identified by Dunst in order to provide the 'extent and nature of parenting supports' that will make a positive difference to children's developmental and learning outcomes.

Research has indicated that many early childhood practitioners feel unprepared for and lack the knowledge to be able to provide appropriate interventions within their regular play-based programs and routines (Bray & Cooper, 2007; Moore, 2001, 2008b; Muir et al., 2008; Centre for Community Child Health, 2003a). A universal systems approach means that every staff member must be professionally 'ready' and philosophically committed to teaching, learning and participatory relationships with all children.

Child care professionals in Victoria have had the benefit of participating in the Quality Improvement and Accreditation System (QIAS) which has provided them with opportunities and incentives to reflect on and renew their overall program or curriculum provision for children. Preschool teachers in Victoria have not had the same opportunities and the same incentives for pedagogical renewal. While individual teachers, special interest groups and some regional teaching networks have been engaged in renewal, this professional obligation has not been sectorwide.

Every practitioner needs to have understandings and skills in monitoring all children's development and learning so that early identification of potential or existing difficulties can be identified and responded to. Currently, this professional knowledge and related skills are not universally available to all children. Early intervention research evidence shows that earlier identification and appropriate responses will result in significant reductions in developmental gaps or differences (Perez-Johnson & Maynard, 2007). Early screening, monitoring (surveillance) and identification of risk are therefore ethical matters as well as an early education and intervention issues that need to be included in pre- and post-service courses.

Early intervention research reveals that children with a disability or developmental delay are not always supported to be included in play experiences and that play contexts may be overlooked as excellent sites for learning in both centre or home based interventions (Bray & Cooper, 2007; Dunst, 2000; Moore, 2001; Rix et al., 2008). Play-based approaches to learning support the concept of natural environments identified in the early intervention literature (Dunst, 2007; Dunst & Bruder, 2002; Hanft & Pilkington, 2000).

Natural environments are places, resources and events which are part of children's everyday experiences. Early intervention research has shown that these environments or contexts are potential sites for learning whether or not adults have planned for this to occur (David et al., 1997; Dunst, 2007). In similar findings, socio-cultural research and theorising, has identified the cultural nature of development and the deeply contextualised and social nature of learning as children are actively engaged in family and community life (Anning & Edwards, 2006; Anning et al., 2004; Fleer et al., 2006; Rogoff et al., 2003; Rogoff, 2003; Shonkoff & Phillips, 2000). Families and practitioners have socially and culturally-based expectations of children, and child development and learning. This is important knowledge for all those who work with children and families and therefore it needs to be embedded in all training and courses.

Working in a transdisciplinary way provides all children's service's staff with the opportunity to undertake shared reading and understanding of current play and pedagogy research within particular research paradigms such as socio-cultural or critical theories. Reflecting on this research as a community of learners or communities of practice (Wenger, 1998) can assist professionals to deepen their understandings of the pedagogical implications of the research (Wood, 2004). It is important that staff have the professional knowledge to articulate to others, including parents, the importance of relationships, play and participation in every day experiences for all children's development and learning.

In addition to previous recommendations concerned with workforce reform, and using 'lighthouse' examples, the Government is urged to use the consultation, development, trialing, implementation and on-going professional learning processes associated with the new Early Years Learning Framework (EYLF) and the Transition to School project, as a way to focus the sector's attention on serious pedagogical renewal. Evidence-based best practice pedagogies are possibly the most effective and economically efficient early intervention strategy to support positive developmental outcomes and improved life chances for all children, and especially for children with additional needs (Guralnick, 1998; Heckman, 2004; Siraj-Blatchford et al., 2008; Sylva et al., 2004).

The State Government has already indicated that they understand the need for sector-wide involvement in the development and introduction of the EYLF. Focusing these processes around the concept of pedagogical renewal for the meaningful participation of all children and families would be a worthwhile whole of sector endeavour.

Specific incentives to support a serious pedagogical renewal movement might include:

 Support for regular regional forums or seminars with pedagogical renewal as the focus

- An annual conference showcasing pedagogical renewal projects using the FYLF
- Professional learning workshops or seminars on specific aspects of inclusive practice such as monitoring and observation strategies
- A service award for best practice in early childhood inclusion through pedagogy included in the annual DEECD awards' presentation celebration
- Establish a trans-professional regionally based pedagogical leadership program for advanced professional learning and action research in early intervention
- Support for services interested in exploring innovations that have been identified in the research as supporting early intervention such a family grouping, family-centred practice or the use of every day experiences as sites for learning
- The establishment of a pedagogical leadership position in children's services to provide overall support for program or curriculum renewal.

## Connecting specialist early intervention into a universal systems approach

Shifting to a universal systems approach in Victoria is not something that can happen quickly - it will take time and the entire reform agenda to be fully enacted as well as further reforms such as those recommended in this review. Victoria has a range of specialist early intervention programs that serve children with a disability or developmental delay and their families. The sponsorship, governance, service and client focus, staffing and programs in these specialist services can be very different across this sector although all would share a commitment to improving the developmental outcomes of the children who participate in their programs. Some of these services have connections with mainstream children's services or allied health services. In a universal systems approach it is important that every early intervention specialist services is systemically or practically connected or joined up with mainstream services. Trans-disciplinary models can help to support these connections. There are sound reasons for recommending these connections:

- Staff working in specialist services have skills and understandings in early intervention which would be of benefit to regular early childhood practitioners if there were ongoing opportunities for professional sharing and networking
- Staff working in specialist services could benefit from the professional understandings and experiences of regular practitioners
- Resources and ideas could be shared more easily if there were systemic or interagency governance connections that helped to reduce organisational and professional barriers
- Children and families may access both specialist and mainstream services and connectedness would help to ensure continuity of philosophy, relationships and pedagogy

- Children and families' transition from specialist to mainstream services or school would be more easily supported if all services were connected
- Connectedness would help to support new and more flexible initiatives in early intervention

Ways in which specialist services could be supported to help them connect or integrate more closely with mainstream services include:

- Adopting a Children's Trust type model would provide the coordination and inter-agency governance support for ensuring systemic connections between specialist and mainstream services
- Supporting inter-agency (mainstream and specialist services) combined professional learning and development workshops or seminars would support connectedness as part of a process of building professional relationships and respect for each other's work
- Recruiting specialist services' practitioners for the Consultant or Key worker role would help to connect all services as these consultants would work across the universal systems
- Show-case examples of specialist services which are already connected or integrated with mainstream services as evidence of the benefits, challenges and possibilities
- Supporting staff from different service types to have time release in order to 'shadow' or work alongside each other on a regular basis as a professional bridge building experience and to support learning from each other
- Identify and show case best practice trans-disciplinary models (Australia and Victoria focus)

While there are some interesting transdisciplinary models within specialist early intervention services in Australia (Davies, 2007; Davies et al., 2005), extending transdisciplinary approaches to include mainstream services and across mainstream and specialist services and home-based interventions is also important for a universal systems approach. Transdisciplinary approaches are a further development of multi-disciplinary models where interventions for the child are provided by a range of different professions who may work independently from each other.

## Improving information systems for families of children with developmental disabilities

Section 3 identified that one of the additional needs of families with a child with disability or developmental delay is their access to timely, regular, appropriate, consistent and coherent information. How this information is presented to families both verbally or in written form is a quality process matter. This information could include diagnostic details, medical treatments, test or assessment results, resources available, early intervention or mainstream early childhood service

details, and home based intervention strategies. As Section 3 mentioned, this information needs to be culturally relevant and respectful of family diversity. Complicating this further, is the fact that information will be provided by a range of different practitioners or services including medical, health or therapist practitioners and services such as maternal and child health or an early intervention service.

In the circumstances, ways of ensuring the provision of relevant information to families need to be explored. These include:

- Review the formal and 'typical' written information material provided to families who have a child with a disability or developmental delay and develop a set of principles or an Information Code of Practice to guide the development and distribution of all such written information by funded agencies, services or government departments. Consistency in the use of early intervention terminology for example would be an important principle
- Ensure that every professional who may be in the position of informing families that their child has a disability or developmental delay has been educated and trained in the ethics of this critical period for families. A Code of Practice or using existing Codes of Ethics could provide the benchmarks for the types of informing practices that have a positive impact on families
- Provide ongoing trans-professional learning opportunities focused on the importance of and how to develop and share information with families

### Monitoring children's development

Linked to the recommendations concerned with improving the information systems for families with a child with disability or developmental delay is the need to improve the way in which information about the child is gained and used in mainstream early childhood services. In early childhood services, practitioners are expected to provide every family with ongoing information about their child's development, learning and wellbeing. This professional obligation requires skilled monitoring and assessment and the use of a broad range of strategies to document a 'rich' account of every child's strengths, interests and needs. Families and children should be actively engaged with or participating in this process (Fleer et al., 2006; Rinaldi, 2006). For children with a disability or developmental delay, this monitoring and documenting should be undertaken in collaboration with families and all of the practitioners who work with the child and family (Cullen, 2004; Williamson et al., 2006).

Currently in Victoria, there is no clear evidence to indicate that there is consistent and best practice monitoring and documenting of every child's learning and development. The different expectations, qualifications, training, skills and experiences across the sector make it difficult to achieve consistent high quality practices in this aspect of program or curriculum provision. In a universal systems approach to quality services and practices, every practitioner with responsibility for groups of children should have the professional knowledge and

skills to monitor, assess and document children's learning and development in accordance with evidence based best practices (See also Section 3 for a list of best practice assessment principles).

Early childhood practitioners need to be confident in using their ongoing monitoring and assessment practices to help identify whether a child with a disability or developmental delay needs a further level or tier of support or intervention. For example, a practitioner whose monitoring and assessment practices within an evidence-based best practice program might show that a child with cerebral palsy is finding it difficult to have meaningful participation in certain play-based experiences. Her response would be to seek support to overcome the handicapping barriers to this child's participation. The support, recommended in collaboration with the family and an early intervention consultant or pedagogical leader, could include a range or combination of interventions such as environmental modifications or specific social inclusion strategies. Further monitoring and assessment would identify if these interventions had worked or whether another level or tier of support was indicated to support the child's participation in play experiences (Coleman et al., 2006).

Evidence-based best practice monitoring and assessment strategies are also important for identifying potential developmental or learning problems. Research confirms that the earlier these matters are identified and appropriate responses are made, the more effective the outcomes for children (Perez-Johnson & Maynard, 2007).

The monitoring, assessment and documenting practices in children's services are part of frontline early intervention support for families who have a child with a disability or developmental delay. Specific strategies for the implementation of this recommendation include:

- Ensuring that the EYLF has a strong focus on evidence based best practices in monitoring, assessment and documentation of every child's learning and development including how to share this information with families in socially and culturally sensitive ways.
- Ensuring that the proposed Transition Statements and Plans, reflect evidence based best practice requirements for meaningful monitoring and assessment for all children and that they are relevant for their families.
- Use the introduction of the EYLF and the Transition project as a time to focus on the importance of monitoring and assessment as a frontline intervention strategy for the early identification of potential developmental or learning problems.
- Provide pre and post service education and training for early childhood practitioners in the process of using a recognition and response type of model for early intervention.

Fund the appointment of an early intervention support person to assist
practitioners with monitoring and assessment. For example, a large child care
services would have one such appointment and smaller or stand alone
services would share this appointment

## Embedding secondary or tiered early intervention support systems into mainstream practices

Research reviewed by the Centre for Community Child Health (2006) suggests that, to achieve better outcomes for young children and families, we need (a) to shift from treatment and targeted services to a universal prevention approach, (b) to develop an integrated tiered system of universal, targeted and specialist services, and (c) to develop better ways of engaging and retaining the most vulnerable families.

To achieve the second of these goals, the capacity of universal services to cater for the needs of a broad range of children and families will have to be strengthened. This will involve several strategies, including training of primary care workers (Sayal, 2006), increased support from specialist services (NHS Health Advisory Service, 1995), and the use of inclusive practices and strategies (such as the natural learning opportunities approach used with young children who have developmental disabilities)(Dunst et al, 2000; Hanft & Pilkington, 2000; Noonan & McCormick, 2005). However, the main strategy needed is to create a more integrated system of universal, targeted and treatment services, and to deploy the expertise of specialists more broadly (Moore, 2008b).

In the existing system, early childhood intervention services are mostly located separately from universal services, there are referral 'bottlenecks' that result in delays in help being provided, and the communication between services tends to be one way. In an integrated system, specialist services would have outreach bases co-located with universal services, would provide consultant support for children who have emerging problems, and would work collaboratively with universal service providers (Centre for Community Child Health, 2006; Gascoigne, 2006, 2008; Foley & Hochman, 2006; Moore, 2008b, 2009c).

For specialist services such as early childhood intervention services, becoming part of such an integrated service system would involve some expansion of the role of specialist early childhood intervention practitioners and the development of some new skills, such as skills in consultation (Buysse & Wesley, 2006) and coaching (Hanft et al., 2004). However, it would retain their core roles and build upon existing skills and strengths.

For mainstream early childhood service providers, becoming part of an integrated service system would also involve some expansion of both role and skills. It would mean accepting that all children can and should be catered for by mainstream services, and basing the curriculum they provide on principles of universal design for learning (Conn-Powers et al., 2006; Rose & Wasson, 2008).

It would also mean accepting that part of the role of early childhood services is to work in partnership with families and with other services so as to provide more cohesive support to families and more individualised support to their children.

In an integrated services system, the interface between specialist and mainstream services would take the form of tiered or progressive intervention systems such as Recognition and Response (Coleman et al., 2006, 2009; FPG Child Development Institute, 2008; McCart et al., 2009), which is a systematic process for identifying and providing the additional forms of help needed by individual children with developmental disabilities.

In introducing these changes, one of the challenges to be addressed is the question of eligibility. Currently, ECIS providers can only see children who have identified developmental disabilities and are eligible for service. However, the expanded role proposed here would include a potential role for ECIS practitioners in promoting the capacity of universal services to meet the needs of all children, or in devising interventions for small groups of children who may or may not be eligible for service. In the US, this problem has been addressed by freeing up a small proportion (15%) of the ECIS money to be spent on this form of service, with the bulk of the money continuing to be spent on direct service to eligible children and their families. Such a scheme would be worth trialing in Australia. Alternatively, the role that PSFOs might play in a tiered intervention system could be explored, since they are not restricted to working with children who meet the current ECIS eligibility criteria.

## 5.7 Summary

This section focused on the ECIS system itself, and began with an exploration of a series of perennial challenges to be faced: how to identify children early, how they should gain access to ECI services, how to manage waiting lists, which children should ECIS serve, how to determine eligibility, how to assess children, how to ensure program fidelity, what intensity of service is needed, what level of funding is needed, how funds should be allocated, and how ECIS can be held accountable. The answers to these questions are clear in some cases, but in others there is not enough evidence to indicate a definite course of action.

In addition to the specific issues addressed, the general question of how the ECIS system might be reconceptualised and reconfigured was explored. The key point made here was that transforming early intervention services and practices in Victoria cannot be undertaken unless there is a commensurate transformation of mainstream services and practices. The universal systems approach with its focus on desirable outcomes for all children and their families to be met through connected, joined up or integrated services and practices seems to be the best way forward. In summary, there are several key aspects of the transformation recommendations

- A universal systems approach requires a new overarching structural authority or body to ensure improved capacity for interagency governance to support integration or connectedness between a wide range of services or supports (including schools) for children and families in every community or region.
- A universal systems approach requires a highly competent workforce who
  can work trans-professionally and in genuine partnerships with families and
  communities. To achieve this type of workforce will require a radical
  workforce reform agenda.
- A universal systems approach to early childhood intervention and early education, care and wellbeing requires that those who work with children and families are confident and competent in evidence based best practices. To achieve the desirable outcomes through this type of pedagogy will require serious attention to sector wide pedagogical renewal
- A universal systems approach to early childhood intervention is based on a
  recognition of the additional needs of children with a disability and
  developmental delays and their families. To provide the appropriate
  responses to these needs, in addition to the above reforms, will require
  special initiatives such as appointing a counsellor or lead professional to
  support every family, establishing guides for developing information or
  funding social inclusion projects in communities.
- A universal systems approach to early childhood intervention would also involve embedding secondary or tiered early intervention support systems into mainstream practices, expanding the role of ECI services and practitioners. While some models of how this might be done have been developed, there are no well-developed examples of what such models would look like in practice.

### 6. CONCLUSIONS AND IMPLICATIONS

## 6.1 Summary and conclusions

As this review has shown, the impetus for change in ECI services comes from three main sources. First, there is the nature and impact of social change over the past few decades, and the profound changes in the conditions under which families are raising young children. Services have not changed sufficiently to keep up with these changes and are struggling to meet the needs of all eligible children and their families. Second, there have been a number of recent state and federal government initiatives in the early childhood field, based on the recognition of the importance of the early years and the need to improve the quality and availability of services during this period. Third, there has been the evolution of ideas and practices within the ECI field itself, leading to a major reconceptualisation of the rationale and purpose of ECI and the development of new strategies for achieving these aims.

This reconceptualisation of ECI aims and practices has been paralleled by paradigm shift in the way that we define and conceptualise disability that has occurred over the past 20 to 30 years. This has involved a shift from a deficit model of disability to a social model that recognises the way that environments can facilitate or hinder the development of functional capacities and the participation of people with disabilities in community activities.

As for the families of children with disabilities, the evidence indicates that they are faced with many challenges that place them at risk of poor outcomes for themselves and their children. However, many such families are able to meet these challenges and even transcend them, drawing on their own personal resources, the support of family and friends, and the help of specialist services. It is also apparent that, while professional help can be very helpful to families, it can also create problems for them when it is delivered in ways that make parents feel disempowered, when services do not consider the demands they are making on families, and when services are hard to access or poorly coordinated.

The evidence indicates that families benefit when ECI services provide a range of supports and services, including emotional support and counseling, social support, information provision, help in learning their role, strength-building and empowerment, parent-child relationship support, and help with additional demands and resources. In addition, parents benefit from key worker models of support, from timely diagnosis, assessment, monitoring and feedback, and from prompt access to early childhood and early childhood intervention services.

A review of definitions of ECI and the research evidence regarding the conditions children need to develop well led to the recognition of the importance of working

with the child's main learning environments - of working with and through the main caregivers rather than achieving change through direct therapy with the child. This amounts to a major shift in what we might call the 'default' position for ECI practice. The previous 'default' position was that the job of ECI practitioners was to change the child directly through therapy and teaching, with inclusion in mainstream environments as a desirable additional option. The new 'default' position is that the job of ECI practitioners is to promote change in the children's main learning environments, with direct therapy and teaching used strategically on a case-by-case basis. From this perspective, the inclusion of children with disabilities in mainstream early childhood programs is not an add-on to ECIS, but a major form of intervention in its own right. Thus, mainstream early childhood programs are not simply desirable settings for normalising or widening children's social experiences, but are major settings for learning and intervention. This reconceptualises inclusion as a form of intervention, and mainstream early childhood programs and settings as essential learning environments for young children with developmental disabilities.

A review of the evidence regarding the benefits of inclusion and the conditions necessary for those to be achieved suggested that much depended upon ensuring that the early childhood programs are fully inclusive and of high quality. A fully inclusive program is one that responds to the individual needs of *all* children, including those with additional health, behavioural, language and learning needs. To achieve this, early childhood programs need to be based upon principles of universal design for learning and use practices such as recognition and response, which is not generally the case at present. What this implies is that realising the goal of inclusion as intervention cannot be achieved unilaterally by ECIS and integration support professionals but requires a matching shift by early childhood programs and professionals.

After this reconceptualisation of ECI aims and functions, the review focused on a number of other key aspects of ECI service provision, including what outcomes for children, families and communities should be seeking, and the importance of using an outcomes-based approach to the planning, delivery and evaluation of ECI and allied services. Using an outcomes-based framework, several of the major models of ECI services were explored and evaluated. Although these frameworks do not describe how the actual services should be provided, they provide a strong basis for the development of a comprehensive evidence-based model of service delivery for the ECIS sector, both at a state and federal level.

Next, the review considered the general question of what interventions are known to be most effective, beginning with a discussion of evidence-based practice, practice-based evidence and client values, and how these relate to one another. The review identified a range of strategies that have been shown to be effective in working with children, with families, and with communities and services. These include the three key elements of effective helpgiving – technical

competence, relational practices, and participatory practices. The implications for workforce competencies were also considered.

Other issues explored in this review included the strengths and weaknesses of the existing ECI system - ECI and allied services have many strengths, but are constrained by the existing service system from exhibiting these fully. The number of challenges facing the ECIS system were discussed, including identification, eligibility, point of access, funding levels and models, intensity of service, and fragmentation of the system.

The review concluded with a consideration of the way forward for ECI and allied services. In the light of all the issues and evidence discussed, it was concluded that a universal systems approach is the best way forward for ensuring that all children and their families have access to the services they need for best outcomes in education, care and health. In a universal systems approach, early intervention for children with a disability or developmental delay is available from birth in mainstream services through evidence based practices and pedagogy and with the support of child and family consultants or key workers or other early intervention professionals. Specialist early intervention programs need to be included in the universal system with the same commitment to child and family-centred practices through play based learning and using every day events and routines as potential sites or contexts for learning. Specialist programs need to be connected to or joined up with mainstream services for children and families. The programs they offer could take place in integrated or hub services, stand alone sites and as part of home-based early childhood interventions.

#### 6.2 Limitations of the review

Before considering the implications of these findings, some limitations of this review should be noted.

One limitation is that, while it sheds much light on the aims and practices of ECIS, the review does not provide definitive answers as what form of service system is best able to provide such services. This is partly because the ideas run ahead of the service models, and partly because the systemic issues do not lend them themselves to conventional research, Hence, accounts of successful service system reforms are not easy to locate in the literature. (This is not a problem that is unique to the ECIS sector, but is evident in many human service sectors.)

A second limitation of the review is that it has not explored all the research on individual disabilities. There is a great deal of work that has been done on interventions for young children with disabilities such as hearing loss, vision loss, cerebral palsy, intellectual disability, and autism spectrum disorders, as well as research on particular conditions or syndromes such as Down syndrome, Fragile

X syndrome, and Prader-Willi syndrome. A detailed review of all this work has been beyond the scope of this review which has instead concentrated on more general research that addresses issues most pertinent to disabilities in general and the reform process in particular.

A third limitation is that the review has not looked at discipline-specific research. Each of the professional disciplines involved in ECI and allied services conducts research relating to best practices in that discipline. As in the case of disability-specific research, a detailed review of discipline-specific research is beyond the scope of this review. While it is doubtful that such research would contradict the general findings of the present review, it is likely that it would clarify those instances in which a direct therapy or teaching approach might be the most effective way of achieving change in a child or family.

A fourth limitation is that much of the research that the review has drawn on comes from overseas. While there is an international consensus about the philosophies and best practices in ECIS, there are some significant differences between countries in the service systems and social conditions that mean that some of the findings from overseas have limited local applicability. When it comes to reforming the system of ECI services, we have to come up with our own model.

## 6.3 Implications and considerations

What are the implications of these findings from this review? There are a number worth noting.

Reforming ECIS and the implications for early childhood services. One of the most significant points to emerge from this review is that the reforms needed do not involve ECIS and allied services only, but have implications for mainstream early childhood and other services. The ECIS system cannot be reformed on its own, but must change in parallel with other services. As it happens, the necessary changes in mainstream early childhood services (eg. move towards a universal curriculum) and in other services (eg. moves towards integrated early childhood services systems) are already well under way. Just as the general changes proposed will require some role changes and some new skills for ECIS and allied professionals, so too will they require some changes on the part of mainstream early childhood services.

How might this process be supported? ECI and allied services need to be familiar with the new curriculum approaches and be exploring how to use these frameworks in planning, delivering and reporting on the services they provide. ECI and allied services also need to be working with early childhood programs, particularly those being incorporated into the new integrated child and family

centres, to explore ways of working together that will expand the roles and skills of both groups.

Addressing service fragmentation. Another major point raised by the review concerns the fragmentation of the current ECI service system. As noted in the introduction, ECIS includes a range of services supporting families and mainstream early childhood services. These additional services and supports, together with the ECIS teams and agencies, make up the totality of early childhood intervention provision for young children with disabilities. The findings of the review apply just as much to these additional services as they do to the work of the ECIS teams and agencies. However, the fragmented nature of the system makes it harder to ensure uniformity of practice and quality across the sector, as well as making it harder for families to access.

Some rationalisation of services and service systems seems called for. There are a number of ways in which the fragmentation of services might be addressed. At the systems level, these include looking at the relationship between the Departmental SCS teams and non-government ECI agencies, and the relationship between ECI agencies and inclusion support services.

A particular issue to be addressed is that of the federal funding for the *Helping Children With Autism* package. As noted in this review, although the funding itself is most welcome, there are a number of problems with the way in which the funds are being distributed and the lack of linkages with the existing service system. During the recent federal election campaign, there was discussion of extending this funding to other forms of disability, which would only compound the problems. It is unclear how this matter can be resolved, although it would obviously be preferable for this funding to be more closely integrated with existing forms of support. If this was a matter of concern to all States and Territories, perhaps it could be raised with the federal government with a view to finding ways of minimising the fragmentation of services.

Developing an ECI service delivery framework. This review looked at several comprehensive models of ECI service delivery, and concluded that, individually and collectively, these provide a strong basis for the development of a comprehensive evidence-based model of service delivery for the ECIS sector. Although ECI service guidelines currently exist, these do not amount to a comprehensive framework encompassing all aspects of service delivery and addressing all aspects of child and family needs. The development of such a service framework could contribute greatly to the promotion of uniformly high-quality ECI service delivery across Victoria.

Adoption of evidence-informed practices. A gap between evidence and practice is a common feature of all human service sectors, and ECIS is no exception. Although there is no direct evidence of the nature or size of the evidence-practice gap in Victorian ECI services, there is plenty of observational evidence that

practices vary considerably and that not all forms of support being offered are consistent with the evidence summarised in this review. This would suggest that there is a need for clear guidance regarding preferred practices, provision of resources and training to support the adoption of these practices, and accountability mechanisms to ensure that practices are being implemented.

Adoption of outcomes-based approaches. The review has indicated that an outcomes-based approach to planning, delivering and evaluating services is an essential feature of best practice. Currently, most ECI services do not use this approach, although some use elements (such as parental evaluations of service received). More services would adopt outcomes-based practices if provided with guidance on how to do so, and resources tailored to ECI services.

Exploring tiered intervention models. One of the strong indications to emerge from this review concerns the desirability of developing a strong universal service platform backed by a tiered set of secondary and tertiary intervention services. For young children with developmental disabilities, ECIS and allied services would form part of the tiered services, providing support to the universal services and a graded series of services of varying intensity to children with varying degrees of developmental and learning problems. There are many questions to be addressed before such a system could be put in place (such as how would one become eligible for service and how would different levels of service be funded). The research does not provide clear guidance on these questions, although some relevant models have been developed and could be trialed. Consideration could be given to ways in which such models could be developed further, piloted and evaluated.

Strengthening professional competencies. One of the keys to building and strengthening professional competencies is for the professional involved to be part of a collegiate group that provides a supportive community of practice. Professional isolation can undermine professional competencies over time. If the ECI and allied service system is to be restructured, then it is important that ECIS professionals, whether ECIs or inclusion support or parent support, should be part of an dedicated professional group large enough to provide collegiate support and ongoing professional development.

Another important aspect of strengthening professional competencies concerns preservice and inservice training. It is important that the tertiary institutions that are training practitioners are fully abreast with the latest philosophies and service delivery models as outlined in this review, and are preparing new professionals accordingly. It is also important that practitioners entering the ECI field receive some form of induction course since few of them will have received much specific training in working with young children with disabilities or their families. At present, only the largest ECIS agencies (eg. Noah's Ark) are able to provide such courses.

## 6.4 Managing the process of change

The reform process is about identifying a pathway to a better service system.

A staged process of change is indicated. There is a considerable gap between some of the proposals and directions discussed in this review and the current funding and service arrangements for ECIS and allied services. While some changes may be possible immediately, others will take time. For some of the changes being sought, there are few strong examples to follow, so some controlled experimentation is called for in the form of pilot programs or arrangements. One of the major approaches for moving science to service more effectively and efficiently (Fixsen et al., 2009) is a staged approach in which implementation does not happen all at once but is phased in over 2 to 4 years. Six functional stages of implementation have been identified (Fixsen et al., 2009): exploration, installation, initial implementation, full implementation, innovation, and sustainability. The stages are not linear as each appears to impact the others in complex ways.

Providing supports and resources during the period of change will greatly increase the likelihood of the process going smoothly and the new arrangements and approaches being adopted by the ECI and early childhood sectors. Supports and resources may take a number of forms, including additional funding, pilot studies, training, and professional resources. Fixsen et al. (2009) describe seven core implementation components for supporting the adoption of new practices: staff selection, preservice and in-service training, ongoing coaching and consultation, staff evaluation, decision support data systems, facilitative administrative support, and systems interventions. According to Klingner et al. (2003), the wide-spread adoption of new practices by practitioners requires top-down support for bottom-up reform.

Developing a comprehensive communication strategy regarding the reasons for change and the change process itself. An important element in promoting change is effective communication. As noted in this review, the insights that ECIS professionals and others have developed about how best to promote the development of young children with disabilities are not necessarily understood by the parents of these children or by the general public. If ECI services are to move in the direction suggested by this review, then there is a major challenge of sharing the new understandings in ways that help parents and others embrace the changes. As Greenhalgh et al. (2008, 2009) found, in complex projects with diverse stakeholders, considerable attention may be needed to finding a common language and format for shared understanding and communication. This suggests that it would be valuable to explore how best to frame public messages regarding early childhood intervention so as to ensure the general acceptance of the reconceptualised role of ECI and any corresponding changes in the service system.

Monitoring and evaluating the impact of changes is also critical. Because human services such as ECIS are complex systems (Glouberman & Zimmerman, 2002; Patton, 2011), the outcomes of any changes introduced cannot be predicted beforehand. Therefore, it is important to monitor and evaluate the effect of changes in order to be able to correct for any unintended outcomes. This is borne out by the account given by Conn-Powers et al. (2010) of an evaluation of the impact of policy changes affecting eligibility, family cost participation and service delivery in a US state. On the basis of their experience, they make the following recommendations:

- First, it is imperative that the evaluation process, from design through to analysis, includes program stakeholders. (In the case of the ECIS reforms in Victoria, this means families, ECIS service providers, mainstream service providers, inclusion support providers etc.)
- Second, evaluations need to be sensitive to both intended and unintended outcomes—that is, to recognise with all stakeholders that there are likely to be positive and negative outcomes to any decision.
- Third, a fair and independent evaluation process can play a very important role when policy decisions confront individual stakeholders at an emotional level. It can provide a means of separating the beliefs, perceptions, and rhetoric that are associated with such policy decisions and of bringing people together to examine results that illustrate what really did happen.

Finally, preserving and building on the strengths of the ECI sector is essential. There is always a danger in making changes to a system as complex as ECIS of 'throwing the baby out with the bathwater', ie. losing the expertise at the heart of the ECI process. In designing a new system and a planning a process of change, care must be taken to ensure that the collective professional expertise is not diluted, but is strengthened.

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